# Logo CBM Transcript Webinar 24. September 2021 on Disability Data in International Cooperation

**Mary Keogh:** Hello. Welcome to this webinar entitled Disability Data in International Cooperation. Thank you for joining us. This webinar is being organised by CBM Switzerland, with the support of the Parliamentary Group Suisse - Solidarité internationale. My name is Mary Keogh. I am the director of advocacy at CBM Global. I will be moderating today's webinar.

I would like to start first of all with some housekeeping rules. This session is being recorded and will be posted on-line after the event. International sign language interpretation is being provided. If you require multi pinning, please let the host know through the chat box, so they can activate that for you. Live captions are also available for this event. Click the CC closed captions button at the bottom of your screen or click on the external link provided in the chat box. In the menu you will find "chat box," and the “questions & answers” box. Please only use the chat box for technical questions related to this webinar. Then you may enter the content-related questions for the panellist at any time in the questions and answers box.

I will present the speakers as we go along. Please consult the programme provided in the chat box for the overview of the speakers and the topics covered in today's webinar. Today's distinguished panellists will speak to the question: How can we strengthen the collection and analysis of data on disability, and why is it so important? They will share their experiences and practical tools in disability related data collection. In that regard, I would like to hand over directly now to Mr. Christian Lohr, Member of the National Council of the Swiss Parliament, which is currently in session. Mr. Lohr, thank you very much for taking time to join us today. We now give you the floor for some opening remarks.

**Christian Lohr:** Good morning to everyone. It is a great pleasure to speak to you. I will take the place now to make some introductory remarks. Thank you for participating in this important webinar hosted by CBM Switzerland with support of the parliamentary group Swiss solidarity international on the topic of Disability Data in International Cooperation, how can we strengthen the collection and the analysis of data on disability? This is the main question today.

According to world report on disability, 15% of the world population has a disability. That's about one billion persons. Of this, about 80% live in low and middle-income countries. Persons with disabilities often lack access to essential services. They are more likely to be poor and more likely to be discriminated against. The availability of data on this group is still scarce but has improved greatly and in recent years. Systematic data collection is essential to ensure we know the prevalence of the number of persons living with disability, which then allows us to identify the needs and to measure the gaps. Only by collecting data on whether or not persons with disabilities are being included in international development and social progress, can we enter their full and equal participation

on an equal basis with others. Disaggregated data can provide a better comparative picture of the kind of intervention work, and what doesn't work. It can also help inform and promote evidence-based policy. Disaggregating data by disability is also essential to monitor progress in meeting the goal of leaving no one behind, established under the 2030 agenda of Sustainable Development. Switzerland ratified the CRPD in 2014 and thereby committed itself to implementing in its entirety both nationally and its international cooperation. Switzerland is also committed to implementing the agenda 2030 and its sustainable development goals, which are closely tied to Switzerland's own international cooperation strategy 2021-2024. Switzerland is also dedicated by the agenda more broadly. The Swiss confederation is hosting the upcoming World Data Forum in Bern from 3-6, October. Bringing together the two communities of data producers and data users. One, central theme of the Forum is leaving no one behind, however, Switzerland is not yet a pioneer in collecting data on disability in its international cooperation. If we are really committed to ensuring that no one is left behind in international development cooperation, we must ensure that everyone is counted. Thank you very much. Thank you to all panellists who are joining us today. We look forward to hearing and learning from you.

**Mary Keogh:** Thank you Christian Lohr, for your warm welcome and highlighting the importance of disability data collection, as well as Switzerland's commitment. We'll hear from you again at the end of the webinar for closing remarks and reflections. Our next presenter is Professor Hannah Kuper, who is Professor of Epidemiology and Director of the International Centre for Evidence in Disability at the London School of Hygiene and Tropical Medicine. Hannah will provide an overview of practical tools and experiences in data collection and analysis including international cooperation. But before handing over to Hannah, we would like to begin with a short video of a young woman with a disability in Bangladesh. Hannah will begin her presentation, directly after the video.

*Video can be viewed and listened to here. Captions are provided*. [*https://www.endthecycle.info/stories/kazol-rekha/*](https://www.endthecycle.info/stories/kazol-rekha/)

**Hannah Kuper:** Good morning everybody. My name is Hannah Kuper, I am the professor of epidemiology at the London School of Hygiene & Tropical Medicine and also one of the two directors of the disability centre there. Thank you for those introductions. Today I will talk a little bit more about disability inclusive data

collection, and why it is so important.

So, as we heard in the introduction, 15% of the world's population has a disability. So, there are many as we saw in the video making up this 15% or one billion people. As we also saw in the video, and as we've heard already, people with disabilities are often left behind in many, different spheres of life. In the video we talked about discrimination, violence, abandonment, isolation. There's also often exclusion, in terms of education, employment and health, but what we also saw, is that this isn't necessary. And that with appropriate supports and programmes and adaptations, people with disabilities can be included on an equal basis with others.

But what that means, is there needs to be disability inclusive interventions to support the participation of people with disabilities. To start these kinds of interventions we saw of a few in the programme about things like, livelihood support or adaptations to houses. We need data. We need data to plan. We need to know what the important issues are that need to be tackled. We need data to implement. We need to know what we should do and how. We need data to evaluate, to see whether what was implemented worked and was appropriate to the needs and the desires of the people with disabilities

So, as an example, in the video, we saw that the woman faced lots of issues around poverty. And so, one of the common ways of trying to tackle poverty is through implementing social protection programmes to alleviate poverty among people with disabilities. So, we may ask ourselves is this something that the Swiss government or others should support, social protection? The first question would be the planning. Is there a need for this? Is there a need for social protection? Well, we've got this evidence from for planning where the data on disability and poverty are linked from surveys. We did a review of 150 surveys from low and middle-income countries. And showed that 81% showed a positive association between disability and poverty. The data shows us that yes, poverty and disability are linked. So, it is appropriate to try to tackle that through interventions. The second question that we may ask then, do disabled people already receive social protection? Or is this something that we should try to scale up further? Here data can help again. So, we help with the national survey of disability in the Maldives. We found that only 26% of people who were eligible for disability allowance were receiving it. So many people who needed this allowance and eligible, weren't getting it yet. A third question is then, does it work? Should we try to scale up this disability allowance? And again, data from the Maldives helped us to look at that question. And once people with disabilities were given this disability allowance, it was shown to improve health, but it showed that there wasn't an improvement in poverty. And that's because the amount given was too small. And so, that was also really valuable data for trying to improve this intervention, by saying in its current format it wasn't working, but if the amount given was greater, then it had the good possibility of trying to reduce poverty. So, when we're starting to think about investments and how to try to support people with disabilities, data can really, really help us work out what's needed and how to do it. So, data helps with planning services, with the best implementation of services, and the evaluation helps us to see what we can do better in the future.

So, how can we get more data on disability to try to answer these kinds of development questions? Well, there's been a really big improvement in the data available on disability in the last decade or so. And that's because there's more

consistency in how we should measure disability. And what the UN agencies recommend is that we use the Washington Group questions. What that means is that there are six questions people are asked. Do you have difficulty seeing? With hearing? With walking? With remembering or concentrating? And with self-care and communication? People can answer those questions and say they have no difficulty, they have some difficulty, they have a lot of difficulty. Or they cannot do that activity at all. What happens is disability, the presence of disability is indicated, if someone says they have a lot of difficulty or cannot do, in at least one of those activities. So, it is not a perfect way of measuring disability, but it is simple. It is just six questions. And it is used consistently around the world. And what this means is we can now start to generate a lot more data on disability to help us to think about programmes. So, for instance, in a programme in a big survey of people with disabilities in Nepal, people with and without disabilities were compared. In turn, they were found to have poorer self-rated health, 75% of people with disabilities, but only 13% of people without disability had poor self-rated health. Of children only 57% of children with disabilities were enrolled in school. While all the children without, were. Only 24% of people with disabilities were currently working in the last year, compared to 75% of people without disabilities. And 49% of people with disabilities faced food insecurity, compared to 26% of the people without. Using this data shows us where the needs are. Which is really important for planning. And the disaggregation of data by people with and without disabilities was identified through the Washington Group questions.

But as well as disability-specific surveys you could start to put disability questions in general surveys. So, for instance, demographic health surveys are done all around the world including recently in Nigeria. And so, you can uncover things like, whether the met need for contraception or knowing about family planning was shown to be a lot lower here among women with disabilities than women without. And the FCDO from the programmes in Nigeria is now using that to try to plan services.

So, what are the kind of options that we have for disability data collection? I've described them a little bit already. So, the first thing we can do, is disability-specific surveys. So large-scale surveys like were done in Nepal, to try to really understand what the experiences are of people with disabilities, compared to those without. And to see how we should target services. But they can be expensive so, they could maybe only be done every 5 to 10 years.

Another option is to include disability measures in mainstream surveys and the Washington Group questions are short but used widely for certain things like the demographic and health surveys, in the mixed survey with UNICEF, and in many censuses around the world. And that allows data to disaggregation, so comparing all sorts of indicators, between people with and without disabilities to see if people with disabilities are being left behind. And so, one of the things that we should all focus on is further inclusion of disability in these mainstream surveys.

But also, the analysis of the data that is collected. Because sometimes disability is included but the disaggregated analyses are not done. And the third way is using routine data resources. For instance, in the UK, people with learning disabilities can register on a learning disability register and receive additional health services. So, in the UK, we have been able to track, through that register, to learn people with learning disabilities were unfortunately more likely to die from COVID. And so, they were prioritized for vaccination. But other disabilities aren’t yet registered. So, there is less data there.

So, we can also start thinking in programmes for monitoring and evaluation, how to include disability to see whether the kinds of programmes and interventions that are funded are also inclusive of people with disabilities. When we think about where to invest and what kinds of things to do, we need to weigh up the pros and cons, in things like costs. We may get more data from the disability-specific surveys, but it is more expensive. These are what kind of opportunities there are. But also, the relevance of the data. So that we’re collecting data that helps us in planning, implementation, and evaluation. And across all of this, we need to think about quality of the data. We need to make sure that the data collected is used to inform programming. That we always work in collaboration with people with disabilities to make sure that the data collection and its use is appropriate. And that this is adequately resourced.

So, thank you very much for your time and attention. And I'm very excited to hear what the other speakers have to say on this topic. Thank you.

**Mary Keogh:** Thank you Hannah for this very informative presentation. I see there's a question in the chat box. We will come back to that at the end, Hannah, if that's okay. And now that we have the overview of the basics of data collection, I would like to invite the next set of panelists to join me for a moderated discussion. Please remember you can post your questions into the Q&A box at any time during the webinar, and please keep the chat box for the technical issues. We will have time for questions, after the moderated discussion. If I could ask the panelists to turn on their videos, please. For a quick introduction. Laisa, Christian and Polly. Laisa, are you okay with your camera?

**Laisa Vereti:** Chantal has to turn it on for me.

**Mary Keogh:** Okay. Chantal, thank you. With us today we have joining us from Fiji, Miss Laisa Vereti, Director of Operations at the Pacific Disability Forum, a partnership of Pacific organisations of and for persons with disabilities. So, good evening, Laisa.

**Laisa Vereti:** Good evening, Mary.

**Mary Keogh:** I also have with us my colleague Mr. Christian Modino Hok, Humanitarian Director of CBM Global. Good morning, Christian. And our third panelist is Ms. Polly Meeks, Independent Researcher and Consultant specialized in development finance and inclusive development. Polly, great to see you again.

So, panelists if we can turn off our cameras and myself and Laisa will keep ourselves on for the moment. Laisa, we would like to start with you first. So, the first question is. You are Director of Operations at the Pacific Disability forum, the constituency of organizations of persons with disabilities in the region. Could you tell us a little about your experience in influencing disability data collection and disaggregation efforts with national governments in the Pacific region. We have approximately five minutes, for your response. Thank you so much.

**Laisa Vereti:** Thank you, and very good evening from the Pacific it is good to be connecting and the opportunity to share the work that we have done in the Pacific region, in terms of our advocacy around disability data disaggregation. So, PDF in short, we have membership around the 20 pacific island countries and territories. And since the SDG in 2015, and then on the use of the Washington Group short set, and thank you Hannah for sharing the power-point earlier. One of the things we had to do as an OPD in the pacific to look after our membership, was first for us to school ourselves what is the WGSS 6 that is used in censuses. So, we had to, one is to advocate for the use of the questions. Two, was to target the countries that was holding the censuses, whether it is a four-year census or a 10-year census and then also to work with the regional organisations, whose work is focused on disability data and that we worked closely with UNICEF in the Pacific, as well as the regional, Pacific regional organisations specifically mandated for data and statistics. That is the Secretariat of the Pacific Community. So, we forged partnership with these two organisations to push and advocate for disability data and the use of the Washington short, set in censuses.

So, we started this work probably six years ago. I started in 2015. So, in every, since 2015 up until to date, 2020, every Pacific island countries, that has held census for the last five or six years, have used the WGSS the short, six questions. So, what we had to do as a regional OPD, we had to support our national members our national OPDs, so they know what is the tool. We had to school ourselves. Build the capacity to understand the tool, before we take it to our National government. The National Statistics Office, whom we are wanting to engage with, so they could take on the questions in the census. So, build capacity on the tool, organise the OPD to understand the questions, what it can and cannot do. Understand what data it is going to produce and how we could use the data afterwards. So, it was critical for us to form partnership with our national government and because we are a regional OPD it is also important that we work in partnership with the regional organisation, whose work is to collect data, and that is where UNICEF and our own regional organisation responsible for data collection and statistics. And they, in turn support the National Statistics Office.

So, all around with the advocacy efforts not only from us as OPDs but from other partners, the UN agencies, with INGOs that we work with and other regional organisations, we were able to, every country, I think I’ve listed 10 in the last, five years that have held censuses, who were able for their countries to use. For them to use the short six. And apart from just the census data that comes out, one of the critical areas that we looked into is just having the census report was not enough for us. We wanted to know exactly how is it disaggregated for persons with disabilities around sector areas or thematics. We wanted to know how many children with disabilities are in school, compared to children without disabilities. We wanted to know how many has employment opportunities, who are at work, who are not at work, for persons with disabilities compared to those without a disability. So, across a few sectors or thematics, we wanted to know the disaggregation, how persons with disabilities, if they are in school or not in school, found work or not able to find work. Have access to clean water and you know have access to services.

So, it did not stop at just advocating for the use of those six questions in censuses through the partnership that I mentioned with UNICEF and the regional organisations responsible for data. After the census and of course, the national statistics office had to produce all kinds of report. We had to work with them, because we wanted a disability monograph out of the census data. So, in those countries that I have listed which is on the PowerPoint, to date, I think we have six monograph, each country has a six-monograph, a specific report, specific report just on disability disaggregated across the sectors. So, you could pick up a disability monograph, let's say for Samoa, and you could see, in terms of education, health, WASH, employment. So, this is some of the things that we have worked together with our members and also with the supportive partners to be able to focus on disaggregated data across the countries.

**Mary Keogh:** That was great, Laisa. Laisa, could I just come in. Thank you so much I don't mean to cut across, it is just in terms of timing it is really interesting and quite an exciting and interesting journey that you've been on with PDF, and thank you for sharing that. Maybe we have a second question to ask you. I think you started to speak about it. Now that you have more data available through the census and additional disability survey. Can you share an example how this data has been used to support interventions, to address the barriers faced by persons

with disabilities and again, Laisa, just to say five minutes. I'll come in if I see you go over that. Sorry to do that, it is just we have so many people to hear from. But over to you Laisa for that question.

**Laisa Vereti:** Definitely. So, for the countries that I had mentioned that has done censuses, most have ratified the CRPD and hence the state obligation. That's why we pushed hard on disaggregated data. Now that we've had in those countries

the disability monograph, one of the areas that have really helped us to push some of the advocacy, in terms of services or even in terms of support. And one of those is social protection.

There are a few more countries who are developing their social protection for persons for disabilities in particularly the disability allowance. These countries that have used the disability monograph data collected through the census, you know as in terms of to add on to the identification of persons with disabilities, so it was easier to go back to the disability monograph and in using those census data through the monograph to identify, in terms of the degree Hannah talked about the responses those responses would indicate the degree of difficulties or the severity of difficulty in performing those activities, whether it is seeing, hearing, walking, remembering and concentrating or communication, including self care. So, because it was new, because it was new for us to advocate and because we wanted support, because the data shows that, not many persons with disability found employment or are at work. So, in terms of income support or in terms of meeting the extra cost of the disability is always burdensome for the family. So the advocacy for the disability allowance went back to use the disability monograph data collected from the census and the monograph. So that has been helpful, because when you ask, what are the data there? We have the disability monograph. You can start here, while you develop systems and processes, and your identification. This is the first place that you could start, in terms of how do we allocate resources? And how would we resource disability allowance. So, it’s new for us in the Pacific. There are many more countries who are developing their disability allowance as part of their social protection scheme. These countries have used this data as a first point of point of reference on how do we identify and understand the severity of difficulty of performing those activities for person with Disabilities.

And this side of the world, for us, we face, you know category four to five Cyclone almost every year. If it is not us, it is another part of the Pacific. The preparedness and response, and recovery. This data that is collected through the census and now with the monograph is quite helpful. And I could add, in terms of

education, you know in terms of employment, in terms of assessing health services, in terms of WASH, and there are many more to add to that. Maybe Mary, I can stop here, with that brief. If there are questions or comments I could take later on after the session

**Mary Keogh:** Absolutely. Thank you very much. We will come back for questions and answers. And thank you so much for sharing the experience from the Pacific region and why advocacy and data disability collection is so important and the impact it can have.

We would now like to move to Christian Modino Hok. Christian will give us a humanitarian perspective on the importance of disability-inclusive data in humanitarian emergencies. Christian, lovely to see you. Christian, the question first and foremost to you is: why is data important to ensure disability inclusive humanitarian programming? Could you give us some examples from your work, thank you.

**Christian Modino Hok:** Thank you very much Mary for your question and Hello everyone. Yeah to, answer disability inclusive data in the humanitarian sector is still an emergent area. So often data collection or disaggregation methods are insufficient which leaves significant gaps in the evidence and inclusion across most humanitarian contexts. Although there has been some progress and effort to raise awareness in developing tools new guidance and good practices from some organisations. Generally speaking, the humanitarian sector is far from delivering consistent disability inclusive programming.

So, what is really the problem or the challenge? One is that humanitarian actors do not know how many persons with disabilities are affected in a given crisis. The second challenge is that humanitarian actors are lacking information and knowledge about available or appropriate tools to collect disability data in humanitarian settings. Often, they use binary yes, or no questions, such as do you have a disability or medical condition? Which leads to underreporting. So, this is one of the main reasons why persons with disabilities face exclusion and discrimination during humanitarian crises.

So why is data important then? First of all, it is to identify populations with disabilities. So, we need to get a sense of prevalence. Just to give an example in the Syria humanitarian crisis, OCHA identified approximately 12 million people in need of humanitarian assistance. Out of which three million were persons with disabilities. So, this gives a sense of the scale. And helps also to plan accordingly. The second reason why data is important is to analyze the risk persons with disabilities face and the factors that contribute to those risks. This includes also the effects of crisis in mortality, in the nutrition needs, food security, health, and other essential needs. Thirdly, data is really important to identify barriers, be it physical, attitudinal or institutional to accessing humanitarian services, but also the enablers. It is important to see also what allows the persons with disabilities to access those services without which, there is no way of providing inclusive services. Maybe lastly, data is really important in humanitarian contexts, to hear and to know and understand the roles and the capacities of organisations of persons with disabilities, as well as their views and priorities. I think, you know without this humanitarian organisations cannot be really accountable to affected populations. Nor to develop fruitful partnerships with organisations of persons with disabilities.

The modalities that organisations use to collect data in humanitarian settings, depend on mainly two, big factors. First, the context you're operating in. For example, in sudden on-set crisis, an earthquake, for example it is very hard to collect detailed, individual data early in the response. So, efforts should be made in those contexts, before the crisis hits, so during the preparedness phase. So, there are contexts in which we know that crises may happen regularly. There are high-risk contexts. So that data needs to be gathered, beforehand. So that when response happens, you have already preliminary data that helps inform your programming. Other contexts, such as displacement of refugees, emergency data is usually collected at the individual level during the registration of refugees. It is difficult to get that data beforehand. And another context, such as protracted crises, be it cyclical or frequent droughts, let’s say in the Sahel region, data can be collected frequently and used to help monitor the performance of humanitarian programming. So that is the modality, considering the context you're operating in.

Also, it is important to consider the sectors of intervention and the objective for collecting the data. So, for example, if you're an organisation focusing on delivering WASH services it might be important for you to understand if some persons with disabilities may be more at risk of dehydration, showing that you need to provide more clean water for example. You may find that some other people have issues of incontinence and need extra water and materials for incontinence or safe waste disposal. Similarly, if you’re an organisation focusing on shelter. You might need to, for example, and working for example in evacuation centres, you might need to collect data on the accessibility and the safety of the premises of the evacuation centres. So, all of these factors determine the type of data collection tools and methods used and maybe lastly it is important to disaggregate the data by sex, age and disability, in order to understand the different ways in which persons with disabilities experience the crises. And so, that you can monitor their access to assistance.

**Mary Keogh:** Thank you. Thank you, Christian just coming to the next question for you. Again, sorry for cutting you off, just in terms of time. What are some of the existing data tools that the sector can utilize for humanitarian programming?

And how have these tools been used so far. It would be great to hear a little about those tools.

**Christian Modino Hok:** Yes, thank you, Mary. There are not a huge amount of tools, but the most widely tested tools used to generate comparable data of persons with disabilities are the Washington Group set of questions. They are increasingly used in humanitarian contexts. They are very useful to get a sense of prevalence and disaggregation, however, they are not useful for the identification of specific health conditions or diagnostic categories. And the Washington Group set of questions do not address mental health or identify barriers persons with disabilities face. So, this is a set of tools, which is more and more being used in the sector. There is also the extended set of the Washington group, which contains additional questions that capture information around anxiety, depression, pain, fatigue, use of assistive devices and other environmental factors. Another tool is the UNICEF Washington group child functioning model. This is slightly longer than the Washington Group but gathers data on children and youth in the range of 2-17 years old. Normally the respondent tends to be the primary caregiver and not the children in question. Humanitarian inclusion has developed a couple of years ago a very good learning tool kit around collection of data and the application of the Washington Group questions. This is a tool that we can definitely share. And it is a self-training tool kit, which is really good. The International Rescue Committee has also recently developed a very good toolbox. It is called the inclusive client responsiveness guidelines. And among other things, it provides very good guidance on how to conduct focus group discussions or key informant interviews, which are inclusive of persons with disabilities. This is particularly important, when

collecting qualitative data, as the Washington Group questions offer a lot more ability to get quantitative data.

But qualitative data needs to be gathered through other tools. It is recommended for humanitarian actors to use secondary data as

well, be it government statistics, refugee registrations or service. However, when using secondary data, it is important also to consider and take that with caution. How is the concept of disability understood for example? Or is stigma a factor? What counts as a disability? Or for what purpose is disability collected? So they have to be used with caution, but they remain a useful resource. When it comes to identify barriers of persons with disabilities, accessibility audits are a good tool. They help evaluate the level of accessibility and safety of facilities and service delivery, for example. Post distribution monitoring systems. There are questions that can be added to the post-distribution, also to assess how adjusted and adapted the services are to the needs of persons with disabilities. And I think,

feedback and complaints mechanisms are also a very good tool to gather more

information. Where we get a lot of demands by the sector is how to make the feedbacks and complaints mechanisms accessible, which is an area of research at the moment.

**Mary Keogh:** Thank you very much, Christian for giving us insights into the humanitarian side of disability data collection and analysis. And I realise there's questions coming in. Don't worry, we will get to them after our next panelist our final panelist. I would like to turn over to Polly Meeks who recently conducted a series of Factsheets on disability inclusion in international cooperation of several European countries, including most recently for Switzerland. Polly, you have recently undertaken this research on the status of aid spending on persons with disabilities in various European development agencies including most recently, as I said the Swiss Development Cooperation. What have you found? What are some of the main gaps in terms of data? Over to you, Polly.

**Polly Meeks:** Thank you, Mary. I looked at 11 major development agencies all together. And in looking at their use of data I was looking from two different angles. First whether they were collecting data on the objectives of their projects. Whether these projects intended at the outset to be inclusive of persons with disabilities. Then secondly, I was looking at whether these agencies are gathering data on the results of their projects, whether those projects were actually accessible to and inclusive of persons with disabilities in reality.

So, to look at the first of these angles on the objectives of the projects. The main tool that I was looking at there was a relatively new tool introduced by the Organisation for Economic Cooperation and Development called the disability DAC Marker, which allows agencies to record data on whether they aim to be disability inclusive and then that data can be aggregated on a centralized database. Positively I found that Switzerland is making use of the tool. That's already a good start, because not every agency that I looked at was making use of it. But then, less positively, I'm going to try to share my screen here. Switzerland was only using the tool for a minority of its projects. So, in 2019, only 13% of Swiss official development assistance projects were assessed using this disability marker tool. So, in other words, for the remaining 87% or projects, we just don’t have any data on whether they aim to be disability inclusive or not.

For the second angle that I was look at, that’s data on the results of projects, as other panelists have mentioned, key tools here include both quantitative and qualitative data collection methods. positively I found that the Swiss agency on development and cooperation has guidance that encourages teams to, in fact, requires teams to gather disaggregated data by at least one risk factor in being left behind. It could be indigenous status, ethnic minority, LGBTQ or disability.

There would be some disaggregated data and there is also an encouragement

To gather qualitative data. But what is missing the systemic requirement that among those different risk factors on being left behind, that the data on persons

with disabilities has to be gathered systemically and consistently across all projects. So, I guess to sum up, what I found was that there's a real opportunity here for Switzerland, because it is already been making a good start, but it could easily build on the start that it has made and become much more systemic in the way it gathers data on persons with disabilities, both in terms of whether there is an objective to include persons with disabilities at the outset of projects and in terms of whether the results of projects are actually inclusive of Persons with Disabilities in practice.

**Mary Keogh:** Great, Polly. Thank you so much for that. And thank you all, to Christian and Laisa for sharing your distinct perspective on the issue of disability data and joining us in the discussion this morning. I think we learned a lot from your different experiences. I'm conscious of time. We roughly 12 minutes left and

great that we have a lot of questions coming through. So, I'm going to just select some of them and suggest that if we don't get to all of them, which we won’t, we will try and find some way to send the answers with the recording, because we

do have the questions recorded. So, Polly, Christian, and Laisa, and Hannah, I think you're also still in the room. Polly, if I could just come back to you because you have spoken about the DAC Marker. There is a question in chat, which one of the colleagues has also answered. But just maybe for a quick in sight from you around the implementation of the Marker so far for the Disability DAC Marker and the reporting of the codes associated with the Marker without going too technical.

Maybe just to hear quickly from you. That would be great. And welcome to the other questions then.

**Polly Meeks:** Thank you very much for the great question. I think in a nutshell there's good news and there's bad news. The good news is that the Marker has been taken up quite extensively. I don't have the exact number at my fingertips but roughly about 20 out of the 30 members of the DAC are already using the Marker. So that's really positive. I think that the less good news is, as you implied with your question. There is still a big question mark over the quality of what they're recording. And based on some of the attempts I've made to triangulate the marker data with other sorts of data, I think the quality is very be variable. But for me, the most important thing is that the Marker is now getting used. I think that as the Marker is used more and as people increasingly use the data for scrutiny and advocacy work, I think the quality will follow automatically through that conversation and that process.

**Mary Keogh:** Thank you for coming back. Absolutely it will take some time for that to come about. Okay so, there's a few questions in the chat, which are very much related to the Washington Group questions. I know our panelists have a vast amount of experience in different technical areas I might just put it open to whoever would like to answer this question. I will just group two of them together. There's one from a colleague asking about how national governments can administer the Washington Group questions effectively and linked with that is, in some countries we see that the Washington Group questions can end up having a lower prevalence rate. I don't know, in terms of our colleagues who would like to answer those questions or address them now. If there's anyone from the panelists that would like to address that. Hannah, there was a question directly to you about your presentation that I will come to quickly as well. So maybe, Hannah do I see you're taking your microphone off, if you're happy to address one of those questions, please feel free to do so.

**Hannah Kuper:** The Washington group short set is designed to be simple and easy to use. In terms of how to use it, you should be encouraged to use it widely, whether added on in the census or added on in other, specific surveys, or considered within things like project evaluation or monitoring. So, there are all different options in which you can use the Washington Group questions. It is only six questions. As is being pointed out, those six questions don't include a focus on mental health aspects. So, it will, underestimate the prevalence of disability, plus the cutoff is people with a lot of difficulties or more. That can be a little bit subjective. So, we do know that it is useful for comparing people with and without disabilities. So, people who say they have a lot of difficulties with the Washington group questions and people who say they don't, to see where the big gaps are.

But we also know that there will be an underestimation in the prevalence of disability. So, we just need to be a little bit cautious, when we're interpreting what it really means. If you really want to know prevalence, you may want to move to more extended sets, which also include mental health questions, things of upper body. I hope that answers that question.

I think the second question someone put in the chat was about this estimate about children with disabilities in school. What it meant was that among children in the survey in Nepal, 57% of children with disabilities were enrolled in school in Nepal, compared to all of the children, without disabilities. So, it showed that almost half of the children with disabilities were not registered at school let alone attending

school, whereas all of the children without disabilities were registered.

**Mary Keogh:** Thanks Hannah. Thank you for answering that and thank you Polly also. I think in terms of just time, I might hand back over to Mr. Christian Lohr, and for some closing remarks and Christian, please turn on your camera there. We would love it hear from you and I will come back then in terms of final wrap-ups for the webinar. Over to you Mr. Christian Lohr. Thank you.

**Christian Lohr:** First of all, I would like to thank every participant and all panelists for the great engagement today. I'm sure we had a really great morning

because we got a formidable overview about different points and I'm quite sure

this morning these different contributions will bring us further today and for the future. We saw today how important it is to collect and exchange data. There are still actions that need to be taken to improve data collection. The data needs to be taken in a meaningful way and within a certain time frame. In order to make proper help and assistance for disabled people. Especially in crisis. We heard today that disability is in most countries of the world linked to problems like poverty, social insecurity, low-level of acceptance or unemployment. But I also say we saw this morning that there are tools available and there are great people that are concerned about making the life of disabled better. I hope that existing problems regarding data can be faced in the future. But don't let us forget data is only

about medical diagnoses, and numbers and figures. But there are humans behind these diagnoses, and we need to see them and their personal situations. Our main goal should be to engage in the life perspective of these people, and to improve it.

Ladies and gentlemen, I look forward to welcoming everyone to the World Data Forum in Bern from 3-6 October to continue the discussion on data and to make sure no one is left behind, including through inclusive data collection and analysis.

Thank you very much.

**Mary Keogh:** Thank you, Christian Lohr for those reflections and I think that really important point that humans are behind data and must make sure to leave no one behind. We're absolutely really looking forward to following the World Data Forum as Switzerland hosts it later in the next, couple of weeks. Lastly I would like to thank you all for joining this webinar today. We've had a very packed agenda. So, I would like to thank all of our speakers for sharing their different perspectives. We will be posting the recording of today's webinar on CBM Switzerland’s website under the same link as the registration. I would also like to thank also our captioners and our interpreters for joining us today and I would like to thank all of you participants for attending and for giving us some good questions and for interaction. I wish everyone a good day. Thank you everybody. Take care.