These are the scripts of the speakers of the COSP-18 Side-Event held on Tuesday June 10th from 11 am to 12:15 pm EDT titled:

“Monitoring Social Development and Inclusion at the Local Level:

Evidence from Diverse Data”

Minor edits were made to the scripts for clarity.

# Alfred Smith of the Global Disability Fund Secretariat is delivering introductory remarks:

This includes having robust evidence and data gathering systems to collect, analyse and use accurate data to inform effective policies and programs at local level.

Our programs address these gaps and ensure an effective bridge between national and subnational data systems and local service delivery. For example, our program in Guatemala has worked to strengthen disability data systems in the municipality of Camatan, to accelerate service delivery across sectors through the integration of Washington group question sets into the administrative registry and embedding inclusive training into workforce competencies. Program partners have conducted surveys and applied georeferencing tools with a local organization of persons with disabilities from Piendo Limites and Vivamos, or breaking boundaries and living better, and through that they've been able to register an additional 713 persons with disabilities to community services as a result.

So the importance of localization and accelerating both service delivery and the meaningful engagement and participation of OPDs (Organizations of Persons with Disabilities) in all development processes is central to the Fund's strategic thinking.

We're finalizing our New 5 Year strategy, which is placing, working at city level through the resilient and inclusive cities’ hub launched at the global disability summit in Berlin and localization and strengthening service delivery and data systems at subnational level really at the heart of what we do.

Crucially, this includes deliberate funding and technical assistance to work with local communities, persons with disabilities and their representative organisations to help shape and monitor the change. Our programmes are trying to deliver and systematically report back to us on how we can and should improve our approach at the local level.

So I think this session today will help us explore how all development partners can better monitor social development and inclusion at local level. And we very much look forward to the discussion. Thank you.

# Claudia Cappa:

Good morning, everyone. Thank you so much, Alfred, for your intervention. My name is, I work for UNICEF in the division of data where I'm responsible for statistics related to children with disabilities.

I've been asked today to be the moderator. I'm obviously very pleased to have this role, but I also feel slightly hypocritical because I normally tend to speak more than the time that is given to me. So I'm gonna try to see if at least for a day, I can make other people enforce. I can enforce rules that I'm the 1st one to break. So without further ado, to make sure, we go smoothly into the program. It's my pleasure to welcome. Now, Elizabeth Lockwood.

Elizabeth is CBM Global’s representative at the United Nations, where she develops advocacy strategies to raise awareness, strengthen capacity, and lobby for the rights of persons with disability. Elizabeth has been working specifically on data and promoting the use and the availability and quality of data for persons with disabilities. So she brings the wealth of expertise, of bringing together the data, passion and knowledge together with the activists. Elizabeth will also share her time with Kasper Bergman, who's from Denmark and Vice President of the World Federation of the Death. He is working as the head of international cooperation at the Danish Deaf Association overseeing development partnerships in over 10 countries globally. So very pleased to start with this intervention, we both have 10 min to deploy yours. Thank you.

# Elizabeth Lockwood:

Thank you, Claudia, and thank you everybody for coming today. I'm very pleased to be here speaking. There are significant data gaps for persons with disabilities, as we all know, especially those of you in this room. And one way to address these gaps is through an intersectional approach and using citizen data. So I'll be talking about citizen data today, and particularly led by organizations of persons with disabilities.

Citizen data defined are data that individuals, communities, or their organizations produce to directly monitor, demand or drive change on issues that affect them.

And citizen data produced by OPDs can critically fill data gaps, especially in that intersectional lens that I mentioned, and in particular, partnering with national statistical offices in an atmosphere of co-creation and co-ownership.

A little bit about citizen data. Citizen data are increasingly being recognized as a complement to official statistics, to measure, especially things like the Sustainable Development Goals or the Convention on the Rights of Persons with disabilities. Citizen data are generated in many ways, including surveys, telephone calls, emails, reports, storytelling, and even social media.

Citizen data can be quantitative or qualitative, structured or unstructured and open or closed. But very importantly, citizen data are a useful complement to institutional data, but not a replacement.

I think that's very important to emphasize citizen data are often local or community driven data as an example, last year in Bolivia, with the International Disability Alliance, we co-facilitated a training on data advocacy to 35 organizations of persons with disabilities.

And what we learned from that training was data do not reflect the reality of the lives of people with disabilities, especially at the local level. Most communities are collecting their own data, but don't really know what to use it for or how to complement it with the government.

Most data being collected have never been collected before. So this is really important, especially looking at human rights, such as access to health, education, accessibility, and language, even within persons with disabilities, own families.

And even when OPD leaders connect with government officials very little changes.

So there's a lot of work to be done. But there is positively a lot of increasing data projects between citizens and national statistic offices with initiatives like the collaborative on citizen data. And this is multi stakeholder in nature. And so we are part of it. And then we have the UN Statistics Division and other NGOs like Open Data Watch. And this is a real, excellent example I think that we can replicate and strengthen. And now I'm going to hand over to Kasper, who will share another example. Thank you.

# Kasper Bergmann:

The World Federation of the Deaf is an international government organization that represents and promotes approximately 70 million deaf people's human rights work worldwide through our advocacy work with 138 organizations which are national deaf organizations.

In our work, we have discovered that there's a lack of data on deaf people and their experiences.

For example, we want to know how many deaf people our native sign language users that kind of information is non-existent. Yet it's essential to have effective public policies which will guarantee our exercise of rights. As a result, the World Federation of the deaf supports, deaf-led research to collect data on deaf people that otherwise would not have been collected.

Very few deaf people participate in general surveys on persons with disabilities. This is because there are no surveys in national sign languages and because of a lack of cultural awareness of deaf people. Deaf-led data collection is especially important for deaf people as minority language users of national sign languages.

Thank you so much, CBM Global, who has provided financial support for us to carry out deaf-led citizen generated, and intersectional research in Bolivia on barriers for deaf, indigenous women and what they encounter when they access healthcare services. The data is powerful. And it's important, since these women are among those most left behind by the intersection of deafness, gender, linguistic identity, and indigeneity. Our data found from the 20 indigenous women who were surveyed at multiple points. I'll share them with you now. Vastly, the majority were raised by hearing families without any sign, language, access in their home.

And most of the hearing families of deaf people do not learn sign language for those family members. Those indigenous women have no access to sexual or reproductive health education. They're in a situation of poverty and limited education, access a little more than half in the data collection, have healthcare coverage. Yet they are unaware of family planning and they may have unintended pregnancies because of their lack of education and access to it. The main communication barrier is a lack of sign language, interpreters in healthcare settings and the lack of health care, education in sign languages, their testimonials, highlighted, powerful stories.

All of the deaf women interviewed were victims of rape and abuse, and many did not even realize that it was abuse. The abuse was from family members and partners. Overall, they had a lack of health information leading to greater health risks. They had a much higher risk of stigma and marginalization related to disability, gender, linguistic and ethnic biases overwhelmingly. There was an absence of opportunities to seek help and assistance in their sign language. They depend constantly on friends and family for health information. They also depend on family members to interpret at healthcare appointments which violates their rights to privacy. And often the family members interpreting could be the abuser of the deaf woman.

They also highly experience misunderstanding, and isolation within their own families. All participants were eager to receive proper sexual and reproductive health education through workshops in Bolivian sign language. This shows the necessity of providing culturally and

linguistically appropriate health information in native sign languages. This example of citizen generated data provides new data that has never been gathered before. Importantly, it highlights, barriers and gaps that need to happen in order to affect policy change. In summary. I'd like to provide some rec recommendations from the research gathered. First, I would like to propose to the health authorities of Bolivia, in conjunction with the World Bolivian Disordo FEBOS, and the World Federation of the Deaf, to provide informational sessions to healthcare staff on how to provide the highest quality of medical care for deaf people, including awareness on deaf culture and the use of Bolivian sign language. Next, I would suggest providing educational workshops and health knowledge for deaf women, particularly deaf, indigenous women about their own reproductive and sexual health allowing them to take charge of their own health issues in their native sign language. Third, I would highly suggest developing decolonial programs in hospitals and schools on how to work with deaf people and the direct participation of deaf experts will be required to address gender biases. Thank you so much for your time and again, thank you so much to CBM for your support.

# Claudia Cappa:

Thank you so much, Elizabeth, and thank you, Kasper, for providing this very powerful example of how citizen generated data can contribute to knowledge that otherwise will be lost in in official statistics. Now it's my great pleasure to introduce Dan Mont. Dan Mont, who is one of the founders and the CEO of the center for inclusive policy. Dan Mont is well known for his extensive knowledge and experience in working on disability, data and disability policy. Dan, you have 10 min. The floor is yours. Thank you.

# Daniel Mont:

I'm going to talk today about inclusive education management systems, the kind of data we need to try to ensure that all children, regardless of disability, receive an education. They have a right to. When we think about data, when most people think about data and talk about data, they're usually referring to surveys and censuses and things like that. That's what 1st comes to mind, something which I think gets neglected. A lot is administrative data and the power of administrative data, its advantages, and how it can be used in a complementary fashion, with survey data to give us a full picture of what's going on.

So a good example of this, where a lot of work has been done recently is with education, management, information systems or EMISs. Now, if I wanted to look at the school system. I want data on several things. I want data on children with disabilities in school and out of school.

I also want to know about the environment. I want to know about the accessibility and inclusivity of the school, and I want to know what barriers there are to receiving that education. When it comes to children with disabilities, I want to know how many of them there are, what kind of difficulties they have, what kind of supports they need. How that varies by age or gender, and, importantly, how their outcomes are different from children without disabilities, or even among different types of disabilities. You know what children are dropping out faster, not getting the education that they deserve. And one important source of information on this are EMIS. EMISs are, if they're run well and they're not always run well, censuses of schools, every school gets asked to report on the children in their school and the environment in their school. And this is the data that the Ministry of Education uses to administer their system and EMIS at multiple levels. It could work at the classroom and child level. Oh, this is a child I've identified as needing some sort of support. It works at the school level as the school administrator. What kind of resources does my school need? What's happening in my school? How can I manage my school? And it works at the national policy level and in terms of what's going on in the country. How do I plan for various interventions or improvements in my system? And one neat thing about administrative data is when it comes to evaluation. Quite often we want to do an intervention. We say, Oh, what's the comparison group? What's the control group? We have to go out and collect all this data before we even start doing anything. Otherwise we can't have a robust way of seeing what happened. But if I have an Ms. That's collecting data on all the children, all the environment. And I do an intervention in that school. I already have my baseline. It's there for me right away. So it's actually, if you have a good administrative EMIS you're set up really well to see what the impact is of your various interventions.

What the EMIS doesn't have is information on the children who are not in school, so we can see. Oh, that a child with a disability gets to school. We can see how he or she is doing. What we don't see are the children who never make it to school. For that we do need those surveys, those household surveys. But what's important is that the way the children are identified as having a disability in both systems, are the same, right? If my EMIS asks you, does this child have a disability, and my household survey is using the child functioning module developed by the Washington group and UNICEF. We can't make that comparison because we're not really identifying the same children. So if we have the Child Functioning Module (CFM) in say, MICS or other household surveys. And we have this child functioning module teacher version, which is an adapted version of the CFM that's been tested and approved in schools, then we can actually say, Oh, these children who are out of school, and these children who are in school have the same functional difficulties. And we can make those comparisons. And we call this data harmonization right? We want wherever data is being collected in the system, whether it's surveys or administrative data. We want to have some core set of questions that are the same

everywhere, so that we can use those 2 different data sources together, and it makes them really powerful.

It also reduces confusion, because, as we all know, one ministry or one survey says, disability is this percent. Another one says it's something else. And you say, what's going on here? You people don't know what you're talking about. But if we have a common set of questions, we can have a better understanding of what's going on. But we want to move beyond the data on the children. We need data on the environment.

Now, already, most EMISs collect information about the environment on the structures of the school, the materials of the school, the human resources in the school. It's all in those EMISs already. What we need to do is to make sure that as part of that information we're asking about the accessibility of the school. We're asking about the human resources in the school, the materials in the school, so that we can get a full understanding of the environment in which the students are learning in. We can do this one of 2 ways. We can take the EMIS as they exist now, and tinker with them, and some countries have done this. Oh, we used to ask, if you have a computer room now, we'll also ask if it's accessible.

This is not great. It's better than not asking what's better, though, is actually designing, emiss with questions that more accurately capture the various aspects of the school, and that is starting to happen. So again, some advantages of this administrative data is the entire population of the is in the program. Every student, if the Ms. Is being run right, every student in the school is being entered into that data. It's ongoing and sustainable. I don't have to raise money and say, where am I going to get my resources to do this survey. It's happening. And it's been happening. It's officially recognized data. So it's government's own data that so it's they can't hopefully say that this wrong and it can also signal the importance of issues. So when we tested the child functioning module teacher version in Belize, a lot of the teachers were like.

Why would I ask these questions? You're asking me these questions, but as they were going through it, they said, You know. I never thought about staying on task, or having friends, as not being able to make friends as an issue that might be indicative of a child with a disability. And you're asking me if my toilet is accessible in the school that signals to me that you care that it's accessible in school, and I'm going to get downgraded if it doesn't show up. So the very act of asking these questions, I think, does raise awareness. I'm trying to think how much time I have. Okay, okay, so what's going on in the world right now, when it comes to EMISs? More and more countries are collecting data on children with disabilities I did. Aa=bout 10 years ago I reviewed 70. There weren't a whole lot of them that asked about the disability status of children.

Now, there is a lot right. It's probably more than half of them. It's my guess. Unfortunately, they're not using the child functioning teacher version. So the quality of the questions identifying children with disabilities does vary. And we want what we want to do is we want to improve those questions. But the fact that they're asking about them now is good.

There also have been gains in environmental data, though not as much. There's been much more effort on trying to monitor the children, but not look at the environments in which they're learning it. But again, even there, there has been some.

There's some advancements. When I was down in Belize I was very happy to see how many questions they had about the accessibility of the school. Were the teachers trained in Fiji? They actually ask, you know, do you have our speech therapists available? How often are they available? Are they available in your school, or do you have to bring them in right? So they're really capturing. There are examples of places that are really capturing the resources, the environments that are there. So I think EMISs are improving. I'm about to take part in a Unesco course in Africa. We're trying to help several countries there improve their EMISs. And I think it's not only good for EMISs, I think it's also a good example for other administrative systems, and for us to think about what we think about when we think about data. The surveys are super important, but the administrative data should be part of the our attention as well. So thank you very much.

**Claudia Cappa:**

Thank you so much, then, for showing how the image can be an important data source ability with the right adjustment that you just mentioned. Now we are going to talk about surveys. We have the pleasure of having Ben Mayala with us, who is an experienced geospatial and data science, professional. With over 19 years of expertise and experience in applying geospatial analysis.

Ben has been until recently served as senior geospatial advisor at the Demographic Health surveys (DHS) that, as we know, unfortunately, has been suspended. The DHS has been an incredible source of data across. Several indicators will be on children and families, including data on persons with disability. So Ben is going to show us how we can actually use survey data to model district level analysis. Thank you. Ben.

# Ben Mayala:

Thanks so much. So I'm just gonna show the advantage of trying to use new technologies to estimate indicators at a lower geographic level, the second administrative (Admin 2) subnational level or district level.

People with disabilities face so many challenges, and including multidimensional poverty and their wellbeing needs to be monitored at national and subnational levels. If you compare functional difficulties questions, you know, particularly from surveys, they are increasingly available at national levels in surveys and censuses. So this information can be used to identify, you know, people with disabilities and to monitor their well-being and rights situation and also measure inequalities and gaps.

Population based surveys are designed to produce estimates at a national level also, sometimes for urban areas and rural areas and also at the subnational level, we call Admin one level. I'm going to talk more about that.

Presenting information at a national level, we might miss some information that are very useful, you know, for like in the realization of human rights.

So why we decided to do this, we, Sophie and other people in the team, we wanted to see how we can take advantage of the Demographic and Health Survey (DHS) data set and see how we could estimate indicators at a lower level, which we believe is useful for decision making.

So DHS, or demographic and health survey, as you know, is a national representative survey. You know it has been there for over 40 years. We don't know the direction, but just to inform you there's no DHS at the moment. We used to conduct, you know, large surveys from 5,000 to 30,000 households. And we collected so many data sets. When I say a lot, you're talking about over 1,000 indicators. And typically this data is we collect after every 5 years at least, we'll go to a country and then collect a data set. I just want to provide a quick overview like what we define when we say, what is admin one level, what is Admin 0 level and what is Admin 2 level. So basically Admin 0 is the nationa level. It is very useful if you want to compare data from different countries. And also the audience for this particular data set is more international organizations, international policy makers and donors.

Now, if you go to the subnational level which you say Admin 1 level, it's more useful when you want to compare regions or provinces, and you want to evaluate what are the differences between estimates in these provinces. But if you go to a lower level, the Admin 2 level, this is u

useful because that's where programs are used to target different issues in areas that have been affected.

So what we thought like, okay, what are the possibilities? We, you know we can, you know, make DHS or surveys more useful. We thought, maybe if we increase the survey or we increase the population, maybe it could be one approach, or we could use data from a health management information system. But we realize that, you know increasing the survey size is very, very expensive, and is not feasible in countries with limited resources. But also, if you talk about the health management information system data, the quality is very, I think most of the people we can agree like, it's very, very low. I mean, I don't want to use the word poor, but it's not a very good data set. So we thought, I think if we have whatever amount of data and then use other information, I think we're going to produce something that is more useful. That's why I talk about the geospatial modeling approach to you guys.

So this is a very simple approach. What we normally do, we use satellite image data set and the data set we're talking about (the DHS). Satellite image datasets are given at a pixel level. We say grid, level, and satellite image can be at a very high resolution even up to meters.

An advantage of a satellite image data set is that at least you have values everywhere. If you're talking about a 1 by one kilometer, pixel, you're going to have a value at that particular grid. So if you're talking about rainfall temperature, you know, population density, and other environmental data set. So the approach that we normally use is that we try to integrate these 2 data sets.

because surveys are sampled. So you might have a point where a surface sitting. And then another point somewhere, like maybe 2 kilometers from here. But when you come to geospatial coverage we have data. So that's the approach that we use to come up with the estimates. So over here, I'm just presenting or showing some examples of the geospatial coverage from different sources.

So just a quick overview. Normally, this presentation takes a lot of time. But I want to just try my best, you know, not to go into the technical terms. So what we do basically our approach, I'll just go to this wonderful figure. So we have a Dhs data set, and then the different geospatial cover it as our input to the model. And then we fit a model. So our modeling approach for me, I can say, is very simple, but basically straightforward. So what we do, we fit machine learning models.

There are different machine learning algorithms that we use. And then once we fit the model and then we have now our final model whereby it's an ensemble. So the output from the machine learning techniques is used as an input in our model. And then, of course, we use like a Bayesian approach to run these models. But if you do like the ensemble, at least you know, you

are sure that you're coming up with a very good estimate. So for people who have some ideas of geospatial data set or GPS data.

so we have a point here and another point here. So one approach that we like to include in our modeling work is to the term called special to correlation. Basically, we want to take into account. If 2 points are close together. They have similar characteristics. That's how we take that into account in our modeling, anyway, I don't want to talk too much about that, but in the end we produce estimates

at the pixel level, and then we use population degree data set to produce. Now estimate at a Admin 2 level which now is very, very useful for countries for making decision.

So in our work that I want to finalize, we were able to model different functional difficulties. So one of the indicator is the percentage of adults who have some difficulty, those with at least a lot of difficulty or those with any difficulty. And, as I said, this data is from the DHS surveys. And we did for South Africa using the 2016 DHS. But our goal is to see if we can also model other countries, even those from the recent surveys.

This map is just showing some variation of the different estimates within the country at the Admin 2 level. But also we are able to make a comparison with the direct estimates from the census at Admin 2 level. And of course, as you can see, we see like there's some similarities, you know, areas whereby we have higher modeled estimate have direct estimates in the census.

And my last slide here shows a map the percentage of those with any difficulties who ever attended school at Admin 2 level.

So the advantage of our approach. Now, at least, you are able to mix or combine data from different levels. And the last slide here, I think, I said last slide, but this, for sure, is the last one showing. Now again, you know, admin 2 level rates for any difficulties again trying to compare also with the community data set.

And so this is something that I wanted just to share with you guys. But there's like a lot of work that is being done, and we have done for so many other indicators and countries. Now, they're like demanding admin 2 estimates, because it's very useful for them, for decision making. And our approach can be used to any indicators, not only the DHS indicators, but even other data sets that they collected GPS location.

# Claudia Cappa:

Thank you so much for your intervention. And now, without any further ado, I'm going to give the floor to Sophie, who is the organizer of this event and Professor of Economics at Fordham University. She's also the founding director of Research Consortium on Disability and the founder of the Disability Data Initiative. Sophie, the floor is yours.

# Sophie Mitra:

Hi, everyone. So I'm going to present on some of the results of the disability data initiative on local statistics. So if you're not familiar with the disability data initiative, it provides analysis of disability data to help advance human rights and sustainable human development. For all.

It is an interdisciplinary and international team of collaborators in Africa, Latin America, Europe, North America, and Asia. So I'm going to share with youa database. So if you want to, while I'm walking you through some of the our results, the database can be accessed on the website. And you can maybe play with the website on your device. The website is disabilitydatainitiative.org. And on that website on the upper horizontal menu. You have “databases”. So if you click on that and then you click on disability statistics estimates database. Then you're going to be on the database that I'm going to present. Okay, so what is the Disability Statistics Estimates database about, or DS-E: it was created to produce estimates of disability, inequalities across countries using internationally comparable methods and data. So it's a novel database and grounded in human rights in a human rights framework. So far, we have results for 40 countries, and we aim to add results on a regular basis with the goal to add more results this December. So our results come from analysis of population censuses and household surveys. And we. So it's basically disability disaggregated data. But you can also narrow down to population subgroups. So if you're interested in women, you could have disaggregated data for women only. Or if you're interested in older adults, you can focus on older adults.

So these you can pick. So these population subgroups, you can of interest. You can pick them on the menu on the left hand side column. You can also pick your. So of course, your countries of interest, your indicators. So we have 29 indicators on prevalence, education, personal activities, such as employment, health, standard of living, insecurity and multidimensional poverty, and on that menu on the left hand side. So the screen you get on the default screen gives you national national results, so cross-country estimates. But if you're interested in within country estimates, then you can pick on the menu at the top estimates within countries. So, for instance, if I'm

interested in Guatemala and in understanding multidimensional poverty among adults in Guatemala. So then, you pick Guatemala. And so you see the map on my slide, a map of the multidimensional poverty rate for adults with disabilities in Guatemala. So this map shows a lot of variation across region. In fact, the poverty rate among adults with disabilities, ranges from a low of 20% to a high of 80%. I think so. A lot of variation with much higher poverty rates among adults with disabilities in the North compared to the South. So this information is also available in a table format if that's your preferred format. And if you really want to zoom in on particular districts, we present statistics for districts. So we have hundreds of districts. If I'm not mistaken. So then you can also get that information for districts. So on the screen is is a screen. You have a screenshot now of the district level results. So you have the results accessible through an interactive platform. But if you want to do an in-depth analysis, you want to do research, maybe map some of our results with climate data at the district level. Or maybe citizen generated data on accessibility at the district level. Then you can download. It's better if you download the data set.

So this database includes subnational statistics for adults with disabilities and subgroups of adults with disabilities at the 1st sub national level for all the countries in our database so far, and at the second subnational level for a subset of countries, those with census data. So we think that there is a lot of potential in terms of informing policy and advocacy at the local level with these local statistics. And we also believe that there is considerable potential for research in terms of merging these local descriptive statistics with other data sets to understand. So what right now, we're only describing what's going on at the local level. But if we want to understand, perhaps, why, in some districts adults with disabilities are more often employed than in other districts, you know. Perhaps merging with citizen data or environmental data can help us identify environmental features or policies or advocacy campaigns that helped in terms of reaching these better outcomes. This database is quite new. So if you want to be in touch. Or if you have comments, the email is disabilitydatainitiative.help@gmail.com. Thank you very much.

# Claudia Cappa:

Thank you so much, Sophie.

Not muting and unmuting. So over the last few minutes. But that's okay. Hopefully, it's working fine. It's I was. I was saying. It's very exciting to see how this initiative has grown and will continue to grow. And it's a tremendous amount of work to do. The background for this type of databases. There is a tremendous amount of hours calculating and reproducing the numbers so kudos to you and the team for having taken on this very significant undertaking. We are not doing too bad when it comes to time management, not thanks to me. But, thanks to you as speakers, so we do have now about 10 min, I would say, we want to be on the safe side for some questions, and there are already questions online. But please do feel free to add more questions. Obviously, participants are eager to know if the Powerpoint presentations will be made available, so which I hope is going to be is going to be the case.

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