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DATA AND THE OPD EXPERIENCE

FEBRUARY 24, 2021

9:00 A.M. EASTERN

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>> ELIZABETH LOCKWOOD: Hello and welcome, everybody. This is Elizabeth from CBM. We will be starting in a few minutes. Thank you for joining.

>> ELIZABETH LOCKWOOD: Welcome everybody to our meeting today. We will be starting in about a minute.

Welcome, everybody to our webinar on "Data and Persons with Disabilities and Their Representative Organizations."

I am Elizabeth Lockwood from CBM Global, and I'm starting off with a few housekeeping items. First, the event will be recorded and shared later.

We have international sign interpretation and live captioning. The international sign interpreter is spotlighted as you can see, but you can also pin and resize the images for the interpreter if needed. The live captions are available by clicking on the closed caption box at the bottom of the screen, and are also available in a separate link that has been shared in the chat box.

Presenters and moderator will use their camera while presenting, but we kindly ask everyone else to turn off their camera, and mute themselves if they are not speaking. We aren't using any PowerPoint presentations or visual materials during this event. And please throughout the event, at any time, ask questions in the chat box, and we will get to the questions during question‑and‑answer time after the three panelists speak.

And if we don't get to you, we will put an email in the chat box, and we'll follow up afterward.

As a brief introduction, our event today is on the margins of the 52nd statistical commission at the UN, and we're hosting this event to highlight the role of persons with disabilities and data advocacy with a focus on key experiences and research findings from national and global levels.

This is particularly important today, because of the global pandemic, and the lack of data on persons with disabilities and their experiences, as well as disability data to measure the sustainable development goals, which is further exacerbating inequalities and leaving people further behind.

We have three distinguished panelists today. I'm happy to say. We have Jose Viera from the World Blind Union and the Stakeholder Group of Persons with Disabilities hosting this event, the stakeholder group.

And then we also have Sally Nduta, with the United Disabled Persons of Kenya. And Bethany Brown with the International Disability Alliance. I will begin with Jose, who will focus on the disability data advocacy toolkit and organizations of persons with disabilities and their role in disability data advocacy.

Thank you very much, and Jose, over to you.

Jose, you have to unmute yourself, please.

Perfect.

>> JOSE VIERA: Thank you, Elizabeth. Good morning. Good afternoon. Good evening, everyone. It is indeed a pleasure for me to be part of this webinar, and not only because I believe the topic of the webinar is fundamentally important, but even more because of the context of this webinar being held. The more we understand the importance of data, the more we realize we really need to advocate with other partners and UN agencies around getting the issue of data and persons with disabilities as part of their agenda. I think this webinar is a clear example of that.

I will be presenting a toolkit that was produced in collaboration between the Stakeholder Group of Persons with Disabilities, CBM Global Disability Inclusion and the International Disability Alliance. Many of you probably have seen, and that is the data advocacy toolkit, but before actually browsing quickly through that toolkit, I want to give you a little bit of a background why we decided to input ourselves in such excellent and endeavor and that is to have this toolkit available.

In 2019, we ‑‑ from the Stakeholder Group of Persons with Disabilities, we realized the need of doing even more than what we have been doing around data and persons with disabilities. Not only because there was ‑‑ there was a clear demand from OPDs but at the same time, we all understood the critical momentum that we were all in with regards to increasing evidence‑based approach when it comes to advocacy and disability rights.

Well, back then, with the support of CBM Global, we established the first data Working Group within the Stakeholder Group of Persons with Disabilities, which was led and continues to be led by Elizabeth Lockwood and I want to take one minute here to invite everyone to be part of that Working Group. I will be providing you my information about that in a minute.

Actually, that working Group was a very active Working Group and one of the main outcomes of the activity of that Working Group was actually the need of having a consolidated toolkit in which OPDs and other relevant stakeholders and partners can work towards realizing the need of more evidence‑based approach when it comes to disability rights.

After several months of intensive work by many of us, the International Disability Alliance with CBM Global have launched the data toolkit that I was referring to, and even though it's very useful, comprehensive document, which I will all invite you to access, I understand that Elizabeth has put a link to the data toolkit in the chat box.

I would like to highlight two important elements. First one is what we say when it comes to the need of collecting data. And one of the most important questions that many OPDs asked ourselves was what does it mean to collect data? Why we collect data? What is the purpose of collecting data? And actually the toolkit actually presents a quite comprehensive list of answers to those questions. Why we need data, what is the role of OPDs and how can OPDs play a significant role when it comes to advocacy with governments and ‑‑ and other UN agencies and international organizations around data.

But at the same time, when we try to address why we collect data, the other big set of questions that we have received through this Working Group was, well, after we collect data, what can we do with it? How can we turn it into more effective advocacy, strategic planning, for instance?

So the data toolkit that we are presenting today also addresses what can be done with the data that we collect, and actually, it goes one step farther and start supporting OPDs in understanding what could be the role of OPDs in collecting and generating data. So for instance, there's a good amount of information in the toolkit that is intended for national and statistic offices, government and international agencies, but at the same time, how all of these actors can interact and work together in promoting the evidence‑based approach with regards to disability rights.

I will then like to say that the toolkit is only one of the many elements that we think are needed when it comes to promote data use in persons with disability advocacy strategy.

We have been extremely lacking and successful in this journey of creating the data toolkit and now we have the data toolkit available in sign language. Shortly, we will have French, Spanish, and Arabic and hopefully Germany and Easy Read format because we are committed to make all of our publications accessible.

And we have already ‑‑ and we have already received quite good number of invitation to different projects. I would like to share we are finalizing the preparation for some trainings around the data toolkit that we present today and how it can be used by OPDs and national statistics offices.

I will just ‑‑ to conclude once again, by inviting everyone to access the data toolkit to use it, to share among your networks and do please get ‑‑ get in touch with the Working Group on data from the Stakeholder Group of Persons with Disabilities through the LISTSERV that I will kindly ask Elizabeth to put on the chat box. I think for those who are interested to more and to see how you can participate, you can go to that link and find out more how to be part of this Working Group on data from the Stakeholder Group of Persons with Disabilities.

Once again, I would like to thank IDA, CBM Global and everyone who has part of this data toolkit and I hope it is a useful tool for everyone.

Thanks, Elizabeth.

>> ELIZABETH LOCKWOOD: Thank you so much, Jose. It's a real pleasure to work with you on this disability toolkit and disability information in general. Please post your questions at any time in the chat box and we will be able to answer them at the end of the presentations.

Now, I will turn the floor over to Sally Nduta from the United Disabled Persons of Kenya and she will be experiencing about the experience of organizations of persons with disabilities advocating for disability data in Kenya. So Sally, over to you.

>> SALLY NDUTA: Thank you very much, Elizabeth. Good evening and good morning, wherever you are. I'm really happy to participate in this workshop.

I'm going to discuss our process in Kenya of getting the Washington short set of questions or module into our national census that was conducted in 2019, and highlight how organizations of persons with disabilities are involved and continue to be involved in this process, and in the larger dialogue around disability inclusive statistics in Kenya.

I will also share briefly our experiences in regards to COVID‑19, because this is the current reality we are in. So our population census was carried out in 2019. And for a period, we identified a gap in terms of generation and management of official data in Kenya.

Where data collected has not adequately informed design of policies and programs in Kenya, in as far as persons with disabilities are concerned.

For a very long time, I think for the past four years, it has been a desire for the disability movement in Kenya to ‑‑ for government and the official structures to adopt the Washington module as a standard for collecting disability data and analyzing the same. So because we know that the Washington module provides the ‑‑ the standard for high quality inclusive and reliable data. We have a situation where disability‑related interventions are informed by data. So just before the 2019 census, we got into training of officials from the Kenya National Bureau of Statistics, this the government agency that is responsible for collecting data. So we took them through the Washington module of collecting data.

Secondly and most important, was the involvement of organizations of persons with diss in this process. Through the United Disabled Persons of Kenya. We had a number of persons with disabilities going through trainings or disability data and how to use the Washington module.

The International Disability Alliance, through its bridge and CRPD SDG training continued to strengthen their capacities of leaders in the disability sector on advocacy for appropriate disability data. And in that regard, we are excited because I think soon, I believe next month, we are going to have a similar training by IDA, specifically for organizations of persons with disabilities.

So this empowerment processes led to the use of Washington group module in the 2019 census. From the census statistics, what has been published so far includes distribution of the population, age 5 years and above by disability status, as well as distribution by disability type. A disability monograph shall be published that shall look on various indicators such as access to education and employment among others.

Through our framework of continuous engagement, with OPDs, stakeholders and the Kenya Bureau of Statistics, organizations of persons with disabilities are now members of a technical Working Group on disability statistics which going forward we have agreed will be consultative or disability data in Kenya, because even though the Washington group module was used, there was still challenges in terms of the numbers, the specific numbers that came out.

The disability sector still feels there are gaps and the numbers that came out were not really representative of the true picture of persons with disabilities in Kenya. So we still have a journey to walk as a country to ensure that a true statistics of persons with disabilities are represented.

In terms of COVID, and how we ‑‑ the pandemic has been progressing in Kenya, there are various efforts from partners in Kenya on ensuring that there is good data on disability. So, for example, in terms of COVID, we noted challenges when it came to disaggregation of data. In the OPD, our initial agenda in the initial months of the pandemic was to ensure that persons with disabilities were part of the response system. So a lot of our effort was to focus that correct information on prevention was presented to persons with disabilities.

We also worked on an advisory and shared with different government agencies to ensure that persons with disabilities were included in the response system that was presented by the government.

So we have rapid service that was carried out to determine the socioeconomic impacts of COVID‑19 on households. They did not disaggregate this data by disability status. We still do not have data on how persons with disabilities accessed hospitals, for example, among other crucial aspects as regards the response to COVID‑19.

So in this lack of data, what we have done and continue to do as UDPK and the disability sector in Kenya, we used research to compliment the official data for policy making and decision making. We have relied on data from organizations of persons with disabilities, as well as from commission studies by different stakeholders. For example, we rely on OPDs at the national or the county level to see if persons with disabilities are aware and are part of COVID‑19 response committees, structures that have been established by government.

Or for example, how many persons who received cash transfers which were offered to persons with disabilities and other vulnerable groups for about a year.

We ‑‑ we also have continued to work with our networks and allies to conduct such research to influence policy and decision‑making. For example, we worked collaboratively under the inclusion project, known as I to I, in the inclusion works project that is currently ongoing, and led by Sightsavers international to collect data around persons with disabilities in Kenya as we continue to experience the pandemic.

And such studies have revealed that over 92% of persons with disabilities that were interviewed on the impact of COVID said that daily lives have been affected, particularly in as far as issues like transport is concerned. There was a period of time, there was restricted movement. Lack of contact with others at school for some time. We also continue to experience a curfew. I think after 10:00, to about 5:00 in the morning. So the job losses is very pertinent to persons with disabilities as revealed by the studies conducted.

As a country, we have begun to talk about vaccines and as we plan and roll out COVID‑19 vaccination, for Kenya, the ministry said that the people to have vaccinations, but mainly for frontline workers, I think beginning of July of this year. But knowing the impact of COVID on persons with disabilities and the challenges and the ‑‑ how vulnerable they are to this, we have called upon governments to ensure that vaccinations are made available to all people, including persons with disabilities who should also be viewed as priority segments of the population.

We have also called upon the government to ensure that sites where vaccinations are delivered are physically accessible and that guidance is provided for those who need it.

And importantly, persons with disabilities and their representative organizations meaningfully participate in policy making and planning when it comes to distribution. We don't involve persons with disabilities, then persons with disabilities are going to more likely be left out of the process.

We are calling upon the government to ensure that all information systems related to vaccinations must collect data, disaggregated by age, gender and disability.

Finally, we have continued to work with other partners to ensure that the gaps in data collection continue to be filled. For example, from the global disability summit in July of 2018 and also in the last year when we had commemoration one year later, we continued to follow up with the government of Kenya which has signed up for the inclusive data chatter, which is a multistakeholder initiative working to include inclusive data globally.

So we're very happy that Kenya has signed and all the data is disaggregated in terms of disability. So in terms of global partnership for sustainable development data who leads the IDC organizations of persons with disabilities helping our government through a parent ministry to develop its own action plan based on the IDC chapter which aims to strengthen disability data and working very closely with the Kenya National Bureau of Statistics.

Thank you very much for listening to me. I'm very happy to answer questions.

>> ELIZABETH LOCKWOOD: Thank you so much, Sally. It's great to have this experience from Kenya. You are doing excellent work and we are looking forward to learning more about your progress and working with not only national statistical offices and other partners. We can really learn from this.

Now we head over to Bethany Brown from the International Disability Alliance and she will be speaking about the findings and lessons learned from the Disability Rights Monitor COVID‑19 survey in which the International Disability Alliance was greatly involved. So go ahead, Bethany and thank you very much.

>> BETHANY BROWN: Thank you, Elizabeth.

Good morning from New York. Thank you to the Stakeholder Group of Persons with Disabilities for holding this webinar. And I have to commend the data advocacy group, they are doing great things and a very special thanks to CBM Global for facilitating and organizing the discussion we are having right now. So glad to be here today with you all to discuss the Disability Rights Monitor report, disability rights during the pandemic.

And you will see I can pop it into the chat right now in case anyone wants to have a look along as we discuss it. It was produced by the Validity Foundation, the Mental Disability Advocacy Center. Disability Rights International, the disability rights unit at the Center for Human Rights university of Pretoria, the International Disability and Development Consortium, IDDC, the Disability Rights Fund and its sister organization, and the disability rights advocacy fund, and my organization, the International Disability Alliance.

We are an alliance of 14 global and regional organizations of persons with disabilities. Together, IDA members promote the rights of persons with disabilities across the United Nations efforts to advance human rights and sustainable development.

IDA supports organizations of persons with disabilities to hold their governments to account and advocate for change locally, nationally and internationally. We supported this survey to gather the data necessary to sound the alarm about the catastrophic impact of the COVID‑19 pandemic on persons with disabilities worldwide, and to catalyze urgent action. COVID‑19 is everyone's problem, but it affects persons with disabilities in specific ways. For example, persons with disabilities faced increased risk of contracting COVID‑19 due to existing health conditions, inequities in underlying health conditions and social determinants of health, as well as contact with support providers, for example, just to give a few examples.

This is why we have a Convention On the Rights of Persons with Disabilities, the CRPD, to articulate persons with disabilities specific equal rights, how they apply in context like this.

So for my presentation, I'm going to start with an overview of the survey that led to the report and explain its methodology, and then go into some further detail on the findings and talk about how the pandemic has specifically impacted persons with disabilities. I will close with some final thoughts on ways forward.

This report is really important. It shows we haven't gained as much ground as we thought what we were going to when the CRPD came into force. It reveals approaches that are specifically prohibited by the CRPD. It reveals the fragility of support systems for persons with disabilities the survey collected 2,150 res from 134 countries between April 20th and August 8th in 2020.

The report was launched in October, a few months ago. Nearly all, over 2,000 of the responses were from persons with disabilities, their representative organizations and family members, making it the largest internationally comparable data set on experiences of persons with disabilities during the COVID‑19 pandemic. And this gives us evidence‑based recommendations for change.

In addition to those over 2,000 responses, individuals also wrote more than 3,000 testimonies. These testimonies were open ended questions that they answered and they varied in length from a short sentence to long paragraphs. The testimonies were then coded and thematically analyzed. The combination of qualitative and quantitative data provides a nuanced, in‑depth insight into the experiences of persons with disabilities and state measures to protect their rights during the pandemic.

It was initially intended to triangulate date, from three different groups, persons with disabilities, governments, and National Human Rights Institutions, but we didn't end up with equal representation among those groups, despite the best efforts of DRM to distribute this among governments and human rights, institutions. 26 governments responded and 12 human rights institutions. The survey also had some other shortcomings that are ‑‑ that are the same that you would find across other online surveys, over representation of wealthy companies and places where there's easier digital access and places where people speak the language that it was translated into.

And each network sought to minimize this with further outreach and print versions, for example. And with those caveats with that sort of overlay of how the survey was conducted, I will talk about some of the specific impacts of COVID‑19 that the survey found.

The first is that the pandemic has highlighted the dangers of institutionalization in a new way. The survey findings shed light on the deadly conditions that resulted into high death rates within large‑scale and small‑scale institutions, housing persons with disabilities.

33% of the respondents who knew about the situation in institutions said that their governments took no measures to protect the lives, health and safety of persons with disabilities in institutions. In the words of the special rapporteur on the rights of persons with disabilities, Gerard Quinn, these places should not exist. Deinstitutionalization is not just an issue of human rights being realized, what this shows is how it should be a public health priority as well.

The situation is dire for older persons with disabilities in institutions. One‑third of the respondents who knew about the situation said that their government took no measures to protect the life, health and safety of older persons. Respondents were also concerned for the effects that the isolation they were experiencing was having on their mental health in institutions.

This was particularly pronounced for all people who were experiencing bans on visitors and bans on residents leaving institutions. Of those who knew about the situation, the majority, 69% said that persons with disabilities were restricted or banned from leaving institutions. A further 84% said that the government had banned or restricted visits from family, friends or others in social care settings, and 82% of those who knew about the situation in psychiatric health facilities said that their government had banned visits. That's a lot of isolation.

In the community, there was also a breakdown of community supports. Many of the essential services that persons with disabilities rely on to live independently in the community were not available during the pandemic. For example, 38% of survey respondents said that persons with disabilities did not have access to personal assistants during this time. 33% said that persons with disabilities did not have access to informal care. A further 23% said that persons with disabilities did not have access to assistive technologies. Those things are really crucial.

And we can't overstate the importance of access to information. This survey included that almost one‑third of respondents said that persons with disabilities did not receive enough information about the prevention of COVID‑19 during this crisis.

The survey has also revealed that persons with disabilities around the globe did not have access to food and adequate nutrition during the COVID‑19 pandemic. Almost one‑third of survey respondents in 81 countries said that persons with disabilities in their countries could not access food.

The ten countries for the highest percentage of respondents reported no access to food were Uganda, Nigeria, Kenya, Bangladesh, Colombia, Cote d'Ivoire, Rwanda and Peru.

Several high‑income companies were also among those with high proportions of people that said they could not access food. More than 25% of respondents from Belgium, Canada, France, the United States of America, and the United Kingdom said that persons with disabilities did not have access to food during the pandemic. The findings indicate that the vast majority of governments did not take appropriate steps to safeguard and promote the right to access food.

There were also more overt reports of harassment from law enforcement. Around the world persons with disables and their family members had no choice but to break curfew rules. Lockdowns were inaccessible to large populations. The majority of respondents, 77% said that they did not have information about penalties resulting from breaking state emergency rules, such as fines, sanctions and arrests that were imposed on persons with disabilities.

The last specific area I will mention today is access to health services.

The majority of respondents who knew about access for COVID‑19, said they were denied healthcare. Several written testimonies from Canada, the United Kingdom, the United States of America, Austria, Luxembourg, Netherlands, Georgia, France and South Africa said hospital triage practices had discrimination against people with disabilities in COVID‑19.

In all of these areas, interactions with police, access to healthcare, access to food, institutionalization hit marginalized persons with disabilities especially hard. Those facing racial or gender discrimination, LGBT persons with disabilities, and those with intellectual disabilities and psychosocial disabilities. Where do we go from here?

As Mr. Vera and Nduta discussed, governments have to hear this. The CRPD requires it, and policymakers working with organizations of persons with disabilities about decisions that affect them drives efficiency. While this report has highlighted some examples ‑‑ I will close by ‑‑ by emphasizing that it cannot do justice to the crucial work that has been undertaken by many organizations to make up for governments' failings.

If there's a lesson to be learned here, it's that persons with disabilities and their organizations are key to the planning, preparation and implementation of any emergency response and their crucial role must be adequately acknowledged and supported with data and they must be integrated into further response.

Thank you very much for the opportunity to present this report and I look forward to a fruitful discussion with you all.

Thank you.

>> ELIZABETH LOCKWOOD: Thank you so much, Bethany. That was very, very, interesting and very important that we learn more about what is happening to persons with disabilities globally in the context of this COVID pandemic.

So now we have time ‑‑ which is so nice ‑‑ for questions and answers. And so please post your questions in the chat box or if you want to speak, raise your hand. And it can go to all panelists or one specific panelist or however you want.

I will begin with the first question that we have. It's for Sally. But I also think Bethany and Jose, you can answer as well.

The question is: What do you think were the reasons for the gaps in data collection in Kenya, using the Washington group questions? For exampling, do you think it was due to context or cultural factors or something else?

So to adapt this to both Bethany and Jose, if you can think about gaps in data in your experiences, I think it would be helpful to add.

Since this is the only question that we have so far, I will go back to the panel and I will encourage you to ask questions to have a nice fruitful conversation.

So I will start with Sally and then Jose and Bethany.

>> SALLY NDUTA: Thank you, Elizabeth, and thank you for that question.

Let me say that as many of us are aware, disability is ‑‑ is ‑‑ can be a very long process and sometimes, be you know, getting government to, you know, come on board and take on, you know, recommendations that are made by persons with disabilities who can take quite a long time, and even not just the disability sector. This is just generally in development.

For Kenya, the whole dialogue around disability inclusive data, especially for the latest census took quite some time. I think it was a journey of about four years, and I remember when we could have meetings with the Bureau, they ‑‑ and then when we talked about the Washington module, they started by saying, oh, no, the question is, it will be very long. So already there was resistance from the start around the Washington module.

So that took quite a bit of time to build consensus around that. But then I would say, as ‑‑ this was a first for Kenya, really, and many times you will find when you try something for the first time, you are bound to make mistakes. Because a lot of time was spent on resistance and getting government on board to ‑‑ to ‑‑ you know, around disability inclusive data.

It took ‑‑ that took time that would have been used for trainings. So we felt that a lot more time would have been allocated to conduct training to the enumerators and this is people who are collecting data coming to households. You find that many of them would not even ask you those questions. So they would make assumptions.

If they come to your house, they already make assumptions if they didn't visibly see a person with a disability, they wouldn't ask those questions. So there was a lot of information gaps, let me say and skills by the enumerators who collected that data.

And to give are you real evidence, we have an organization known as Development Initiatives that did a study in May 2020 on the status of disability in Kenya. So they did a background paper on statistics from the 2019 census. And that issue that I just shared, where there's more training to the enumerators was brought out on that study, because their number ‑‑ the actual numbers of persons with disabilities that came out is still not agreeable with the disability sector.

So it's still a journey that we have to go. There's also other issues around translating ‑‑ translation of these questions into local languages. So in cases where, for example, the questions were translated into Swahili, probably some meanings were lost. So that affected the quality of data that was collected.

I hope I have attempted to answer the question. Thank you.

>> ELIZABETH LOCKWOOD: Thank you so much, Sally. Actually, we have a lot of questions. So Jose and Bethany, if you don't mind, I will ask these other questions because they are more specific to you. But first, I'm going to ask Dinah, she raised her hand to go ahead and ask her question orally.

>> Thank you very much. My question goes to Bethany. It regards the COVID survey and I want to know whether IDA sent the COVID survey to the World Health Organization, because as far as I know, the World Health Organization really did forget disabled people and the distribution of vaccine. And my endeavor or the endeavor of disabled peoples internationally, that the vaccine is distributed in a just way, in a equal way so that all countries get access to vaccine, not only the rich countries.

Thank you.

>> ELIZABETH LOCKWOOD: Thank you so much, Dinah. I will ask the panel a few more questions and then I will go back to the panel.

Also for you, Bethany, about the COVID‑19 survey. The question is that it's ‑‑ it was ‑‑ was it in English only? Because many persons with disabilities around the world don't know English. So was there an initiative to translate this into local languages so the number of OPDs could respond? So that's one question.

A second question to all panelists, is there any experience among the participants in collecting data for the purposes to measure disability inclusion?

So this is an issue for people in different countries in this case, Bulgaria. So this person would like to know.

And a third question to everybody. This person faces questions regarding data protection. So the question is if data collected bite increase discrimination and what risks do you see in this and what is the possible damage toes with disabilities? That's a good question.

And the last question, what role could interfaith leaders play in reducing data gaps? That's also an interesting question.

So I'm going to start with Bethany and then go to Jose and then Sally. And you can choose how you want to answer.

So go ahead, Bethany.

>> BETHANY BROWN: Thanks very much. And thank you to Gina and others for your questions.

I will start with popping another link into the chat that outlines the guidelines ‑‑ that is a link to guidelines to vaccines that the International Disability Alliance has developed regarding reaching the farther behind first. This is an ongoing conversation that we're having with the WHO and I'm really glad that you brought that up. I think it's important. They have ‑‑ they have the benefit of the bully pulpits. They are the ones that everyone is turning to. We want to make sure that the measures that they are sharing about vaccine prioritization include persons with disabilities and some of them ‑‑ and some of them do.

Not as well as we think that they should be but that's something that we can improve that we're continuing to talk about with them.

On the question of where there are gaps in the date, I think that there are a lot of gaps right now. There are a lot of questions about what is happening with violence for people who are ‑‑ who have disabilities who are already lockdown? There are questions around how ‑‑ how much gender‑based violence, how much violence against children with disabilities is taking place. Just general domestic violence under these ‑‑ under these conditions. And that's something that we really don't know yet and it's a hard question to answer. It's a hard ‑‑ it's hard to reach people who are ‑‑ who are experiencing violence in the home, when they can't leave, and be able to ask them those questions in an ethical way that wouldn't invite potential further retaliation. It's a really challenging situation, but it's one that we're thinking about a lot that's very concerning.

And in terms ‑‑ in terms of the question around privacy, I would also just note that that's something that we covered in ‑‑ in our guidelines around ‑‑ around the COVID vaccine. Privacy is really important for everyone, and persons with disabilities certainly have an equal right to the protection of their privacy and health data. So that's something that we would push for as well. Thanks for the floor.

>> ELIZABETH LOCKWOOD: Jose, go ahead. Thank you, Bethany.

>> JOSE VIERA: Thank you, Elizabeth. I will try to answer some of the questions by a few reflections I would like to share.

I think both Sally and Bethany clearly outlined a good example of the different challenges that we have ahead of us, but let me quickly say that when it comes to analyzing the different gaps around data, I would say to you explain it at least in three different blocks. I think there is ‑‑ there is a clear need of getting this first lock around design and implementation of efficient and effective data collection tools. And that is very much connected to the need of more training, the need of more in the field activities by OPDs and other relevant stakeholders when it comes to decide what tools to use, how to adapt the tool that we want to use, for instance my colleague Sally was explaining the issues around translation. And we don't have to get how we can make those ‑‑ that data collection tools accessible because in the end, no matter how we create information and we generate data that can then be used in an accessible format by OPDs.

So I think this block of design and implementation of data tools is critically important. And clearly, some of the issues that were raised throughout the questions actually touch upon those gaps that we are still experiencing when it comes to data collection.

The second block that I think is critically relevant that we ‑‑ that we ‑‑ we quickly start doing more and more, is actually around the articulation between the different involved parties within this data collection world, let's say.

And for that, we really need to invest more in the capacity of our OPDs when it comes to equip them with resources, knowledge, skills, technical skills, et cetera, et cetera to not only generate data but at the same time, how to use the data. How existing, perhaps ‑‑ existing data can be used in a more effective way.

We have been discussing a lot in different Working Groups, how the registries of OPDs can also be a great source of information when it comes to data and persons with disabilities.

And therefore, we really see that even though there has been a lot of great initiative in place, in relation to fostering this conversation among OPDs, the national statistical offices, et cetera, et cetera, I think there's still a lot to be done in that regard.

And the third block ‑‑ sorry ‑‑ the third block, it's more about what's next. So we have ‑‑ and I think it makes sense, focused a lot on creating the environment, creating the preconditions to promote data selection, but at the same time, we also need to develop further this work stream around what can we do with it data. Bethany was explaining in her first intervention all the excellent results out of that first global, I would say extremely important survey conducted by IDA and other organizations around disability and COVID‑19.

While the challenge is now and I think it was raised through one of the questions, what are we going to do with the results of service like the one that Bethany was talking about? Are we going to advocate with WHO? Are we going to connect those results with SDG framework, et cetera, et cetera?

And I think this type of webinar, as long as with other tools, actually it is a good way of trying to address some of those gaps and try to see how we can at least reduce them in a way that meaningful participation of OP D.s, evidence‑based approach strategies are more and more a common and daily tool for OPDs.

Thanks.

>> ELIZABETH LOCKWOOD: Thank you so much, Jose. And Sally, please go ahead.

>> SALLY NDUTA: Thank you. I just wanted to also add to what my colleague Jose has said, in terms of involvement of persons with disabilities. In the whole question of research and data collection and the processes that follow with that and just to give us a specific example, force us here as UDPK, because we ‑‑ we want to move also away from always ‑‑ you know, as we push the conversation forward, in terms of how do we address the question of disability inclusive data ‑‑ (No audio).

>> ELIZABETH LOCKWOOD: Oh, Sally, I think you froze.

We only have four minutes left, so I am just going to ‑‑ unfortunately, I don't think we can go to the next questions, and Sally will probably come back. But I want to just see if Jose and Bethany had any closing words in the next four minutes.

Bethany, go ahead first.

>> BETHANY BROWN: I would just like to close by saying one of the really great things about this survey that we worked on is that it was really meant to have a human rights foundation. My favorite to think about the way that human rights are is that they exist to govern the relationship between individuals and their governments.

So the point of having this data is really to provide the ‑‑ to provide the backup for explaining how governments need to realize the rights of persons with disabilities to show where the shortcomings are and that came through so loud and clear.

So the participation of persons with disabilities in our own advocacy is really buttressed by having this ‑‑ this data at our fingertips to push for change at the national level as well as international level.

Thank you.

>> ELIZABETH LOCKWOOD: Thank you. Jose, final words?

>> JOSE VIERA: Thank you, Elizabeth. I would like to invite everyone once again to actually help us in translating all the discussions that we have at the global level around data into concrete actions at the national level. I think that is ‑‑ that is the biggest gap that we face, not only around data but in general, and that is how we can transfer the knowledge and the discussions happening at the global level into the real action at the national level.

And, of course, for that to happen, we need better equipped OPDs but at the same time we need advocates. We need statisticians and we need researchers that are convinced of the need to work in this direction.

So we have from the Stakeholder Group of Persons with Disabilities a toolkit, the Working Group on data and the LISTSERV and many other mechanisms that I really encourage everyone to use and to participate in order to make this a reality.

>> ELIZABETH LOCKWOOD: Thank you so much. We have one minute left and I would like to just close by thanking our lovely panelists, the international sign interpreters, the captioner, for IDA for their support, the CBM Global for their support, and all of you for attending. I'm sorry we are not able to get to everyone's questions but I will follow up. My email is in the chat box. Please be in touch with us. We are happy to work with you and email me with any questions.

We are going to share a recording of the presentation with the transcript and the presentations in a few days. And thank you so much for joining. Have a great day. Be safe, and we will talk to you soon. Thank you.

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