Module 3 Seminar B

Friday 5th March 2021

RICHARD: Hello and welcome everybody to our seminar B, module 3, on health. We are going to wait just a couple of minutes for a few more people to join us. And, also, we're down one signer at the moment. So we're don't really want to start until we have that sorted out but don't go away, we won't be long before we start and we've got some interactive sessions like last time with you on the chat. So in fact seven questions in all we want to do in three blocks. So be ready for those. We've got some just a few, myself and Sarah, actually presenting here live on Zoom. But other people on film. I'll introduce it in a moment.

GEMMA: Richard maybe you could ask everybody to remain on mute and with their videos off? I will repost the captioning link into the chat.

RICHARD: Okay so the captioning link is in the chat. And if people could remain with their microphone and their video off so you are just receiving and watching. And then when we go into the chat sessions we'll bring some of you in to speak. Okay, I'm going to I think get started because --

GEMMA: That's okay Richard. We think that Susan's on her way so we can get started.

RICHARD: Okay just click those two, yes, click for that. Okay. Off we go. So, formally then, I'll welcome you all. My name is Richard Rieser, General Secretary, with me is Sarah Kamau our Acting Chair and Michael Njenga from Kenya, a mental health expert on our Executive, we will be speaking on some filmed interviews I did with him earlier in the week. Unfortunately we don't have Sruti, although she has put together a number of bits on the presentation, you'll have seen her on that and the course book I'll be leading on most of that. But, first of all, over to Sarah to say some things by way of introduction on this module. Sarah.

SARAH: Hello everyone. Welcome to this seminar once again. I'll start introducing this health module by a quotation from Gerard Quinn, the UN Special Rapporteur on Disability which he made during the 13th conference on the state parties of the UN. And he said this: "Looking back we had come to expect the slow but steady progress of the convention on the Rights of Persons with Disabilities and especially the new framing on disability that it exemplifies. How wrong we were. Basic truths have a habit of coming to the surface during a crisis. So it was with the COVID-19 pandemic. Basic services were swept sway. Preventive measures were not adequately communicated. Food, nutrition and health care services were rationed. Institutions became even more obviously dangerous places to be. Home became an incredibly dangerous place for women and girls with disabilities. As the Disability Rights Monitor Report of October 2020 has vividly shown, the old framing of persons with disabilities as objects and not as subjects came to the surface during the crisis and we have been trying to put it to one side ever since." I'll talk also about disabled people's experience as shown from the summit and surveys CDPF road to government in June. And from those surveys what was found out is that, one, disabled people's organisations are generally not being consulted by government with a few exceptions, in Malaysia, Guyana and Cameroon. There's lack of information access has been dressed in most countries, the stigma is still an issue. Number three, there's lack of support for personal assistances, food, welfare, medicines, and usual medical procedures. Unemployment and lack of reasonable accommodates, especially for self-employed. There's a lack of access to online schooling and erosion of support for disabled students. There's also a higher fatal iterations for disabled people in institutions, people with learning difficulties and those with chronic conditions who need shielding support from government. Any of these issues got worse in the second and third wave of the pandemic. According to the Disability Rights Monitor Report, the failure to protect the lives of people in residential institutions which have become hotspots during the pandemic need of prioritising people into the community, respondents pointed out that many institutions have been locked down with fatal consequences. Widespread rigid shut downs that caused a dramatic breakdown in essential services in the community, people could not access basic goods. Including food and support such as personal assistant, strict enforcement of this lockdowns by police and security forces has sometimes had tragedy results. Serious and multiple human violations against under-represented populations of disabled people. Women and girls have experienced a major up tick in violence, disabled children have been denied access to online education and homeless disabled people have either been rounded up, detained or left completely to fend for themselves. A concerning trend of denying basic and emergency health care including worrying reports about the adoption of discriminatory triage procedures. These reports are on the website and you can see the link there. Where you can get them. I want to introduce now Article 12 on rights of persons with mental health issues. And from the services mental health issues the rights are widely ignored and many Commonwealth countries have laws that directly contradict the rights contained in Article 12 of the UNCRPD. The CDPF Committee observes that in most of the state party reports that the committee has examined so far the concepts of mental and legal capacity have been conflated so that where a person is considered to have impaired decision making skills, often because of a cognitive or psychosocial disability, these are legal capacity to make particular decision is subsequently removed. This approach is flawed for two key reasons. One it is discriminatorily applied to people with disabilities and, two, it presumes to be able to accurately assess the inner workings of the human mind and when the person doesn't pass the assessment it then denies him or her a core human right. The right to equal recognition before the law. Article 12 does not permit such discriminatory denial of legal capacity but, rather, requires that support be provided in the exercise of legal capacity. You'll also get that in the link that is on your website, on the website. And now to the language that CDPF use. CDPF uses disabled people and why we choose to still call ourselves disabled people? In the common wealthy disabled people because of the development of the Social Model of Disability. In the 19th and 20th Century, a person's medical condition was thought to be the root cause of the exclusion from society. An approach now referred to as medical or individual model of disability. We use the social model of disability, where the barriers of environment, attitude and organisation are what disabled people with impairments and lead to prejudice and discrimination. So to call ourselves persons with disabilities is to accept that we are objects and powerless. We also view ourselves as united by a common oppression so are proud to identify as disabled people rather than people with disabilities. When we're talking about the UNCRPD we shall use the words "persons with disabilities". Thank you.

RICHARD: Thank you very much, Sarah. More on that later. Now, we looked around for a film that encapsulated in a region where we have lots of members and ESCAP, which is the UN Commission for Economic and Social for Asia and Pacific, have done a lot of useful work on this and they came out with a film about some of the issues which includes non-Commonwealth countries but also includes Malaysia and Bangladesh and Pakistan, India and so on. So we thought this is worth having a look at. (VIDEO)

RICHARD: I don't think I can do better than that young person who said, "We are the force" and really we have to find a way of marshalling our force because although we have made some breakthroughs it is very true to say. Can people mute please. It's true to say that as Gerard Quinn said there, in the quote Sarah read out, really, we have had a rude awakening, if we thought the world was well on the way to embedding disabled people's rights, that hasn't been the case during this pandemic. And it shows the cracks. What are those cracks? Well, they are in health and well-being, care and support. Livelihood. The extra risks that many of us have of contracting COVID, the additional mental health strains, not just on ourselves but also on the whole community. Lack of access to information. The fall out on education and the increased domestic abuse that people have been subjected to. So I will go through some of these in a little detail now. Those with physical disabilities affect the immune system. Those with lung function or other related factors are put at higher risk for serious complications such as confusion, delirium and liver failure and now we have long term COVID, a new component created by the virus so there will be people for many years whose functioning will be affected, they will have a new impairment and therefore join the ranks of disabled people because they had COVID but survived. Health care workers are not equipped to deal with disabled people. They also, for much of the pandemic, were not equipped with the right equipment even to save themselves and many health and care workers were high amongst the fatalities early on. Many have triaged us to the back of the queue for ventilators and PPE. This issue is a really important one. Eugenics was the idea of selecting who should survive and who shouldn't, it came from the Ancient Greeks. They believed as we found out in module one that the body perfect also related to the moral and indeed the soul that was perfect and good. Which, of course is nonsense. So the idea that certain people as one of the doctors on that film said would survive and others would not, it seems to me the fairest thing is to draw lots for it and to have equal chance of get getting the health where there's a shortage rather than doctors deciding you are more likely to live. It reminds me of the doctors who stood at the queues as people got off the trains in concentration camps in Germany in the 1930s and 40s and said, "You go this way and that way". Deciding whether people should go to the gas chambers and die or be put to work in the slave factors and later die. No one has the right to do that. We have to challenge that, if our medical establishment has done it, we challenged it in the UK and the British Medical Association withdrew their guidelines as did NICE saying that early on. But it was really important to show this idea that we were treated as second class citizens. Those livings in care homes are at the highest risks, in orphanages, in prisons and so on and of course the infection has spread much more quickly there because it likes human beings being close together. And, therefore, it has shown up that we shouldn't be really having these institutions, we shouldn't even be having care homes, that Article 19 of the Convention as we talked about last week makes very clear that people should be supported to live in the community, in their own homes, and get the money from the state to support them. I know many lower middle income countries can't yet afford to do that. Nevertheless, if we don't demand it, the tax base won't be raised to actually pay for it. So we have to keep raising these demands. Under-represented groups of disabled people such as deaf/blind, psychosocial, those with learning difficulties, particularly hard hit. We had new data came out yesterday in the UK showing that young, disabled people were much more hard hit than non-disabled people in term was COVID over the period from January to November. That backs up these statistics which we shared with you in the film. I wanted to explain how do we, in the UK, get these statistics when most people around the world don't seem to be able to get them. The reason is, because we ask quite clear questions in our ten year census and this data nearly ten years old, now. Do people have a lot or a little limitation in doing a whole series of thing. And people are therefore recorded, status of being significantly disabled or mild or moderately disabled. But both count under our definition in the UK. That's why we can track those individuals against what they said to the census and then determine that what their fatal iterate, the death rate. You can see the death rate is just under 60%. Could you, whoever's talking about their JAWS system please mute, thank you. So we had to add to that about 9% so it brings us up to about 68% of the deaths were disabled people. Yet they are only 17% of the population and that has been maintained in new studies done by the Office of National Statistics through until November and will be shown again in the last spike that we're just coming out of in the UK where our deaths are no at over 125,000 in the UK. In term was livelihood, jobs and employment, it wasn't just people in the more higher income areas as this shows from two surveys that were done by Leonard Cheshire in not being able to work in Bangladesh and Kenya. And having higher job insecurity, these are very high figures. Countries such as India, Malaysia, Bangladesh, Pakistan and so the big companies, they went for furlough, they allowed people to telework and work from home and they didn't lose their jobs. But other people did lose their jobs with an immediate loss of income. Most self-employed were overnight made poor in a country like India and many others when they went for lockdown. Many of them did not receive any financial assistance or free rations and I know they had a system in India but the evidence is it didn't get to a lot of people who should have this it and there was a larger portion of people who were not registered as disabled in India. So they don't get it anyway. We need to look also at the impact that the social isolation and loneliness has been associated with both an increase in heart and dementia and other health problems but, also, with mental health issues and this has been a really big issue for people all around the world particularly in poorer countries. With behaviours such as physical distancing as well as socio and economic impacts having a worse consequence. Research on psychological impact must show that the pandemic might particularly harm the mental health of marginalised populations who have less socioeconomic resources and less supportive networks to survive. There are unique stressors and challenges that could worsen mental health for disabled people during this crisis. And have indeed done so. Research on past pandemics has shown this to be the case and data from the World Health Organisation shows it is also the case now. The issue is also about how we build back from this situation and we can talk about that a bit later. On education, 1.6 billion children were locked out of school, that's an awful lot of children. And much of the progress that we had made or the last ten years towards a more inclusive education for girls and particularly for disabled children may well have been lost by this lockdown. Some of the schools have been locked down for nearly and year and although they substituted distance learning, your socioeconomic status was very much determinant on whether you have a IT, monotone at home and could get on learns. Even if you have a wind-up radio because many countries like Sierra Leone and Gambia did radio lessons to fill the gap. You still had to have that radio and some people have solar-powered and wind-up radios and that's great but a lot of people don't have that. We will see that will be a big issue on getting education back. Some countries as I say introduced those lessons. But all of the lessons that were introduced, the curriculum and materials were not differentiated. They were sort of ended at the middle of the class. So for the children who wanted more stretch materials to interest them, they didn't get it and that's often people in the neurodiverse community. So they would have got turned off, perhaps broken their laptop as the young man in the film out of frustration. Lack of peer support and isolation led to increased anxiety and depression. On the other hand, some young people really benefited from who didn't like the school regime had lack of empathy, bullying and so on. And are actually saying we actually prefer to be taught remotely. But of course governments like the UK Government is saying ten million children go back to school on Monday, all in one go, which we're worried about we will start spreading the infection again. But the idea that those children who might want to be distance learning could have some choice is not in the equation. Also, many children rely for their main knew tribes daily meal on the school lunch and they have not been getting that and that means the effect of that is likely to be more stunting and disability as a result of it. Staff as well of course are impacted and staff absences have been affected quite significantly by COVID situation. Amongst teachers who kept schools open. UK surveys show a disproportionate negative impact on disabled children and we have had a lot of surveys now about the special education consortium in London has collated 25 different studies all of which show negative impact of the lockdown on disabled children. So then we need to go on and look at the impact that this had had on women and girls. Clearly being all thrown together in the same household and they are not allowed to go out, not being at work, has generated a lot of frustration and as many men take out their frustrations on the women around them or, indeed, their children, which of course not acceptable, and bullying and harass them verbally and sexually, this is not acceptable. We know work done by ADD in Uganda there was a big increase in risk when they talked to DPOs there, 70% of women and 80% of men reported an increase in economic physical psychological sexual violence. We know that from work done in Bangladesh a similar thing asking 39 DPO leaders, 47% reported that their members are at greater risk of violence at home and of in the community. We know this has been something that has happened and is, again showing us the tip of an iceberg that's not really addressed in normal society but it has been magnified. So this is something else we're going to have to get to grips with as we come out of this situation. And the global monitoring report which was mentioned by the Sarah earlier on had 25 testimonies of grave human rights abuses which included multiple forms of assault. So we needed more safe places for people to go, to escape this, and campaigning groups of women with disabled women such as sisters of Frida in the UK have campaigned for this to happen. As regards were we consulted sufficiently? As the COVID went on, more disabled people's organisations were involved. But we know from the first wave that Bangladesh, Cameroon, Gambia, Uganda, parts of India, Malaysia, Maldives and New Zealand and in parts of the UK particularly Scotland where they have devolved government, they were listening and in discussion with disabled people's organisations and, indeed, in Singapore. And in a number of those countries, that level of corroboration in Singapore, Maldives and New Zealand has led to the very low level pandemic which has happened there. So there is a win/win situation. And, remember to quote article 4.3 and article 33 when you are approaching any government at any level, they have a duty to actually consult with us as DPOs. Okay, so that's the bit on COVID. What we would like to do now is go for our first couple of questions on the chat. I'll read them twice and then give you a minute to think and to write down on the chat. Like last week and the week before Gemma will read out a selection where there's something interesting we will ask those people to unmute and come on and tell us about it for a short time. So the question one: what was the worst impact of COVID on your life as a disabled person? And, question two, what was the best response to COVID-19 in your country for disabled people and why? I'll read those again and then I'll give you a minute to think and get it written down. One: what was the worst impact of COVID-19 on your lives as disabled persons? And, two, what was the best pons response to COVID-19 in your country and why. Give both your answers, one and two, at the same time, that will help us to get through this. Okay thank you I'll stop talking now. Which means nothing will be going on, except your little grey cells working away and then your hand and eye coordination whichever way you do it typing into the chat. Thank you.

RICHARD: Okay Gemma I think we can start reading some of these. Can I just say before you start, because now we've got 112 people to the call I wanted to make a point about access to these seminars. We have had some heartfelt concerns reflected to us, particularly from the neurodiverse community which we are trying to take account of. One, too much sensory overload in the presentations. Too fast and not enough space to think and we're taking account of that. We still haven't got it right. And we are going to work harder on the next two presentations, 5 and 6 which we're filming on Monday. To cut town the amount of the screen while still having scripts for our presenters, so you'll be hearing what they're saying but it won't all be on screen which we think will make life easier. And we'll also try and cut down on background noise and the way we use film clips and we hope that that will help people to participate and we apologise for not getting everything right, which of course it's always difficult to do but we're trying when you raise issues with us we will try and take them into account. So thank you for that. Gemma would you like to now go?

GEMMA: Okay thanks I would like to start by warning you I have a noisy dog nearby! And that might make things difficult but, anyway, here we go. Somebody said the bad thing was the cost of medicine for my glaucoma and the good thing was I received a scholarship and got a job interview due to new inclusion laws.

RICHARD: Where is that person?

GEMMA: That person is in Nigeria. This person is from Kenya. In Kenya, persons with albinism were accused of the spreading the virus and mostly stayed indoors because of fear. Somebody else in the UK actually, personal assistances couldn't come to my house to support me because of the risk to my health. I only had one source of income and that was part time but after the COVID no more than income I had to get. I'm trying to find some where there is a second answer. John, who I think is in Kenya, says in answer to question two: there was semblance of meaningful involvement of persons with disabilities as government and regional governments developed responses to the pandemic.

RICHARD: Does John want to say a little bit more about that to us.

GEMMA: John would you like to unmute? John in Kenya. It looks like we're unmuted now, John.

RICHARD: Can you share with us, John? John.

RICHARD: Can you tell us what happened in Kenya to get representation?

JOHN: Hello?

RICHARD: Yes, we can hear you. We can hear you, just speak. Okay, we'll have to come back to you John. Let's go on.

GEMMA: Somebody said it's a positive thing. They can work from home, became very convenient and could be done on a regular basis, also. Somebody saying the best response was when I saw people being given food by well wisher action, different organisations and families and such. Being deaf already isolated. Lockdowns exacerbated this situation.

RICHARD: Where's that person from?

GEMMA: They haven't put their country. This is somebody in South Africa who has put the answers to one and two. The worst. I was on a disabled learnship \*\* with the year contract. Upon expiration of the contract during the pandemic the contract wasn't renewed so basically the learnership didn't fulfil its promises given it was permanent employment due to my disability and pandemic. But number two was the best was learning how to use technology in its optimum use.

RICHARD: Good, who is that?

GEMMA: Somebody in South Africa. Lizzy Way.

RICHARD: Would they like to see more about it?

GEMMA: Lizzy Way, are you able to speak to us?

LIZZY: Hi and good afternoon to everybody. I had this experience because I had a learnership and in South Africa it has a problem with employment. So the best way I went about it was going through a learnership for people with disabilities and under a learnership for a year from 2019 June and then upon the expiration of a contract we were told we would probably get a job or probably get some sort of promise into the industry. Upon the pandemic happening and upon the contract expiring, they didn't fulfil those obligations anymore and those premises and we were excluded. So that was the worst experience, I think, as well, COVID made it even worse. But the fact that we were discriminated against as well as disabled people we were in a lesser of a position, yes, thank you.

RICHARD: Good, thanks for that. Okay. Do we have any more there? If people could think about what the best responses were and put a few more in. I'll tell you something we heard this morning which you won't hear on this call I don't think. We were told by a colleague in Uganda that the deaf community there were particularly hard hit by the heavy policing methods that were used and the lack of awareness amongst the police, if they shouted for people to stop or shouted instructions people wouldn't hear them. And one person was shot and subsequently died, and the police officer had a prison term now. And the second person was shot in the legs and had to have a leg amp at a timed and there were legal things happening and we'll get onto this when we talk about training for staff in humanitarian situations which of course COVID was one such that work needs to be done with all these first responders. So any more for us to take Gemma?

GEMMA: A couple of positive ones. The best thing that is to witness the inclusion persons with disabilities with local efforts. We have having a vaccine clinic specifically for persons with disables on Monday and this is one of the efforts that has helped.

RICHARD: Who is that?

GEMMA: Do we know which country that is?

GEMMA: Kerry Anne, I think it might be Barbados, it has a BA on the end, and I haven't remembered the numbers! There is another one Andy, I'm not sure what country, increased disability advocacy even started an awareness programme via social media called Bulge TV.

RICHARD: Do we know where that is?

GEMMA: We don't, Freaky Andy could you tell us which country that is?

RICHARD: Maybe they will put it in, in a bit. So the best of times and the worst of times, really. What I think happened in many countries that ordinary people did -- >>: Can you allow me to share about Uganda's experience during COVID-19?

RICHARD: Okay.

>>: My name is Buata from Uganda. The worst experience here ... where we work. During COVID-19 we lost one of the disabled women, her business was of lockdown and there was no public transport, ... During COVID-19 there were many factors that were implemented by government that affected persons with disabilities whereby especially the blind, someone goes to the nearest centre, maybe to buy something and maybe in the next needs to walk back home. Confused appearing like (inaudible) and then the person is arrested or beaten but maybe he doesn't speak but beaten up or arrested so that became a big challenge here in Uganda. And when you move to some public places, like government areas, there are some, the SOPs sanitisers that were provided by the UN agencies in Uganda. This sanitiser was very difficult, especially for disabled persons who use wheelchairs, use them. Because they couldn't, they can't press them, because they are very hard. So you cannot know whether (break in connectivity) you move back home and it's a challenge.

RICHARD: Okay, if you could make your last point.

 >>: Yes.

RICHARD: You are breaking up a bit.

>>: The response to COVID-19 in our country especially for us here we appreciate COVID-19 has got access to technology, whereby we can now access Zoom online, thank you.

MARY: Can I talk something on Kenya, I'm sorry you couldn't hear my brother, who wanted to comment on the action that was taken this Kenya. My name is Mary and I'm a member of the County Assembly of Nairobi. We have seven counties and what happened is all the governors for those counties came together under the fellowship which the core council of governors and they mobilised resources and everything and they were able to help. It didn't really completely solve the whole purpose, but they came together and put resources together. Medical, ambulances, and everything and people were helped. I know also in Nairobi the Government organised and we were able to help people who live very poorly in the ghettos or slums. And they were able to be helped. So the national government, also the minister of health continually on a weekly basis was given updates on COVID and the President also was doing it every now I think a fortnight. So people were encouraged to wash their hands, sanitise, keep their distance and also wear a mask. In fact up to now, mask is a must. So the government tried its level best but I know there were a few cases of inappropriateness of some money being squanders. We had read across helping here and there and so generally the well-wishers were very good. Also neighbourliness they brought out some good spirit of people just going out of their way to help people with disabilities, and I remember even people who have mental disabilities were also being helped by neighbours because the neighbours understood that their mental problems would be exacerbated if they were not helped especially with food and that kind of thing.

RICHARD: Thank you Mary I'll have to stop you there because we've got to get on but some really useful information.

MARY: Thank you.

RICHARD: As I was saying we had the best of times and the worst of times, I think. We're showing a lot of human spirit and solidarity for people. And at the same time really bad things happening as we heard from particularly the responses from Uganda and elsewhere. We heard earlier on this morning a mixed things happening across the Indian subcontinent and so on. So I think we will press on now. Thanks for all those contributions. I think we're now going on to Sarah is going to talk about Article 25 and SDG3. The wider, not now on COVID but looking at the whole health area, there are responsibilities for equal access to the same standards of health care and services as others. All governments must take appropriate measures. We're looking at that now. So, Sarah, would you like to come in that?

SARAH: Thanks Richard, yes. I want to talk about Article 25. Which is on the right on equal access to same standard of health and care, health care and services, as others and must take all appropriate measures. And SDG number 3. Article 25 of the UN CRPD re-enforces the right of persons with disabilities to obtain the highest standard of health care, without discrimination. However, the reality is that few countries provide adequate quality services for disabled people. Also, very few countries collect data to enable disaggregation by disability in the health sectors. SDG3 with goal 3 aiming to ensure health lives and promotion of well-being for all at all ages. Disabled people are an important "disadvantaged and marginalised" group to consider within the SDGs, as they are a large group, making up an estimated 1 billion people worldwide and they experience a range of exclusions owing to multiple forms of discrimination and inaccessible environments in many spheres of life, including SDG3 targets. I'll talk about the barriers to adequate health care for disabled people. There are many barriers prohibit costs. Affordability of health services and transportation are two main reasons where disabled people do not receive much needed health care in low-income countries. Just over.

GEMMA: Sarah, could you slow down a little as you are talking please?

SARAH: Okay. Prohibitive costs are an issue because health services are quite expensive and even transportation to the health services and even accessibility in this health services themselves are an issue. We'll also talk about limited availability of services as another barrier. There is a lack of appropriate services for disabled people where many studies have revealed high and met needs, for health care. Among disabled people due to having an ability of services especially in the rural and remote areas. Another barrier that is there is physical barriers of uneven access to buildings, the hospitals and the health centres are inaccessible. Okay we also have inaccessible medical equipment, poor signage, lack of interpretation, narrow doorways, internal steps, inadequate bathroom facilities and inaccessible parking areas, create barriers to health care services. Another barrier is inadequate skills and knowledge of health workers. Workers, disabled people were more than twice as likely to report finding health care provider skills inadequate to meet their needs. Four times more likely to report being treated badly and nearly three times more likely to report being denied care. These are some of the barriers and some of the issues around those barriers are the issues of accessibility, the issue of affordability, and availability for disability people, vis a vis those without disabilities so we would like you to respond in the chat for the questions that are going to respond to how health care in your countries are accessible. If persons with disability are able to access them. Given the barriers that we've talked about and many others that are not there, affordable, the costs of health in most countries are affordable and then available. Other services available. And, if not, why are they not? So what else can be done by DPOs to improve the situation? So therefore I will call upon Richard maybe to elaborate further.

RICHARD: Yes. Okay thank you Sarah. I'll just set it up again. So get your thinking caps on as another one where you can respond. What we're looking for is, in your country, is health care accessible? Affordable? And available? The three As. For us as disabled people. And, if not, why not? What are the reasons why it's not? And then the second part, if you put that under three. And, number four, what be done by us to improve the situation we just talked about? So that will require you doing a few lines, accessibility, affordable, availability, why is it like that? And what can we do to improve the situations? Again, I will shut up to allow you all to think and to start putting stuff in the chat. I would urge as many people as possible on give us their argument its. We save the chat and everyone will be able to see it, it will be up on the website area eventually on you can gain from the instant survey that we're sorting here, we have 116 people online so that's quite a base to base some of your follow-up questions on when you are doing the course book. So I'll be quiet now for a minute or so while you think and type into the chat. Thank you.

GEMMA: Richard I have had a request, please can you repeat the questions?

RICHARD: Question three: is your health care system in your country accessible, can you pay for it, is it affordable? And is it there, does it exist? At all? For disabled people. And if it doesn't, why? On that's the first part. So get that down. And then when you've done that, and identified a couple of barriers and thought about why that is, what can we do about it as DPOs to change the situation? That's number four, okay? So three is barriers, accessibility, affordability, availability for disabled people. And why it isn't and then number four when you've done that, what can we do about it as DPOs? Kurt, you are making marks all over my screen, I don't know why that's happening but Kurt Allen, can you stop doing it, from Trinidad I think. It may be your JAWS that is doing it but it's putting lots of yellow lines all over the screen. Okay Gemma I think we've given people quite a bit of time there to come up with some ideas.

GEMMA: Okay I'm going to start with someone from Belize. Is health care available? In Belize only private hospitals are accommodating walk-ins. No many can afford private hospital, clinics go through a long series of waiting. Standard screens for temperature checks are done, the health works do minimal to the patients after they have a waited so long. And the answer to what can DPOs done to improve is that they can lobby that the government provide more PPEs for public health workers. DEP is can also provide a list of critical cases to public hospitals to consider critical due to disability.

RICHARD: That sounds a well-reasoned argument. We may come back to you Belize about but let's have more.

GEMMA: I think someone's from Ghana. Accessibility is a question and issue persons with disability fighting over with the government for a couple of years now. It's worth noting that new government buildings are now accessible. Also, as a result of introduction of health insurance schemes, health care is relatively affordable.

RICHARD: Well, that's good.

GEMMA: I'm sorry if you are not great Ghana, Steven Agaim. Somebody in Uganda said DPOs should come up and sensitise and support in training the health workers on how to handle disabled people.

RICHARD: Good point and, in fact --

GEMMA: Do you want to talk to them?

RICHARD: Yes, get them up.

GEMMA: Okay that's Namo in Uganda. Namogabway. ... on how to handle disabled people, are you able to talk to us, can you unmute please?

RICHARD: No.

GEMMA: It maybe they are deaf and wish to sign? But I don't are that --

RICHARD: They can say in the chat. I'll say something on that while they're signalling to you through the chat that they need some special arrangement. This is a really important point. It's not going to change, the vast majority of disabled people haven't gone through the paradigm shift. Don't see this as a human rights issue. Have a sympathy approach to us or a dislike of us approach. And that has to be challenged and because of the government signing up to this convention they are parties to Article 8 which means awareness raising. So DPOs one of the wig things they can do is train up people like yourselves on this call to actually do the sort of thing I'm doing with you but to the health workers, to the teachers, to the Government officials, disability equality training to get them to change the way they think about disabled people and then change their practices. So this sensitisation is a key thing to change in the environment for us as disabled people and we can play an active part in it. It can also, because governments have money, it can actually raise income for the people or for their organisations. We shouldn't do it for nothing, we should charge for it. Okay. Have we found out some more points now?

GEMMA: Nicodemus from Kenya says it's accessible, no, because of the high cost the transport and the transportation is poor. So it's not affordable and very expensive for the disabled to afford and he says the DPOs should create awareness. Somebody else in Nigeria says, I'm not sure what he is referring to, he says it is in Nigeria, many of those things but not accessible in remote areas. It's not affordable for those who have financial challenges. Disabled people are not given special place, they have been treated like other members of the public.

RICHARD: Yes. That's an important point. I don't know if you want to come in on that, do you?

GEMMA: That's AbuBakar in Nigeria?

RICHARD: I'm not picking the right people today.

GEMMA: That's okay.

RICHARD: I think the point you make about rural areas I think is really important. Some of the solutions to that have been to create mobile clinics on vehicles or in Bangladesh we've had some examples of clinics boats that are getting round to people. One of the things we could do as DPOs from the urban areas is go out into the country in similar ways to actually spread the word amongst disabled people living in rural areas so that they can campaign for their rights and give them some of the tools that we have used to get it in the town areas. So that's another way we can approach this.

GEMMA: Can you just wait a moment? Abu Bakar is on video only. I'll ask if he wants to sign his response.

RICHARD: Okay.

GEMMA: Yes, he is in Nigeria, maybe we need Susan as well.

RICHARD: Let's see if we can make it work.

GEMMA: I'll ask if he can start his video. Here we go. >>: The interpreter is asking if he can see us.

GEMMA: I'm wondering if he can. AbuBakar, can you see us?

 >>: I'm sorry we can't see you. Apologies. Are you able to move into some light on we can see you?

THE INTERPRETER: He has gone.

RICHARD: We have someone raising their hand, I don't know, Collins, is it? Would you like to come in and then we'll have to move on.

GEMMA: I think AbuBakar is -- trying again. Sorry.

RICHARD: Yes? Who is that?

>>: Collins here from Kenya.

RICHARD: Okay go on then, quickly.

COLLINS: Thank you very much I wish to contribute on this and say in Kenya however much the government is trying to decentralise health care access to the country in Kenya devolution has come with unprecedented challenges. In Kenya you find most counties are trying to make easy access to health care services to persons with disability by giving free services to these individuals with disability as long as one produces a registration card that identifies them as a person with disability. Other counties are making it very difficult because there's no awareness of this specific disability needs to the persons in our county government. So it makes it even harder for such services to be accessed by persons who have to access health care to be able to continue.

RICHARD: We are running out of time we have to do one more part of the module. So what would you suggest is the way to change the view in the counties?

COLLINS: Thank you very much the DPOs need to come out strongly and champion for access, ease of access to health care services, not only by reach to hospitals but also creating awareness to the medical staff in the various hospitals. Thank you.

RICHARD: Thank you for that. And that's a good point that we'll end this round on. We'll go on now to the last part today's module which is we're talking about Article 12 which is a very important article. This is the right to make your own decisions. We're going to hear from Michael Njenga who is from Kenya. (VIDEO).

MICHAEL: I think Article 12 impacts all the organisation and this could be small organisation like what to wear, where to go, the kind of friends you want to have, and could be about a decision also about owning land, owning property. It could be about the enjoyment of a whole area of the human rights. For example the right to vote. Often you'll find in laws that persons of unsound mind cannot vote, or they cannot stand for elective office. For me it affects small and big decisions and also across the board, and effects the enjoyment of fundamental rights and freedoms.

RICHARD: We'll come back to Michael on several points on this. But Article 12 just so people are clear -- most people take it for granted they can make decisions and be respected by others. But legal capacity which is Article 12 is the ability to hold rights and duties and the ability to exercise those rights and duties. It is about both big and small decisions as Michael just said. And it is a pre-requisite for enjoying all your human rights. Historically many groups have been denied this right to legal capacity. Many false scientific approaches have been taken such as IQ tests, such as various spurious statistics, developed by eugenicists such as Spearman, the statistics, Spearman's road test carries the name, but they were trying eugenicist trying to prove that disabled people were in inferior and trained through the European and North American system spread throughout the world, dealing with issues that have spread out from the imperial powers and that has led to the incarceration. Then you have local ideas like tying people up and restricting their rights. So persons with psychosocial intellectual disability are very much disproportionately impacted on by this and let's hear a bit more from Michael now. (VIDEO).

MICHAEL: There are two ways which we are addressing this. The first thing we're doing is raising awareness around Article 4. Secondly, doctors most of them are not trained in human rights. They are not aware about the convention on the rights of persons with disabilities, so we have to engage with them and make them understand about the paradigm shift. Then, the other tool that we use is the one with peer support groups. So for example I go to a peer support group and if I was to get into distress the members know what I like and what I don't like. But even when I'm in hospital, they are able to say no, this person does not like this kind of medication. So there are practical things that we are doing in the country towards the realisement of this particular rights. The other thing is that we're advocating a possible advanced directive to be put into the law so it's not a question of people are acting out of goodwill or charity but they are obligated to follow the provision for example of the mental health care bill which we want to enact in the new mental health law.

RICHARD: How is legal capacity denied? Well, full or partial guardianship, this is against the convention. Where family or friends or relatives make the decisions for someone. That's not allowed. Mental health laws that allow for involuntary admission, that's admitting people to hospitals and clinics and other things against their will. Involuntary admission. Forced treatment, like being given ECT or drugs that you don't want to have. And deprivation of liberty on the basis of disability and impairment. This is a very widespread thing and the Governments that have all signed up to the UNCRPD need to start talking to DPOs particularly those representing people with mental health issues about how they change the law in their country. Inform guardianship is an informal arrangement of substitute decision making where family members make the decisions on behalf of the person. And let's hear a bit more from Michael about that. (VIDEO).

RICHARD: Came very much from a biomedical model of the person seeing the problem in the person and that there were certain people who were not allowed to do things. What is your reaction as someone with mental health issues to that whole view?

MICHAEL: I think for me we must really distinguish what we call mental capacity. And mental capacity is a decision-making capability. Indeed this varies from one person to another, vis a vis legal capacity, the right to make your own decision and to have those decisions respected by others. I think the assumption here is always that, when you have a mental impairment then you are going to make wrong decisions and the fact of the matter is that we can't afford to know the inner workings of a person's mind, there's no way of knowing that. That notion from the medical model is outdated and this was something that was borrowed from the British common law system. And just to illustrate for example in election processes for example, in Kenya, in 2007, people who the law says are of unsound mind did not vote. But everyone else who could vote was of sound mind voted and then after that we had post-election violence. So the whole discussion about people being of unsound and sound mind, there's no objective determination of that. Because, in Kenya, the people who are sound voted and then they almost brought the country to war. People who were not unsound did not vote. For me it's approximate about there's no objective way of determining the way a person makes their own decision and we should allow people to make -- we should give them the dignity of decision making.

RICHARD: All persons with disability are presumed to have legal capacity and States must take all appropriate measures to ensure this is realised. So this would mean it prohibits all involuntary practices, in voluntary admissions embraces supported decision-making paradigm. So that's the person with mental health issues, neurodiverse, learning difficulties. Having the right to make decisions, recognises the will and preference to be.underlying principle in all decision makes. Everybody can point to a picture, one picture or another, or point with their eyes or say yes or no or shake their head up and down or sideways. They have will and preference. It is not true that people don't have this. We need to provide safeguards against abuse and undue influence from those who say they represent these people and we need to recognise the rights of persons with disabilities to own property and access all financial services on an equal basis with others. We need to distinguish as Michael said so clearly there between mental capacity which can vary hugely in many different dimensions and separately that we all have legal capacity and in order to exercise that we might some support. So I'm going to give some examples of support here that inform information providing accessible format, might be a good start. That there is an evaluation of all available alternatives. That support is provided to implement a decision, for example appropriate safeguards are provided. Peer support, Michael mentioned that, that's a group of friends or relatives who the person trusts and says, I want them to be in my circle of support who will help me when I have an episode.

GEMMA: Richard.

RICHARD: Yes.

GEMMA: I'm going to interrupt you please. Our man in Nigeria would like to make his point from earlier. We were not able to do that before.

RICHARD: Let's take him as the first one when we go to question again in a moment, shall we?

GEMMA: Okay. I'll message him to hold on.

RICHARD: Yes. Tell him to hold on and we'll come back to him. Advanced directives, this is where you are perhaps not undergoing an open code of mental health difficulties so you are right. If I have this, I want the following treatments, I don't want my brain to have electrodes in this, I want this and this. People who have been in the mental health system for years will know what works for them and what doesn't. And they can say that they have a circle of friends they choose that will hem them with that, they can make support agreements and family support. Of course social workers can help, and I'll just come back to Michael for one last point and then we're going to go on. (VIDEO).

MICHAEL: I think we have to look at the general comment number one on the rights of persons with disabilities. When a person cannot make their own, when they're having difficulties in making decisions, maybe they are in distress or in a crisis, then the principle is always that we have to make a best interpretation of their will and preference. So we don't act in their best interests between make a best interpretation of their will and preference. The question is, how do we do that? For example, as a person, you may have interacted with me. You know what I like and what I don't like. So even though I'm not able to express myself because I'm in distress or in a crisis, using my previous preferences, attitudes and action, you can be able to determine what is the best interpretation of my will and preference. You can also use other tools like directives and this is something that we're trying to put for example in the law in Kenya. Whereby I can write in advance and say for example, if I'm in a crisis or in distress, I do not want to take this kind of medication. I do not want to are ECT. So I think there are specific things that we can do, patterns in a person's life, whether verbal or non-verbal, for us to be able to determine the person's will and preference when they're experiencing difficulties during a crisis.

RICHARD: That is general comment number one. I won't spend time on that. I'm going to go on to this last set of questions. But before we take that, I'm going to allow the person from Nigeria to come in and talk to us. But I'll leave these up so that people can see the questions that we're talking about there. Does the law in your country allow universal legal capacity? Who does not have legal capacity? How can this be changed? It's really all-around legal capacity. But Gemma, let's go back to the man, was it AbuBakar that we couldn't take before?

GEMMA: It's AbuBakar and we have him waiting.

RICHARD: Okay let's have him.

GEMMA: If someone's going to communicate with him directly first.

RICHARD: Okay.

THE INTERPRETER: AbuBakar can you see the two interpreters? AbuBakar? I can see you but can you see me? Can you tell us your situation? You had your hand up before, would you like to say something? You had your hand up before, or do you not want to comment? Go ahead. It's a very difficult situation for people in Nigeria. They do not have the supports in place. We think he is saying that it's not recognised. So deaf people are not recognised in the community in our country. Speaking of elections, we're having difficulty understanding, apologies. He isn't communicating in International Sign.

RICHARD: Local sign.

THE INTERPRETER: It is, apologies; beautiful because of time can you give us a summary of your question or comment?

RICHARD: Okay I think we'll leave it there. We did get two points from you AbuBakar, it's very difficult for deaf people in Nigeria, needs are not recognised. I think you were going onto say that there were also problems around elections for deaf people registering their vote. So thank you for that contribution. We'll hear from you again later in the course. We need to just finish up the main thing of what we were doing. I'll just come down to the last slide. I think we're not going to have time for that last question but people can do it for themselves and send it in, if they want, or do it. I'm now going to play to finish up on this, health thing, and Antonio, the general secretary of the UN made a very powerful, this gives the signers and the captioner a bit of a rest because it has got both on it, about COVID and disability on the 3 December and I think it's really important that we take this on board. Thank you. (VIDEO)

RICHARD: Very powerful words there from the Secretary General and I think it makes the point that we don't have the time for that now. I'll stop the share and ask Sarah to say a few words to end up this seminar. If you are still online, Sarah? And then I've a few things to say and then we're going to end.

SARAH: To conclude this module and this seminar, we have seen that health is a very vital and important aspect of responding better for persons with disabilities to be able to access services and their well-being, being taken care of as a human right. And, therefore, we would like to encourage the implementation or the execution of the lessons that you are learning in your country so that the Government are held to account, that their laws are implemented and infrastructures are put in place and services delivered to persons with disabilities with regards to health for all the different types of disabilities. And, therefore, I want to call upon all participants to be more active and put this cost to use, moving forward. Thank you.

RICHARD: Thank you, Sarah. 90 minutes seems like a long time but it soon goes. I hope we've made some key learning points that have re-enforced your reading of the course book and the presentation that you saw. Obviously, we can't cover the whole terrain. You do have follow-up activities to do and maybe this seminar will make it easier for you to do those. They are in purple print in italics in the course books. And they are numbers. We're dealing with module 3, so you have 3.1 to 3.7. We would like you to send those in, email was sent to you yesterday about where to send those. We think we want to get some idea of how many people are actually doing that because we have very variable numbers on these calls. So we want to have some idea of how many people are serious about this and we have a waiting list and bring some more people onto the course who can still get the accreditation at this point. Tonight, the module four film will go up which is on access and assistive devices. Absolutely vital for us as disabled people, huge array of things that we need to have in place which other people don't need for their equality. This is unique for us as disabled people for our equality to have access to assistive devices so the seminars next week will have people from the different parts of the Commonwealth coming in and we're following up then with employment which we've already been record ago lot of good, interesting examples from around the Commonwealth and if people have them, send me an email. If you've forgot something that you want to add in on employment. Or, on humanitarian situations and natural disasters and the environment and I'm particularly looking at people on the call from the small islands communities, if you have something important to say on that, again, contact me and we will set up a Zoom call at time appropriate for you where you can do a three, four, five minute bit which we can incorporate and that is a way of you getting your voice into this training. I would like to thank everybody for participating in this. I hope you are still finding it useful. If you would like on unmute or put your camera on, we can all say goodbye to each other. That would be good to see who is on the call. It's not time for everybody to speak. But it is time to say hello. Bye bye.