Friday, 14th May, 2021

CDPF Module 12B

RICHARD: Hello everyone, Richard Rieser here, General Secretary of the Commonwealth Disabled People's Forum and I'll be joined by Sarah Kamau, Acting Chair from United Disabled Peoples Kenya. She'll introduce this module in a minute, the subject today is disability and data. We are trying to drill down a bit to make sure people have a real understanding of what data means and why it's important, rather than will you with too much information. We've got three interactive sessions, and three and possibly four films depending on how much we use the interactive session. At the end I've got a few housekeeping things to say. Without more ado I will pass it over to Sarah to do the introduction of this module.

SARAH: Thank you Richard. Hello everybody, welcome to this module on disability and data, which is very important for persons with disabilities to be known by numbers and type, so that they can be planned for and by way of introduction I will start by saying the journey starts with a need for data, so that it can be used for evidence‑based advocacy, to get the data for evidence that advocacy needs to happen, to ensure that those responsible for collecting and gathering data do so. This is where important advocacy work at national and international level needs to happen to influence those required to create data. This is beginning and is foundational to all other efforts. The second aspect is once the data exists, it is vital to understand how to analyse, use and trust it for advocacy messaging. This is both to protect the integrity of advocates and to ensure that the change sought is based on an understanding of the reality of the situation and what works. Gaining an understanding of these aspects, particularly for those working at the grass‑roots level, to better understand the use of data in their advocacy is vital. Data literacy and turning data into a compelling message is a crucial part of gaining implementation of SDGs and UN CRPD. This can be found in the website, that is quoted there in your book, you will see in your course book. Also I'll share a snapshot of global disability statistics. There is one billion and above people who live with a form of disability currently. 200 million of these experience extreme difficulties in functioning. The prevalence of disability is on the rise. This is due to aging populations, and a global increase in chronic health conditions. Two‑thirds of all the years lived with a disability in low and middle income countries is due to chronic diseases. I will also talk about better health of people with disabilities, according to the World Health Organisation. I'll just try to increase the font because I'm not able to read it very clearly. I think Richard you can help me, I can't see it very well.

RICHARD: Is it in the wrong place, maybe, or something because I've put over.

SARAH: Two of them in the same, so this one has become very small.

RICHARD: Okay, well I'll help you out with the first one, what it says is, over one billion people globally experience disability, that's 1 in 7. People with disabilities have the same general healthcare needs as others but are two times more likely to find the healthcare providers skills inadequate, three times more likely to be denied healthcare, four times more likely than non‑disabled people to be treated badly in the system. Half of people with disability cannot afford healthcare, 50% more likely to suffer catastrophic health expenditure problems, these out of pocket healthcare payments can push a family into complete poverty. Rehabilitation and assistive devices can enable people with disabilities to be independent. What are we talking about here? Well, 970 million people need glasses and low vision aids, 75 million need wheelchairs, but only 5 to 15 million have them as we heard from our speaker on motivation, a few programmes ac. 466 million people have disabling hearing loss, but only about 10% actually get hearing‑aids and only 3% in low income countries. Making healthcare services accessible to people with disabilities is achievable and reduce unacceptable health disparities but it will require access, it will require making it affordable and it will required training for all health personnel and investing in specific services such as rehabilitation. Now we have seen over the COVID pandemic, globally how health services have not really been prepared to meet the needs of disabled people. Can you read the other one or shall I go on Sarah? The other thing that is on here on the screen is mental health, the cost of stigma. This isn't based on such wide data, it's based on sixteen countries, mainly developed countries, but three in twenty working age people are affected by moderate or mild mental health difficulties and one in twenty have serious mental health difficulties. People with sphere mental illness die on average 20 years earlier than other people. Depression is the leading cause of disability in higher, middle and low income countries. So that's across the world. Children with disabilities face malnutrition because food is saved for other children and household members. A study over 19000 people in 16 countries found 39% think that seeking help would mean losing friends. 49 think seeking help would mean limited opportunities. What they also say is, that the effect of mental health is a 4% drop in GDP, contributed by people being in long‑stay hospitals, lost hours of work, emergency healthcare, increased care and low productivity. We'll be talking about the Sustainable Development Goals later, but there is a goal here, under 3, 3.4, reduce premature mortality from non‑communicable diseases for promotion and treatment and promote mental health and wellbeing, so we can talk about that when we come on. So, sorry I had to read that for you Sarah, but I'll carry on shall I.

SARAH: Yes.

RICHARD: Recent estimates from the World Health Organisation, estimate there are now 2 million disabled people, we said one million there, but in 2021 they said they think it's upwards of 2 million. It all depends where you put the line in terms of who you consider disabled and who not. We will look at an example from Zambia in detail so people will understand how that is. But these are the global figures that they are coming up with, currently. 1.3 billion people are affected with some form of blindness, visually impaired, it represents 17% of the world's population. Many countries don't count wearing classes, that's why the difference comes up quite easily. 466 million people have a disabling deafness or hearing loss. 200 million people have intellectual disability, this is represents 2.6% of the world's population. 75 million people, same as the others, wheelchair‑users or potential wheelchair‑users, these figures remain at an evolutionary average, one thing is certain, at the number affected by any form of impairment, represents the significant part of the world population. From adults to children, it's also important to underline the facts that some people have multiple impairments, so counting them, the data becomes a very important issue. There are lots of different sources of data and we'll see in a moment from a business why they can use the data for their business case, but for us, as activists and DPOs it's important that we understand that you can get data from surveys of the whole population, which is called a census, usually takes place every ten years, the questions asked there are vital, you can fill in data between surveys, by doing sample surveys, I'll explain a bit more about that in a minute. You can gather data from things that gather data every day. Children that go to school every day, whether they are or not recorded in the register, so we actually have data for all children in the world whether they're in school or not that day. If we record whether they are disabled as well, and what type of disability they have got, we can actually get data for school attendance for all children in the world. Or, if they're not in school at all. So you can see how that sort of data would make a huge difference if it was properly collated and collected. So, some of the data that has been gathered is put to a business case here by Barclays, so we'll have a look at this. [Video Playing]

RICHARD: Okay, some interesting points there the, the effect that the money that we have is a big commercial factor and therefore businesses that don't get us in. So, that statistic is being used to encourage people to make reasonable accommodations in their businesses and to employ more disabled people, it's also about using it to make sure that the business is more accessible in terms of the portals that it uses for getting information. So these are all quite positive things, so we can see how data can be really important and if you bring it down to the level of low and middle income countries where we have much less data and most disabled people are not recorded we can see that there is a big challenge that we face. So, let's see what you think about this. Our first chat activity for today is two points, why is it important to know numbers of disabled people in country and the world? And two, is it important to break these figures down by different types of impairments and why do you think that is? I'll say that again, could you put answers in the chat for both of them that same time. one, why is it important to know numbers of disabled people in your country and the world? And two, is it important to break down the figures by different types of impairment and why do you think that is? Okay, so put your anxiety one and two in the chat and you have got about 90 seconds to do that now.

RICHARD: I think that's about 90 seconds. So, have we got some answers in the chat please, who is going to read them out? Sarah, or Gemma, or the two of you?

GEMMA: Sarah, are you there?

SARAH: Yeah we some chats Richard.

RICHARD: Okay, do you want to start reading them out?

SARAH: Deepa, says to provided reasonable accommodation. Abdullah, knowing the number guides in planning, as planning then there is also Simon, also for planning and implementation of programmes and programme purposes.

RICHARD: Yep.

SARAH: Joy, it is important to know the number as this would inform the policies made and crate an equal opportunity that accommodates all.

RICHARD: Good, yeah.

SARAH: Grace, so that you can ensure that disabled people are recognised and to ensure it's the right enough support and resources out there for disabled people. This will help in budgeting from Conya, ([Inaudible] it becomes easier for the government to take informed decisions ([Inaudible]) it's very important, it can show the clear statistics of disabled people and give government the proper planning and advocacy by the DPOs. Lesley‑Ann, to know the prevalence and know the population for working processes, it's important to break it down, disability is divers and should not be generalised, that I think is number two.

RICHARD: Lesley, by the way, congratulations on your degree which you circulated to us, well done on that.

SARAH: Okay. Agonda, for planning purposes, budgetary allocation and to address their needs based on the data, also to be part of the decision‑making table.

RICHARD: Yes.

SARAH: Fiona, knowing the number acts as an advocacy tool and also helps in budgeting purposes by different stakeholders. I think planning and budgeting has come up several‑‑‑

RICHARD: Planning and budgeting and influencing government I like the way of creating opportunities and reasonable adjustments. I think that's covered that. Any other points on why we should disaggregate, number two, break it down by different impairments groups or are they the same answers.

SARAH: Okay. I see a different answer here, some people can recognise what a sizable proposition are disabled people in the world and support them as such. Umm... let me scroll down... for better utilisation of manpower according to the nature of disability by allocating the work properly.

RICHARD: Yeah. Okay.

SARAH: That is from Kingsley Joku, sorry I didn't mention the name?

RICHARD: Thank you Kingsley.

SARAH: I'm just trying to school down and see if there are any different responses, there are many and still coming in Richard.

RICHARD: Menially similar, we do record the chat and put it up so people can have a look through it.

SARAH: Okay.

RICHARD: Thank you for that and thank you Sarah for doing that. So how does this work? Well DPOs and activists who are around the DPOs need to see that the monitoring data, the level of data, the quality of the data, how good it is a really key job and there should be someone in every organisation, whether it be a single impairment DPO or for a gender DPO for women for instance or children, who has got their eye on the data that is being produced and look for gaps, what isn't there and frame questions to advocate for better data. So we need to monitor what is there in our country to see it and then to advocacy for better data. If the country is still using old style questions such as: are you disabled, or do you think you are disabled? They are going to get very low results. We know from the research that's been done at the people don't answer positively to that in many cases. So, we need ‑‑ the data ourselves to use to advocacy for better provision, for changes in the law for better services, for places in Parliament. There are a number of Commonwealth countries such as Uganda at the have a designated places for people in Parliament and at every level of local and regional government. How many places we have will depend on how much data is there, for example, in South Africa I think there are six places in the government but there are probably far more people that should be in the Parliament if we are going to have a representative group of disabled people and using positive action like that is a way, because otherwise it's very likely that disabled people wouldn't be voted in, if it was a general vote. That's why, sometimes, those methods are used. So, we can use data in that way. We can also contribute to fill in the gaps. There are several ways that DPOs can fill the gaps. First of all we can do our own little surveys, mini surveys of the data to show up what is missing. One way is to go out to a rural area and knock on the doors and find out how many children are not in school because they are disabled. That's a way that we can immediately confront government, there is a duty for every child and you have signed up to it, to say have primary education, so why are these children out of school. We can do a qualitative study, that's different from gathering numbers, it's gathering people's opinions. We might want to ask the mothers and families why they are not sending the child to school and present that as data that the government needs to think about. So there are lots of different ways that DPOs need to be involved and really there needs to be a subcommittee and a national DPO, there needs to be someone in each DPO who is keeping an eye on the figures and bringing them to meetings so that people understand what is going on, so that everybody can use data in their advocacy, when they go on the local radio, papers, local television. These figures catch in people's minds if people have them. So, here is someone from UNICEF, who is going to tell us a bit more about their collecting of data that they are doing. [Video Playing] children with and without disabilities, play and learning together.

GEMMA: Can you turn it down a little bit please.

RICHARD: Yep.

GEMMA: Bit more.

RICHARD: So, you can find those on the UNICEF website if you put in data you will get those five videos. We will see a second one during this seminar and in the presentation that is in up on the website we are using the third one two of the longer one you will have to look up yourself. Now, to show you why data is important the UN CRPD Committee, that's the committee of disabled people elected by States Parties and now for the first time is gender balanced and I think all but one of the people on the committee are disabled people themselves. When countries are asked to submit reports, DPOs and other civil society organisations can put in comments, and this takes us back to the comments that were made by Reimer last week in terms of what she told us about the aboriginal and Torres Strait Islanders, they were disproportionately in the justice system, that was picked up in the report, Australia in response to the absence of national data disaggregated by disability at all stages of the criminal justice this system including data on the number of persons unfit to plead who are committed to custody in prison and other facilities." Collect data by gender and ethnicity at all stages of the criminal justice system including on the number of persons unfit to plead who are committed to custody and prison. Now that clearly came about, not because the Australian government went to the committee and said we're not very good at doing this, it came about by the Shadow Reporting system, or parallel reporting system as its also known and organisations it putting this in, either in writing or going to Geneva in‑person to actually make this point. The advocacy message is, disaggregated data on age, gender, location and ethnicity is important for understanding the population of persons with disabilities, whatever it means, pressuring government that highest level through this, we should be looking at what they are doing all the time and in regular mix witness them saying you are not collecting data on this, you are not disaggregating it by disability or even types of impairment. A second one, Kenya, and this I'm sure is to do, and Sarah you may have a comment on this, the committee is concerned about the multiple forms of discriminates faced by women with disabilities, absence of measures to prevent and combat different forms of discrimination against them. It is also concerned about the lack of information on public policies and programmes on gender equality. Include the Rights of Women with disabilities. So, again, lobbying must have taken place for that to be flagged up by civil society and DPOs. So the committee recommends systematic collection of data and statistics on the situation of women and girls with disabilities, living in rural and urban areas belonging to ethnic areas and we heard last week from someone from the pasture list community. So, again, advocacy leading to the committee recommending government change its collection of statistics methods. We urge our government to ensure that the data and statistics on women with disabilities is collected so it can be used for the development of better programmes. Sarah do you want to say anything about this on Kenya, how this came about? Maybe she's left us, temporarily. Sarah? Okay, I'll ask you again when you come back on. The third example, again from the area where we had a lot of members, the Pacific Disability Forum, I think we had thirteen members in their area who are Commonwealth countries, all mainly small islands apart from Australia and New Zealand. Disabled people's Pacific disability forum working with national DPOs across a range of countries to advocate for inclusion in the Washington Group Short Set, which we'll go on to in a minute in the national census it came out of a housing survey that neither the DPO or the government had capacity to carry out, carried out regional training with the Washington Group and the national body. They developed a disability mono graph which was funded by d what the Australian foreign affairs and trade ministry, since the production of the Kiribati disability mono graph, [Inaudible] so, often the capacity isn't there to do this and we have to work with government and other international agencies to build that capacity so that we can actually get the data. So, let's now get down to the nitty‑gritty in terms of what it means in terms of collecting data. If there was complete equality in this graphic representation of employment and disability, those two bars would be that same height. We already saw this bar being used by Barclays showing a 30% gap in the UK, in most parts of the world the gap is larger than that. It's something that should be more considered and initiatives taken. It's a simple use of data making sure that this disaggregated variable is available, it's always published and you can give awards to companies that increased the employment of disabled people and so on, you can give tax breaks and other thing, so you can actually change the situation and monitor it by using data like this. But to illustrate the measures for the general population, let's have a look at Zambia as an example, a small African country. The tools chosen to measure disability in the population mirror the different wisdom about disability and back in 1980 and 1990 they reflected the pre‑paradigm shift, so really medical model approach. One dimensional approach, cause and effect model focuses on impairments based on medical normative views, the question is do you have a disability? This was the actual question that was asked in the census, are you disabled in any way, if you answered yes you then went on to be asked, which of... these fits you best, blind, deaf, dumb, crippled, mentally retarded, multiple disabilities, and because of stigma and shame around disability, many people wouldn't have answered this, and, indeed, only 0.91 become, less than 1% of the population answered yes to it in 1990. Another survey was done using more detailed questioning in 2000 and found 2.7% of the 11 million population did now say yes, it had gone up more than two and a half times. However, when a survey was done that used the Washington Group short questions, in 2006, on household survey, this is on living conditions, let me explain how this works. It's not a census where every household door is knocked on, it's a statistical sample usually randomised, so you put all the names of households maybe on the electoral register into the computer and you pick out a random number of them, or you can stratify it so that you want 50 or 100 in each sector or region and then randomise it. That's how the numbers would have been got. They went and asked this question: because of health problems do you have difficulty seeing even if wearing eye glasses. Do you have difficulty hearing, even if you zine a hearing‑aid, do you have difficulty walking or climbing steps? Do you have difficulty remembering or concentrating? Do you have difficulty with self‑care such as washing all over or dressing? Do you have difficulty communicating, for example, understanding or being understood by others? Then, the enumerator, this is an important point who collects this data, people are trained, not very well to collect this data they go over the questions and how to answer them and tell ‑‑ not to introduce bias or put people off. So, if you pulled a face and said, is there anyone with a health problem and scowled then you would get less of result. Four, a discreet response categories were offered to the enumerator, if they said no difficulty that was as far as they went, if they said some difficulty, they would put a mark against which of these six that they had some difficulty. A lot of difficulty a mark against that. Unable to do it at all, a further mark against it on their sheet. In total in this survey 5751 households were included in the sample, this represented 28,000 individuals, or 0.24% of the Zambian population which at that time was eleven half million. 3090 individuals, that's 11% of the sample population were identified as having a disability. But it got more complicated than that, because once adjusted, following the sample of in‑depth interviews, the level of inclusion for disability prevalence is at least some difficulty. So, some difficulty in carrying out at least one of the six, they found that 17.8% said that they had some difficulty. More conservative cut off point was used, at least some difficulty on at least two of the domains or two of the indicators, it was 13.4%. Now, how different is that to the 0.91% that we got back in 1990? To show how the degrees in difficulty work, so remember what those are. Some difficulty, more difficulties, or unable to do it in D3. I'll put those up as well, at least some difficulty is D1, a lot of difficulty D2 and unable to do it, D3. Look for the different domains, 4 sung vision 4.7 a lot, 6, and 0.5 blind they couldn't do it at all. 1 in 200 people are blind in this survey. Hearing, 3.7%, some difficulty, 2.3% a lot of difficulty, who would benefit presumably from a hearing‑aid, and 0.5% would be profoundly deaf. So they can't hear at all. 5.1% had some degree of mobility problems, 3.8% a lot of difficulty, and 0.8% couldn't mobilise. So, if you add that up, that's 8, 9... 9.7%, 9.6% of the population and that's 1 in 10, had a mobility impairment. Remembering, 2% had a problem with some difficulty, 1.5% a lot of difficulty and 0.3% couldn't remember at all. They may have had dementia or they may have had severe learning difficulties, we don't know. It doesn't really matter for this, it means that they have a difficulty and they are facing barriers. Self‑care, that was washing all over or dressing. 2% some difficulty. 1.3% a lot of difficulty and 0.4% couldn't do it at all, and would really require personal assistants or family care. Then communicating as well, there we had 2.1%, on the sum difficulty, 1.4% a lot of difficulty and 0.5% on the severe. If you remember the second slide that was shown, it said 200 million people have severe difficulty. It would be adding up the D3 column around the world would be how you get to your 200 million. Remember, also, that if we take the D1 in to that it is likely that it's going to be 2 billion people around the world, so we are very likely to find at least 20% of people have some difficulty in most countries. Then, what was the conclusion of this? For the multiple purposes of promoting inclusive economic social development, measuring the level of functioning in a population, or providing services to people with disabilities, it is more appropriate to measure disability through multi-dimensional set of parameters, rather than all or nothing are you disabled or not. I think that's been shown by this data and similar data have been gathered in many other countries to show the same pattern. Data from Zambia have illustrated that different instruments to measure disability based on different approaches to disability yield quite different estimates and prevalence. So, beware, beware of people saying prevalence rates. Ask, what tool did you use to get to this? Drill down into it and ask yourself, as a disabled person, what would I have answered to this question that has been asked here? What would other people I know answer? That will give you an idea of what to lobby for to change surveys and other governments and agencies do around censuses. Okay so we're now on to the second activity on the Washington Group questions. What do you think there are advantages of the Washington Group set of short questions over asking people if they are disabled or not, that's the first one. What are the advantages of using the multidimensional approach that we have seen there, I'll put it back up on the slide when you are thinking about that. What has been left out of those six domains, are there areas that have been left out that we should be adding? And, last one, just for those people that want to share it with us: have you experience of either being interviewed or trying to gather data yourself, that may be there is a point you want to make to us. Okay, so those are the things to think about in this second activity. One, what do you think are the advantages of the short set of questions, over just asking the one question? What might left out from the Washington Group and do you have experiences you want to share with us? I will go back to, that's the six questions there. So, first question, just asking people are you disabled or not or asking those six questions, what's the advantage of that. What's left out of those six questions, is the second one. The third one, if you have any experiences you want to share. Okay, we'll give you again 90 seconds to get stuff written into the chat.

RICHARD: That's the questions, hopefully we have got some answers from people that we can share. Yep. Right. So, the timer, as I said is now up. Who wants to read this one out, Gemma do you want to have a go at these.

GEMMA: Okay. So answers to number one, it is... we've got a lot of ones here. To provide reasonable accommodation. Knowing the number guides and planning. For planning and implementation of programmes purposes.

RICHARD: You're not reading out the first lot.

GEMMA: This is to do with the first one, sorry.

RICHARD: Yeah, I'd heard those before ‑‑ [Laughter]. This is activity two.

GEMMA: I'm so sorry. I thought there was a lot, I thought there was a lot of chat there, okay, hold on! It's difficult because of the way they were‑‑‑

RICHARD: Sure.

GEMMA: So it's kind of a polite way of asking, more empathetic.

RICHARD: A nice way of asking.

GEMMA: It makes the question more specific, which allows more data to be gathered for disabled people.

RICHARD: Yes, yes.

GEMMA: People are more open to answer to their difficulties, rather than the actual question of our you disabled.

RICHARD: Yes.

GEMMA: A person would be more receptive to answer if they have a hearing problem, rather than are you deaf.

RICHARD: Yes.

GEMMA: It's non‑discriminatory, it's short, clear, to the point and precise. It creates confidence amongst disabled persons and recognised. It's the polite way of asking questions. It's more comprehensive to gather such data without fear of stigma. It's better to ask more questions than one. More subtle, better language. The short form questions have the advantage of being easy and quick to administer.

RICHARD: Yeah.

GEMMA: Some questions are two discriminatory, hence disabled people find it difficult to open up, it's therefore important to ask questions that don't directly mention disability.

RICHARD: Yep, that's a good one.

GEMMA: It's easy to answer and understand.

RICHARD: Hmm.

GEMMA: It's polite, specific questions. The questions keep in mind to ask in a dignifying and respectful manner, properly use the right diction or language that doesn't show discrimination or racist statements. They allow others to recognises their own disability if they did not already know.

RICHARD: Let's go on to, what might be, what was left out from those six domains that ‑‑ has anybody put down what they think might have been left out?

GEMMA: Yes, are you using an assistive device, e.g., wheelchair, cane, walker, service dog. Less, all or none, more practical, if it doesn't assume everyone is using the same definition of each type of disability. Umm... not too many on this one.

RICHARD: My only criticism, that I can tell you that's come out, that people with psychosocial impairments have said, well there is nothing really here for us, to say, we don't necessarily have communication, or memory problems, we have other issues.

GEMMA: Yes.

RICHARD: And so the‑‑‑

GEMMA: Somebody has actually said that, they have put number three, which is my fault for not reading the question I just saw the number, mental health is not explicitly mentioned, that is missing.

RICHARD: Yes.

GEMMA: Someone else says as well, this is good, do you have any tactile dysfunction, issues with touching or feeling certain textures.

RICHARD: That's one, I don't think they have I think put one in now, they have adapted it to include some other things, but texture and touch hasn't been mentioned yet, I don't think. So that's a good suggestion. Are there, is there anybody on the call who is actually either been on the receiving end of an interview, or has been involved in in gathering data and might have something to share with us. Maybe put your hand up if you have got something to say on that and we'll come to a few of you.

GEMMA: Ah, yes, freaky Andrew do you want to unmute?

RICHARD: Hi, yes, tell us your experience.

>> I do research into disability and I had the opportunity to carry one out on quality of life.

RICHARD: Aha.

>> Yeah, so for me, what was interesting about it was even identifying a tool that I could use that would, that would cut across. So, persons with disabilities, so this is what I ended up doing, I used the short form questions, the World Health Organisation, quality of life version, then I limited it to persons with physical disabilities.

RICHARD: Okay.

>> That way I was able to capture [Inaudible] as opposed to trying to impose questions across the board, also qualifying that I had to do activities of daily living just to help with ensuring that the questions were very robust and getting answers. The other challenge I had was having to work with persons who were, persons who were without disabilities in administrating questionnaires, it took a lot of training to get them to ask the questions respectfully and get answers, so those are some things that‑‑‑

RICHARD: Yeah, I think that's an experience that has been reflected everywhere, it's the one result that came out of what you did that you can tell us, or is it not there to be told about?

>> Oh yes no, we actually published research, and while we were able to, of course, establish is the quality of life for persons with physical disabilities is low and that a lot could be done to improve quality of life.

RICHARD: What country was that, I forget, forgive me I can't remember.

>> In Nigeria.

RICHARD: In Nigeria, so your survey showed that the quality of life for people with physical impairments was low.

>> Yes.

RICHARD: Did you make suggestions of how it could be improved?

>> Oh yes, we did that, I did two researches, one also had to do with functional assessment of persons with disabilities. In joining both researchers, one of the recommendations I made was to do with allowing persons with disabilities to work, because they are functionally able to actually work and make income and have impact physically having as opposed to just being on welfare, which is what, you know, so...

RICHARD: That's a general point, because in many countries and we had this I think last time in South Africa, that if you are on a pension, then you are prohibited from working, whereas in the more developed countries the pension is for the extra cost of being a disabled people and you are still allowed to have a job and to earn as well. So there is a real issue there that needs to be tackled, there is an attitudinal one. People will say, well if they can work why should we give they any money? Well the reason that we need it, our quality of life it costs much more to get around the barriers than everybody else. So that's a really useful thing you have started us thinking about, so thank you for that. Okay. Thank you, for that. We will go on now, oh, I think maybe we can take one more I think, yeah, one more.

GEMMA: Okay, there is a few with their hands up?

RICHARD: Okay.

GEMMA: Bendina, in Belize.

RICHARD: Let's have one from Belize, we haven't had one from there in a while.

>> Good morning from Belize, can you guys hear me?

RICHARD: Yes, we can hear you well, your experience.

>> So my experience is getting better engagement from people with disabilities, we use a database, as a social worker here, I will usually do family assessments and, ask individual members of the first one, I don't think our database is very through. It usually will ask about, like the first person will be like for example, a to the Head of the Household and it will just list the disability, if they have issues with hearing, seeing, self‑care, walk remembering, are visually impaired and then the person gathering the data such as myself, would have to be rated as none, none, no issues, some issues, a lot of issues, or kind of any at all, our database is very‑‑‑

RICHARD: That's the Washington set by the sound of it, would you say it's largely based on that.

>> Yes, umm...

RICHARD: Sounds like it.

>> I'm not able to identify when people, when people have issues with speech, I can't tell from this if I don't know already if they have intellectual disabilities, functions, mental disorders or something (over talking).

RICHARD: People with autism, is that picked up on your survey?

>> No, well I work with, I work with them then I would know, but this doesn't capture it, I'm just identifying it that our method is kind of falling short.

RICHARD: Okay, thank you for sharing that with us, obviously you have got some advocacy to do in your workplace to get a better survey going. So thank you for that Bernadette. All right, we'll press on, I know we could have had more people speaking and thank you for putting up with that, we'll see if you can come back to you. [Video Playing] children, with disabilities playing and learning together.

GEMMA: Richard can you turn it down please collecting and analysing data on people with disabilities, [Captioned Video Playing]

RICHARD: So that's really interesting. If you look down the left signed of the screen there, I'll read it out, functional domains they are covering in 5 to 17, remember there is another one for 2 to 4‑year olds, seeing, hearing, walking, self‑care, communication, being understood, inside or outside the household, learning, remembering, concentrating, accepting change, controlling behaviour, making friends, anxiety and depression. So we can see that this is an attempt to move to include the psychosocial, mental health as well, as just learning difficulties. So I think there is a big improvement in this and the testing of it has shown that it does pick up people on the autistic spectrum and other psychosocial conditions like ADHD and so on. So this has been very useful and it's been applied in more than 60 countries and tools that she mentioned there are really tools that you need to make sure that people carrying out surveys do. Because it's crucial to have a good idea of the number of children with various difficulties in our populations so that we can adjust our school system for them. What's very clear, because the number are quite large, is that the segregated solution of the past, separate special schools is not the solution, the solution has to be the training and accommodation and, in the cools, removing barriers and so on. If we don't get this right from the early years onwards, then we are going to have further generations of disabled people who are disadvantaged, so it's a really crucial thing that we actually take this on board, that's why I included it particularly in today's seminar. We are going on now to preparing for our third and final activity around the SDGs, we might get another one in, I don't know. Remember we put in the presentation film and I'm going to, it's in the course book, but I'm going to go over it again. There are something like 245 indicators on the 17 SDGs and 11 of them mention disability. If you think we are 20% of the population, that isn't very good! [Laughter] We need to think about others that we might want to add. So, poverty, which is SDG 1, eradication of poverty, any one indicator, proportion of the population covered by social protection floors, broken down by sex, children, unemployed persons, older persons, persons with disabilities, pregnant women, newborns, work injury victims and the poor and vulnerable, a catch all phrase that we do not like. We don't like vulnerable because people are not vulnerable in themselves because they have an impairment, they are vulnerable because of the barriers at the exist because society has not been transformed so people can have a fair and equal access. So vulnerability puts it, it blames the victim and we don't like that phrase. People at risk of exclusion, people at risk of not being, of not having this indicator is our chosen preference for that in the disability movement.

       Quality of education. This is, we have just seen how crucial it is and we have in fact got two indicators here. 36, equal access to all levels of education and vocational training including persons with disabilities indicator. So that's a general one. Then, proportion of schools with access to adapted infrastructure and materials for students with disabilities. It's how that's measured that is really the point. I think they are measuring it with the numbers of ramps and accessible toilets, not necessarily access to the curriculum. The indicators for 8, which is work, 23 indicators, average hourly earnings of employees by disability. That will very much show not only whether people are in work or not, but also what their earning. Unemployment rates also by disability and then we have reducing inequality, number 10, we have 25 indicators and here we have 10.2.1, proportion of people living below 50% of median income, sex age and persons with disabilities. Sustainable cities and communities, we have got two there, I think, or maybe even three. Yeah, three. 11.2.1, proportion of population that has convenient access to public transport, you have got to be able to get on to that, the disability indicator. That's an important one in city spaces, particularly, average share of the ability up area of cities that is open space for public use of by ex, age, persons with disabilities, whether the packs are accessible. Proportion of persons, victims of physical or sexual harassment by sex, age, disability status and place of occurrence in the previous 12 months. Gender‑based violence that's absolutely crucial and will actually reinforce the figures that we have talked about when we talked about, about that in our women's module. Then, last of all, 16, peace justice and strong institutions, there are 14 indicators for that and we have two. Proportion of positions in the national and local institutions including the leg stature, that's the parliaments, the public services and the courts, the judiciary compared with national distributions by sex age and persons with disabilities. So this will be quite an important factor, how many parliamentarians do we have, how many judges, how many people in the public services, teachers, social workers and so on. Administrators. The proportion of population who believe decision‑making is inclusive and responsive by age, sex, disability, so this is going to be a survey rather than an indicator. Okay. So bear in mind what those are, remember we have got 1, 4, 8, 10, 11 and 16. To remind you what those are I'll run through them. So 1 is poverty, we have none for hunger, none for health. 4 is equality of education. None for gender, except for that one under cities, which is gender‑based violence but nothing else. None for clean water and sanitation. None for... a Fordable and clean energy. We have for work. We had two there. Industrial innovation and infrastructure. We have nothing there. We had the reduced in qualities and we have sustainable cities. We have nothing for responsible consumption and production. Ply mat action. Think back to the programme we did on humanitarian and climate emergency of the issues there for disabled people. Living below water, maybe not so much there, but life on land certainly. Peace, justice we have. But partnerships for the goals, no mention of disability, other than the general catch all that when we talk about vulnerable peoples, and I've explained what we don't like about that, it includes disabled people. So, by the back door we are there. Now, the activity is this: I've kept them up there as an aide‑memoire, the ones with a blue cross on it, 2, 3, 5, 6, 7, 9, 12, 13, 14, 15, 17, no specific disability indicator, on the left‑hand side there is an indicator that I just read out, 1, 4, 8, 10, 11, and 16. What I want you to think about and suggest, is an [inaudible] you can do a little bit of thinking on here, on hunger, on health, on gender, on sanitation and water, on energy, on infrastructure, on consumption and production, climate, land and water, and partnership. What shall we be measuring to show that this is an all-inclusive Sustainable Development Goal. You might say, well we haven't got very long, nine years, I think that's true, but I would put this point in the air. What happened with the Millennium Development Goals that we started in 1990 weren't reached, they just rolled them over and said we'll give you another 15 years, they didn't include us at all, so we didn't have any benefit from that, other than the general uplift that took place. What's likely to happen in light of COVID that's rolled things backwards and the lack of investment which is also causing broadening of the gaps between rich and poor are getting greater, we will probably have the countries of the world saying, well let's roll them over and not do it in nan years, but let's do it in 19 years to 2040. I'm only guessing but I think that's what will probably happen. So it's important that we do some thinking about what other indicators we want to show that we are moving towards disability equality in the Sustainable Development Goal. So that's the aim of this activity. I hope that's clear to everyone, you need to think of ‑‑ pick one goal that isn't, we haven't got a target for, i.e. one of those with a blue cross and think of an indicator which would measure progress for disabled people on that Sustainable Development Goal. Okay, I'll give you two minutes to think about that and get it written down. It's just coming up to quarter past now, so we've still got fifteen minutes on the call so we should be able to have a good discussion about this.

RICHARD: For anyone who is lost we are doing activity 3 which is on the screen, you have to identify a goal with no disability indicator, ones in red show the ones that have an indicator on the side. The ones with the blue cross, 2, 3, 5, 6, 7, 9, 12, 13, 14, 15 and 17 have no disability indicator. Pick one of those and say what it is that you would want to measure to show progress on disability equality on the Sustainable Development Goals. Okay, I think that's two minutes. Sarah do you want to read out what people are saying here?

SARAH: Yeah, there is a lot in the chat, but I'll start with the last one here, 16, 16 could mean no racial discrimination especially. Those who have double or triple discrimination, but I don't know what indicator that would.

RICHARD: That would come under 16 I think, wouldn't it, how it would measure it I don't know.

SARAH: Okay SDG 3 inclusive health services are a standard tool for universal health.

RICHARD: Hmm.

SARAH: Inclusive healthcare.

RICHARD: Yep. What, does she mention what we should use to measure that?

SARAH: No.

RICHARD: Regardless of background factors everybody has the same access to healthcare, that might be the way of doing that. Okay.

SARAH: Grace 17, DPOs involved in goals and they should be included in the formation of policies, if evidence shows that DPOs are involved then the goal is complete. That's 17.

RICHARD: Yeah.

SARAH: Terry says activity 3 for SDG 6, percentage of people not able to access a water point or public toilet because of a physical disability. That's an indicator for number 3.

RICHARD: Yeah. That's a good one, number of adapted toilets.

SARAH: Yes.

RICHARD: That would be a good measure we could argue for their quite easily.

SARAH: Okay. Number of women and girls who experience GBV and availability to justice and support services, SDG 5. GBV, gender‑based violence.

RICHARD: Gender‑based violence, there was one in Number 10 on that, no number 11, it was for cities wasn't it. So people in rural areas are not covered by it, so it's good at the five, all disabled people subject to gender‑based violence would be good. We would have to measure it by people who reported it, of course, there is massive, massive under reporting, but if people knew that by reporting it, it would get recorded and you would have to at the same time have the criminal justice system doing something about it, then it would work. Yeah. Okay. More?

SARAH: Yeah, there is Laurie, no poverty could mean no food banks required or no homelessness, although this could be not what you mean, maybe. But no poverty could mean no food banks. I think that is number 12.

RICHARD: It's probably 2 or 12.

SARAH: Zero under number 2, responsible consumption.

RICHARD: Number 2, no food banks. Another would be that everyone has a required daily intake for a healthy life and you would have to measure that by sample surveys I think. But that would also be quite you know, what the level of malnutrition is. The UN does collect data on people, particularly for children who are under nourished, which leads to stunting, which is a form of impairment because you are, people have frailty and are shorter than they should be. So, yes, it could be built on Laurie thank you for that. Yep.

SARAH: Is Bernadette, saying SDG 15, life on land, number of people, number of disabled people who own land. They should be, there should be a number. There should be a number of disabled people who own land for housing, property, for assets and family. That is an indicator that can be used for SDG 15.

RICHARD: Yeah, it might be owning or have secure access to, with a lease or something like that. Yeah. Or a rental agreement.

SARAH: Another one on gender‑based violence again.

RICHARD: Yeah, yes.

SARAH: Laura, says on health section there is no mention of accessibility, for disabled people, but this section is very important for all kinds of people. Severe physical impairments, mental illness needs therapy and rehabilitation. Very hospital aren't accessible for them.

RICHARD: I think we also had, raised this morning which I think is important for women, access to reproductive health. I think that might be a good indicator there for disabled women, how many of them get access to reproductive health.

SARAH: Fiona on SDG 17, again all partnering for the goals includes organisations for persons with disabilities in order for their voices to be heard. So there should be, maybe measurement on linkages and the networks.

RICHARD: I think the advocacy point is there that if we are to partner at a national level, then our DPOs need one, to have a base of local organisations that can gather views and information for us, so they need some sustenance to do that and local DPOs also need to be funded by government if we are to be partners in this process, what we find is that governments in many parts of the world aren't funding DPOs and therefore we can't really be proper partners in this arrangement. Maybe the indicated would be the number of DPOs that get proper government funding at national and local level and that would show how many it's a genuine partnership. So I think that might be a way of measuring that. Okay. Any more?

SARAH: Hmm...

RICHARD: Okay, we'll stop there. Thank you for all of that everybody. I'm not going to show this film, but I wanted to talk about it. Daniel Mont, you can find this on the internet, and it's an interesting film. What he's been doing is looking, as I said earlier, at where there is a large amount of administrative data like the school surveys, and his been training people up and it's now been developed as a whole country system in Fiji, so that they can actually train teachers to identify using Washington scale data, how many disabled children there are in their class and then align it with in their locality getting mixed surveys which are household surveys to identify using the same data in the same catchment area the number of children not coming to school. That can then be used to plan and prepare for the school to meet the wider needs of disabled children, and if it's incorporated into the planning cycle of the Ministry of Education, they can then resource the schools and train the teachers with regard to the numbers that are actually there to be measured. Obviously, you would need to moderate it because it will be very simple for the teachers to make up large numbers of disabled children to get extra resource and that has happened in some parts of the world, but if it was moderated it would give us a way of management from annual school surveys and so on, which would then be translated into resources. This has been done in Fiji, and it's written about in the course book on this module. So I would draw your attention to that, as a way forward. So, I think we are reach thing end of our time, more or less. I've got a few things I want to say to people. So I'm going to come out of this thing and say hello to everyone. I'll come to Sarah in a minute for a last word as well, but I think we've learned from today that you have to, as disability activists, as people running DPOs you have to drill down and be sceptical when people give you statistics. You have to ask questions. What is this data based on? Where was it gathered? Who gathered it? How did they gather it? Which tool did they use? How was it checked that it is accurate? I think if we are asking those questions we don't have to be trained in statistics to ask the right questions, that's the important points, we are not trying to give you a course in statistics here, it's data. A lot of data can be represented graphically as we saw at the second and third slides and that can make it much easier for many people to understand than lots of tables of data which is actually quite difficult for people to understand. If you say 1 in 5 people or 1 in 10 people in this area are disabled people, that makes it easy for everybody to understand. The other thing we have learned, is if we c questions which don't shame or make people feel belittled by the question, but rather ask questions about difficulties rather than disabilities, we get much higher numbers of disabled people. Then I think that's also very important. So, that's all I wanted to say on this, Sarah, a last word on the statistics data and then I've got a couple of things I want to say to everybody before we all say good bye to each other on this one. Sarah. You are muted.

SARAH: Thank you Richard. Yeah, data is very important, but unless it is translated into some meaningful action, then it is just figures out there and so what we are saying is that, yes we are advocating for disaggregated data for disabled people and we would like that data to be turned and translated into actions, into policies in to infrastructure development and that can only happen when we, as disabled people organisations push and advocate for governments and duty bearers to be able to account for us and to make sure that our data is important, for planning purposes we need, we need to push our agenda for make sure we are included in develop as a whole, as DPOs. Thank you so much.

RICHARD: Thank you. (distortion on the line) it's a good trailer for DPOs how they fun function, what their role is and so on. We have got a course book that will be going up tonight on that and a film. There is plenty for you to get your teeth into and then we can discuss it at the next week's seminar the final one, the week after will be on influencing government and on that we will have an hour, and the last half hour we will take views on the course, which we will record, we will have some people asked to give a prepared view on it, and then others will give their views on the course after that, we'll use the last half an hour and then I'll say something about how we want to take it forward. We have already written to you all, if you want to be part of a network after this, sign up to become a Commonwealth Disabled People's Forum human rights advocate and we have got 57 of you have sent in those forms. They are ‑‑ complete it and send it into Martha@commonwealth Disabled People's Forum. She's doing the database on it the second thing is to ask everybody to make sure that they did send in the monitoring form on the first seven modules. It's really important that we have your responses on this because we are bidding for more funding to be able to spread this course off‑line on to computer sticks that we can take out into rural areas that are not in, not connected on the internet, in many parts of the world, but this seminar will be on that stick so everybody can, so we need money for that and we need people's views on the course, hopefully positive, and... that will be very useful. Deadline for course work is the ninth June, but if that's too difficult for you I'm ‑‑ there is no detriment to anybody, if you want to get in the course work, but you haven't been able to get it in on the time scale we talked about, if you get it into the level you want to get it in, remember are four levels to get it in, then we will able to accredit you in the two weeks after the 17 September, those who get it in by the ninth June, we hope to get you an accreditation by the end of June the reason we want to have the views, we're going to hold a side meeting at the Conference of States Parties, the third week of June, in New York, but it's online. That's more important because we will actually not be having CHOGM this year, it's been cancelled again, that's the heads of government of the Commonwealth meeting. We will be able to feed in more of what we have learned from this and other consultations that we have got going. So those are some extra news points to bear in mind. Now take your, put your cameras on, put your microphones on and let's say good bye to each for today. Okay, it's been a useful seminar for today, thank you to the signer, the captioners, thank you to Sarah and Gemma and thank you, to all of you for sticking with us. Bye‑bye.