RICHARD: Good morning or good afternoon everyone or good evening, depending where you are. This is Richard Rieser, General Secretary of the Commonwealth Disabled People's Forum, welcoming you to seminar A, the morning seminar of modern 13 of our disability equality capacity building course. And our theme is building DPOs, campaigning and increasing our voice, our voice being the voice of disabled people or people with disabilities. We will be using both sets of words today because we'll be looking in some detail at some of the pronouncements of the UNCRPD committee and so on, who use persons with disability as indeed the consequence does. With me today this morning is Thandiwe, our vice chair and she will be making some comments to start with on this. And then I'm going to go into it. We are focusing really on joint interactive activities today, there are actually five down on the list, whether we can get through them all will depend partly on me and partly on you, how much you want to say on the earlier ones. The two last ones are probably the most interesting but we do need to make sure that you've all got the basics in this because there's a huge amount of confusion about who speaks for disabled people in the world.

GEMMA: Could you slow down a bit Richard please?

RICHARD: Yes, on okay so I'll just put the screen up. Thandiwe would you like to say your thoughts about this whole area for about a minute or two? Thank you.

THANDIWE: Thank you very much. Good morning everybody, my name is Thandiwe, and I'm the chairperson for, the vice chairperson for the Commonwealth. I would like to start by saying all of us are going to participate and become so that we can cover the food programme. But also, I'm going to start by saying in general on equality capacity building process at that we're going to have is to have members or learners on this programme where we are going to talk about the involvement of the organisation of people with disability leading their own development. By what you mean we are saying, we are asked to succeed as people with disability, we need to have our own voice. We need to make sure that our own voice can be heard. But that can only be heard by self‑representation which means organisation of people with disability needs to be the one leading around their development. Needs to be the one guiding, giving directions to all these organisations. To government, private sector, to everybody who is being involved in disability. Because we're saying nothing about us without us, there's nothing that you can do speaking on our behalf. We can speak on our own and we can do things on our own. Thank you so much.

RICHARD: Thank you. Okay, so we're going to look for the first part here at a very important document that's often overlooked. The UNCRPD committee which as you know has got 18 disabled members on it, as of last November, it has equal, well, they're coming into power in January, equal number was men and women from around the world and all, bar one I think, are disabled people themselves. And elected by governments, the Governments who have signed up to this convention and then voted from those nominated and half is elected every two years. And, so, they are there as you know to hold governments to account and are also open the comments from civil society, particular DPOs. But it says representation of organisations of persons with disabilities or as we say it disabled people's organisations which was the first label that was used by disabled people's movement and many of us around the world still want to stick with that.

I shall interchange between them. But what it says in paragraph 11 which is really important is these organisations are persons with disabilities or DPOs should be rooted, committed to and fully respect the rights and responsibilities recognised in the convention. And it's worth remembering we won the battle in the convention for the paradigm shift to a social human rights model. So the problem is not us needing care and attention and rehabilitation, thankings part of what we need. But the key issue is removing the barriers beyond us and therefore that's where the politics of this is coming from.

It also says that those are led and directed and governed by persons with disabilities. So representative organisations are not run by non‑disabled people. They are not governed by non‑disabled people. They are led directed and governed by disabled people. A clear majority of their membership should be recruited amongst pensioner with disabilities themselves and when we ask people to John Commonwealth Disabled People's Forum we ask this question: do you have a majority on your board of disabled people? And is a majority of your membership disabled people? And this includes organisations of women with disabilities, children with disabilities and persons living with HIV. Are organisations of persons under this convention. Now, there's a lot of prejudice still about HIV but they are part of the disability movement, as are people with mental health issues. And other psychosocial. And, therefore, their organisations also need to be run and controlled by them as far as possible.

Organisations have the following characteristics. They aim of collectively acting expressing, promoting, pursuing rights of persons with disabilities. Collectively, that means by democratic means they arrive at not one person's view, it's a discussion. And deliberation that leads to the view that they have. They employ and entrusted by or specifically nominate persons with disabilities themselves. Which means that DPOs should really be employing disabled people, whenever possible, to do the functions. Now, that's not always possible. But the people who are in the leadership should be disabled people. It means that they are not affiliated to a particular political party and I know that at various times that has been the case. That in Zimbabwe it was linked to the ruling part for a long time. In South Africa there was an alliance with the ANC. But it's still maintaining independence is really important, whatever is the governing party.

They may represent one or more constituencies based on actual perceived impairment and can be open to membership of all those persons with disabilities. So they could be only blind and visually impaired people, it could be people with psychosocial, it could be people with mobility issues or it could be people with cross impairments, the whole range of impairments.

They represent groups of persons with disability reflecting their diversity of their background and this is really important because we've looked at issues of gender, we've looked at issues of race, and refugee status. We've looked at the impact of ecological issues and we clearly need to represent all groups affected by these issues. So it's not just about having views about disability, we obviously have intersectional views about all of these things as we've demonstrated in the course. Most importantly it can compromise people with a range of impairments. DPOs can be very local, very, very local, just a block. A local area. A region, a nation, an area across a nation, groups of nations or across the whole world. They can operate the individual organisations owe collisions or umbrella organisations, and this is most important, seek to provide a collaborative and coordinated voice of persons with disabilities in their interactions with, amongst others, public authorities, internal organisations, private entities and governments.

There's distinction between organisations of persons with disabilities, or DPOs as we called it and other civil society organisations and perhaps the key thing here, organisations of persons with disabilities, alternatively, disabled people's organisations, should be distinguished from organisations for persons with disabilities. The ‘fors’ have traditionally been the service providers or organisations set up by parents for particular groups of children and have often set up for the best reasons in the world provision for them which, in the end, over time, has become segregated and oppressive provision.

So, as things move on, such organisations prioritise the purpose as private entities over the rights of persons with disabilities. Whether they be a service provider, whether they be an international NGO, in the end, it's their budget and how many people they employee and their profile in the media. To get more money that comes first, rather than the needs of the people of disabled people. And that is why we have emphasized several times in the course that you need to have tests about the NGOs that you work with. Are they genuine in actually standing back and letting us lead in coalitions, giving us their resources and money but with control given to disability people about the direction of where they're going.

We would prefer that they didn't exist, they do exist because of history, but, they should be now working for their extinction so DPOs are actually the empowered organisations.

State parties should give particular importance to the views of persons with disabilities through their representative organisations. Support the capacity and empowerment of such organisations and ensure that priority is given to ascertain the views in decision makes, this is not Richard, this is not Commonwealth Disabled People's Forum, this is the UN committee's advice to all state parties.

The distinction should also be made between organisations of persons with disabilities and civil society organisations. The term civil society includes research organisations, organisations and service providers and other private stakeholders.

DPOs or OP Ds, are a specific form of civil society organisation. We come within that framework. They may be part of an umbrella but the important thing is, in accordance with article 33.3, all civil society organisations including organisations of persons with disabilities have a role in monitoring the convention. State parties should give priority to the views of organisations with disabilities and when addressing issues relating to persons, give priority to our views, your views of DPO as develop frameworks to request civil society organisations and other stakeholders to consult and involve organisations persons with disabilities.

GEMMA: Richard could you slow down a little?

RICHARD: In their work to the rights enshrined in the convention and other areas. So that is a very strong statement and it goes on, in this things, to say they should also governments therefore should also provide funding for DPOs. Not for NGOs but for DPOs. There's no obligation to provide funding for service providers. But there is an obligation to provide funding for DPOs so they can function and have this representative role. So we're talking about then different sorts, it says, in paragraph 12, umbrella organisations have represented DPOs usually the national council. We prefer there to be one representative organisation of all the organisations of disabled people in the country. That could be organisations of blind people, of deaf people, of deaf blind people, of people with intellectual learning difficulties and other organisations. Women's organisations. They should all be in the umbrella organisation. It can be cross disability organisations of individuals with some or on all of these impairments. Self‑advocacy organisations, there are often laws in the country prevent them from formally being an organisation because they prohibited from running an organisation. This is particularly true for people with autism and learning difficulties and dementia and therefore often families set up the organisation so there's a formal structure but the emphasis has to be on self‑advocacy. And the test should be, what are you doing to develop self‑advocacy amongst your members, how are you including them on your board, how are you empowering them? Organisation including family members or relatives with disabilities, same criteria apply, yes, we understand that they have to be there but if they're not making efforts to involve and develop the self‑advocacy of the people they claim to represent, there is a real issue and we have to question whether they are really part of the disability movement.

Organisations of women and girls with disabilities and we understand why from our module on girls and women, why there is the extra issue of sexism and patriarch I did not around the world and why women and girls often need to organise in their own space to then become part of the wider movement. And the same is true for children who have a growing awareness and, again, there are organisations of children with disabilities, disabled children, and we need to have adults who do some of the functions but what those organisations stand for need to be decided by the children who are the members of those organisations. Clarifying the issue on families, and this is again from paragraph 13 of the convention, general comment number 7.

"organisations including family members and/or relatives or persons with disabilities which pivotal in facilitating promoting and securing the interests and supporting the autonomy and active participation of their relatives with intellectual disability, common and/or children with disabilities, when these groups of persons with disabilities want to be supported by families as united networks or organisations." perhaps the most important part comes at the end of this, "the role of parents, relatives and care givers in such organisations should be to assist and empower persons with disabilities to have a voice and take full control of their own lives. Such organisations should actively work to promote and use supported decision making processes to ensure and respect the rights of persons with disabilities to be considered and to express their own views."

That's really important and I think we've probably all come across examples where well‑meaning organisations set out to do that but then over time bureaucracy cuts in and the voice they're meant to represent are not foremost and the programmes meant to empower them are not happening many. The supported decision making is not happening. So we have a responsibility, if these people claim to be part of the movement to ask them the question: how much are you doing? How much self‑advocates do you have on your board, how many programmes have you run for self‑advocacy, what is the progress of those people? So the first activity is, I'm going to read these out and I would like you to then put in the chat which is a DPO or OPD and why? I'll leave heat these up and read through all five and you can put one, yes or no, if you consider it a DPO or an OP D and the reason why you're saying that. So the first one, a national charitable foundation that provides mobility aids and training. The board is made up of a wheelchair user and four non‑disabled professionals. Is that a DPO? Two, a local self‑advocacy group of adults with learning difficulties, disabled people, who have supported decision making to plan their campaigns. So they are obviously support workers there but very much self-advocates in control. Three, a national charity for people with autism and their families. The board is made up of non‑disabled adults who plan activities for the members. That's number 3. Number 4, a national umbrella organisation of DPOs representing people with different impairments, each of which is run and controlled by disabled people as is the board of the whole umbrella organisation. So again is it a DPO and why on each of those, one to four, and the last one, an alliance for inclusive education of teachers, parents, disabled children and non‑disabled peers, the board is elected at the AGM and categories of membership ensure a majority of disabled people on the board. So they are up there, I'll leave them up there. What we want you is to put in the chat, number one, yes or no and why you've made that decision. Number two, the same, number three the same and number four the same. I hope everybody understands that. Using the criteria that I talked about before, from general comment number 7: are these organisations DPOs or not?

GEMMA: Richard could you just read them out again please and then give us a couple of minutes?

RICHARD: Okay, so the first activity then you have five organisations, we want know whether you think they are DPOs or not. That's the first thing. And why you come to that decision. Just short answers. First, a national charitable foundation that provides mobility aids and training. The board is made up of the family wheelchair user, therefore a disabled person (founding) and four non‑disabled professionals. Two, a local self‑advocacy group of adults with learning difficulties who have supported decision making to plan their campaigns. Three, a national charity for people with autism and their families, the board is made up of non‑disabled adults who plan activities for the members. Four, a national umbrella organisation of DPOs representing people with different impairments, each of which is run and controlled by disabled people as is the board of the umbrella DPO as a whole. Five, an alliance of inclusive for inclusive education of teacher, parents, disabled children and non‑disabled peers. The board is elected at the AGM and categories of membership ensure that a majority of the board are disabled people. So you have to write the number, yes or not, to being a DPO, OPD, and why.

RICHARD: Okay how are we doing, Gemma?

GEMMA: Good. We're still getting answers coming in.

RICHARD: Shall we give it another 20 seconds?

GEMMA: 20 seconds will be grand, yes.

RICHARD: Okay let's go.

GEMMA: Okay, so I have a mixture of short answers and then some people have expanded.

RICHARD: Shall we try and get a consensus on the five.

GEMMA: Okay do you want to do ‑‑

RICHARD: One at a time.

GEMMA: Okay. So number one most people are saying "No". See if there's an expanded one. Nadia said it's mainly run by non‑disabled people.

RICHARD: That's a key point.

GEMMA: Somebody else, the majority are non‑disabled. Majority control is non‑disabled people. Somebody said there's a service provider. And Joanne said, no, it's a majority of ‑‑ not a majority of disabled people running the foundation. Okay, so that's number one.

RICHARD: These types of organisations do exist and the founding member can often be very charismatic and spend a lot of time talking on the media and so on. But it's important to recognise that these people only speaking for themselves, they're not speaking on behalf of anybody else. Because it is not a representative organisation. So let's go to number two.

GEMMA: So number two, let me see. Lots of short ‘Nos’. That's interesting. Let me see if there's a yes. Yes, Nadia said run by disabled adults. Someone from Bangladesh said yes.

RICHARD: A yes is the right answer here. Because let's break it down. It's a local group but you can have local groups. It's self‑advocacy which means it's people, disabled people representing themselves. Adults with a learning disability as they have concluded an intellectual impairment but they have supported decision making which means they have adults, non‑disabled adults helping them but they are the ones making their decision so it ticks all the boxes as a DPO.

GEMMA: Some other people are saying yes, run by disabled persons.

RICHARD: Number three.

GEMMA: Okay number three. People are saying "No", disabled members not ruling. Three, no. Majority controlled by no one‑disabled people. Trying to see if anyone disagreed with that. No, run by non‑disabled. Three, no.

RICHARD: It may well be that there are such organisations that have set themselves up.

GEMMA: Somebody has said yes actually.

RICHARD: Can we get them on to say why they think yes? I don't think it's as clear cut as some of the others.

GEMMA: Okay I have a couple that said yes. Either Runak in bang Derby or Monir H Usain? If either of you want to come on. If you want to sign just put your video on and case to us. If you want to speak put your mic on please. So that's Monir or Runak. If either of you want to talk.

RICHARD: Maybe they don't.

GEMMA: That's okay.

RICHARD: I'll say, remember that we did read out that organisations which are run by families need, could be included, but they need to have a perspective of developing self‑advocacy and there's nothing here to suggest that there are any self-advocates on the board or that they have any programme to move in that direction. So I said that there he is a challenge to those organisations to see how much they are actually working. And they may well not have a majority of disabled people on their board organisations like this. Many autism organisations don't. But they do have some self-advocates and have been included into disability movements. It's on the edge, they're not service providers but they're trying to set up an advocacy organisation for their relatives but how much are they committed to self‑advocacy and developing that, is the issue we need to ask there. So it's on the edge that one. Number four, ‑‑

GEMMA: Yes, number 4, people are saying "yes", so Adam says yes because it's membership and board take full control of the decisions and advocacy interventions. Joanne in New Zealand said, yes, it's run and controlled by disabled people. Shruti in India said yes. Richard in Uganda said yes because all planning is done by disabled people. Disabled people know best what they want and how they can achieve all their goals.

RICHARD: Very good.

GEMMA: And in fact he may have been referring to five as well there, but it looked like it was for four.

RICHARD: Let's go onto five because this is more contention because a lot of purists if you like, the people in number four, who are saying it has to be run entirely by disabled people, have been against such organisations saying they're not really DPOs. But we need to look at what the convention says. It says work with the evolving capacity of disabled children. Their capacity is going to evolve as they grow up but this also is about peer support so their non‑disabled peers are here and it's about the people who deliver education and care for children. But there are disabled children and non‑disabled peers. The issue to me seems to be it's the majority, the AGM ensures a majority of disabled people on the board. So what were other people's views on this one?

GEMMA: A lot of people are saying yes to this one. Joanne again said, yes, borders a majority of ‑‑ Shruti in India said yes; Joshua in audio began did a said no. Somebody else said yes. Genital in bang dash said, sorry, number five would be no and also someone else said no as well.

RICHARD: It does cause confusion. We had an organisation like this in the UK, it's now got a board entirely of disabled people but, no it hasn't, there are a few non‑disabled, it's a majority disabled people. But elected directly. This was different sections electing. I think it's problematic because we have to accept that disabled children are not going to bring about inclusive education on their own. And that most adult organisations are not very interested in children, disabled children, and what they do. So who are the people who are most keen for inclusion to take place, will be the parents of the disabled child and we said when we looked at inclusion it was led by parents to start with. This is about allyship, what is the aim? To get inclusive education. And most children on their own don't have sufficient power so they need to gather people around them. Allies, who support their aims and those aims need to be clearly stated but the people developing the decision making is by the way of voting a majority of disabled people. So again it doesn't quite fit the mould but I would say, yes, but it really depends on whether the majority of disabled people are really making the policy or not. But it's interesting, how else do we set up structures if they don't involve that they are pants and indeed their teachers who, these will be teachers pro‑inclusion one assumes, if they're not going to be championing it as allies and I think that's a useful word here. Allies of the struggle for inclusive education. Okay so interesting responses there. Let's go on. We have another one coming up in a minute, right away actually. So I'm now going to put these tests to some actual organisations. The first one and all you have to do is put yes or no into your chatbox, we'll do them one‑by‑one. A: the UNCRPD conference of state parties. This is a meeting about disability and happens every year, COVID providing, in New York at the UN. And it is all the states that have signed up to the convention so that's 182 of them turn up. It is open to non‑state party observers who can participate and speak. And they are something like 1500 currently registered for the one that's going to happen in June, although it will be largely online. You have a lot of disabled people there. Putting their views. But, in the end, is it a disabled people's organisation in we want a yes or a no on A in your box. Okay, what are we getting?

GEMMA: We need a little tiny by the Longer.

RICHARD: Okay. I'll say fingers on your buzzers for the next one, be ready to put a yes or a no into your box on each one.

GEMMA: Yes. But we have to allow for the captioning so just one second.

GEMMA: Everybody is saying "No".

RICHARD: I think that's right. Of course you have all the NGO there is as well and although it's about disability, it is not run by disabled people. There is, on the other hand, before that an international day of disabled people's organisations, the can you cuss day that happens the day before it and we could perhaps say that was run by disabled people. So I think not entirely.

The world federation of the deaf, these are organisations that are linked up across something like 160 countries where deaf people particularly sign language users in each country have elected representatives who are deaf people to go and represent them at a global level. Yes or no?

GEMMA: We have lots much yeses and one no.

RICHARD: Interesting, the no person, would they like to share their view? Because I think yes is the right answer but I'm just interested why they say no.

GEMMA: .Olinka? Would you like to speak?

>>: Hello?

GEMMA: Had I .

>>: Good morning.

RICHARD: Just interested to why you said no to World Federation of the Deaf not being a DPO.

>>: Well, the reason I said so is because DPO, to me, is meant to be (distortion in sound). Organisation that allows for (inaudible) share their thoughts. And to empower them. I think federation to me is more kind of (inaudible) like that,) distortion of sound).

RICHARD: We've got a very poor line with you but what I think you are saying is because it's a federation and it's not focused on issues that will take deaf people forward, is that what you are saying? Because I don't think that's true because I think they are the biggest champions in the world for sign language as an alternative language. Which is certainly something that deaf people, the capital D, those who rely on sign language, would be campaigning for and they are definitely disabled people, although there is some argument in some parts of the world that deaf is a linguistic minority but even where they argue that, they do take up their place in the disabled people's movement. And, in fact, the world federation of the deaf is a member of the internal disability alliance. So interesting. But let's move onto the next one.

>>: Okay yes thank you.

RICHARD: Thank you. The European Disability Forum. If people can mute. This is the representative organisation of national councils of disabled people across Europe. But they do allow family organisations as well. What to do people think on that one?

GEMMA: Most people say yes. Joanne said yes sewage majority ... likely family groups are associate members. Everyone else has said yes.

RICHARD: Yes. That is the issue. They are representative body, they are on IDA representing the region with you they do have family members and they're not just associates for instance, their vice chair can and are sometimes non‑disabled people from the family connection. But I would say the majority of people involved with it are disabled people. And they do get money from the European union so they are able to carry out their functions.

The UNCRPD committee, remember how that, I told you how it was elected, it is a majority of disabled people. But it is elected not by disabled people, it is elected by governments. So is it a representative voice of disabled people? Or is it a committee of disabled people which are overseeing the convention? Is it a DPO or not? Okay. Majority view?

GEMMA: Majority is "No" but there's, it's not a huge ‑‑ well ‑‑ I don't know. I would say maybe three fifths. So some people are saying "yes", someone said quasi DPO. Somebody ‑‑ Rubel said it's um bell people for disabled. Olienka, "it's a good representation of disabled people, yes". So mixture of no and yes on this one.

RICHARD: Formerly, no, though it clearly is a voice within the UN structures for disabled people's views and they take representations from disabled people when they consider state parties reports and, under the optional protocol, they will investigate complaints. But formally they're not a DPO. They are a majority disabled people but who is electing them is state parties from a wider list of disabled people and non‑disabled people who are put up by the at a time parties. So, in the past, we have had doctors and lawyers, some of whom are disabled and some are not. They have an interest in disability on this committee. So at the moment it is by far a majority of disabled people. But it is not a DPO. Definitely not. What about Leonard Cheshire International, particularly in Africa and some bang dash, very active, putting forward programmes to support disabled people providing services, they have a Leonard Cheshire homes all around the Commonwealth where disabled people can stay but they also are doing a lot of work on inclusion. Is this a DPO? No or yes. I'm going to click through the others quite quickly now because I think we're taking too long on this.

GEMMA: Okay. Mixture of no and yes on this one.

RICHARD: Right well it's definitely not a DPO, it is an NGO‑T does not have a board of a university of disabled people, it does not have a membership of disabled people. It gets money from individuals by charitable means and from governments and it does things in the name of disabled people but ‑‑ and it does employ a few disability people. The head of training and so on is an individual. But it is forgot run by disabled people. That is the most important thing here. And I'll go through the others. The IDDC which is a coalition of both organisations of and for but the ‘fors’ are in a majority, ie the charities are in a majority so the IDCC is an ally, we hope. But it is not a DPO or a DPO organisation. The international disability alliance is a DPO um bell organisation representing the views of disabled people and families across the world, for instance, inclusion international which is an organisation international organisation for people with learning difficulties which does promote self-advocacy but their representatives on IDA have been non‑disabled academics and researchers. And, so, the problem is, if you don't have something that's strongly DPO based you end up with an organisation that says it supports and on paper does but maybe doesn't in exactly the same way but what we've got at the moment. And the IDCC and the IDA really certainly international New York level are what is getting all the money for developing capacity building, for instance the bridge, programme and so on. But there are questions. Commonwealth disabled people's forum. Well, we are organisations which are run by disabled people. We have I think three organisations at the moment which have family members but we ask questions about are they supporting self-advocacy. And they are only associates. Inclusion international, again, the issues family organisation under paragraph 12 would come in. Of that document I talked about. Action on disability and development and international, Gemma's employer, is an ally, they are supporting us in developing the common Commonwealth Disabled People's Forum but it's not run by disabled people, they have some disabled people, they have a chair who is a disabled person, they have had disabled people working for them but their board is not a majority disabled people, that's right isn't it Gemma?

GEMMA: At the moment, yes, it's about 40% I think.

RICHARD: Right. So there's an issue. If you a spectrum and we would say ADD is a good ally to us as the Commonwealth Disabled People's Forum, perhaps more of an ally that IDA who just turned us down for membership for instance. Because we don't represent enough around the world which is a bit strange. So it's a bit of a mixture so what people tend to do is blur the edges. I don't think that's helpful. I think we need to think more. So let's think about why it's not helpful. Just recapping on what we did on ways of thinking in module one. Most no disabled people especially doctors this disability an individual problem. People think we're limited in what we can do because we're not the same as the rest of society. This is often called the medical model of disability and has been around a long time. Example: if someone who using a wheelchair cannot get upstairs to a meeting people blame the wheelchair and not the stairs. Over simple indication but I want to make clear. Disability is society's problem and oppression with social and humanitarian rights solutions. Disabled people's movement has developed a very different way. Looking at disabled. We have learnt disability isn't caused by us, it's caused by society. This is often called the Social Model of Disability. What stops us is the fact that we live in a world which ignores our needs for access, information, understanding, transport, education and employment. Taking the simplified example again. The building was built were no lifts and the people organising the meal didn't move to the background floor. Temporary adjustment would have been to move the meeting to the ground floor. A longer term adjustment would have been to put the ramps all the way along outside of the building or put in a lift. So it's a long time and we talked about this, when those 4 pun hundred people left that conference in window peg in 1980, the conference rehabilitation international and came back next year to form disabled people's international in Malaysia, they adopted this definition, impairment is the loss or limitation of physical, mental or sensory function on a long term and permanent basis. Disablement, and they called it handicap at the time, is the loss of limitation of opportunities to take part in the normal life, the community on an equal level with others, due to physical and social barriers. That is the definition that has largely come into the UN consequence because of the efforts by disabled people and their DPOs. But it's one that people forget about and we shouldn't. So when we call ourselves persons with disabilities, are we persons with disablement? Are we persons with an impairment? Which is why we prefer to say DPOs. And we've explained that several times. But the world is confused on this issue. So it will continue to be. The UNCRPD definition just to remind you, the purpose is our inherent dignity. Recognise disability is evolving concept, interaction between persons with impairments as you attitudinal and environmental barriers that hinder their full effective participation in society. That is in the convention and what we mean by disability. So it's in people with impairments, disabled by society. So why call it persons with disabilities, I don't know. Why we call ourselves people with disabilities I don't understand, it doesn't fit the definition even in the convention. Persons with disabilities include those who have long term physical, mental, intellectual, sensory, impairments. Which in interaction with various barriers may hinder their full effective participation in society on an equal basis with others. I think as an embarrassment about people calling themselves disabled people. Because people say, that reduces us to being just disabled. No, it doesn't. Gives us a common cause alongside all the other things we might want to do with our lives but to find solidarity and therefore disabled people's organisations are there for disabled people, people with different impairments. So the confusion will continue, unfortunately, because we have the convention and most people are using the word persons with disabilities, people in this organisation use it as well. But let's remember these are what bring us together that give us solidarity, we are posing these barriers. Folk already, custom, beliefs, negative attitude, lack of education and training. Inaccessible information and communication. Denial of human rights. Inaccessible buildings and transport. Lack of income and support. Violence, rape and bullying. None of these things I think you will agree are to do with us, they're not to do with our impairment. These are all things that happen to us filtered through the attitudes, organisations and environment of society. That's what we as DPOs are set out to change. That is our raison d'etre so even if a DPO doesn't have that in its aims and objective, I doubt it's a DPO. Give me three reasons why we need organises that we as disabled people control and run. You identified that quite well earlier, this is the third activity. Three reasons, A, B and C. Why we need these organisations that we control and run as disabled people.

RICHARD: How are you doing?

GEMMA: Yeah.

RICHARD: Quite a few coming in? Okay let's start, I think, because I have two more interesting activities I want to get through in a few minutes so let's not take too long on this one.

GEMMA: Okay. So to start with, sturt in Uganda said I think the best answer is nothing for us without us. Adam, we can always build a mandate on a common goal. Dipti, lived experience, nothing about us without us. Nadia says, because they understand each other, and the barriers disabled people face and they are in the best position to break down barriers. DPOs help to understand and focus disability empowerment. Someone in Bangladesh, we understand our problem better than nobody else. Nadia again, they can share their lived experience. We always tailor programmes and other advocacy interventions based on key priorities for our barriers. Someone says to be the voice for of people with disability, to fight our goal and to encourage each other. Shruti says because we know what we're facing, we can control what we want so having organisation fully controlled by persons with disabilities will help us feeling more at ease. Someone says only disabled people know what is best for them. Sorry I'm just going to have to skim through these now because we've got a lot there. Only disabled people have the best possibility to understand the requirements, disabled people would empower themselves by this. They will balance the power structure in society.

RICHARD: Okay we've got a got mixture there. I think we'll be able to put these into practice in the next couple of activities. I think just one thing I would add there, the idea of coloured and the finding of common cause helping each other to develop and grow is really important. Understanding our particular needs. But, also, on the negative side, prejudice, scrim nation, disablism, whatever you want to call that, is still rife in the world, negative ideas about us is still there so we really need solidarity and understanding. So thanks for all of those. Now let's press on.

>>: I think to add to that one, Richard.

THANDIWE: Also is to say we learn from each other as people of disability. And it's easier to understand it better from another disabled person's perspective. Thank you.

RICHARD: Yes. Thanks for that one. If being disabled is an oppression, what do we do to counter the internalise the oppression we've experienced. ... but as most people have experienced it, if you have acquired the impairment it happens after you've acquired it. If you are born with it, you have it as a life‑long message that success sent to you from the first time that you arrived in the world onwards in people's lives, the way they look away from you, the way they don't involve you in everything, the way they are overprotective and the way that people bully you, the people that people have low expectations of you. If that's going on the whole time, you do take it inside yourself and have an inferior view of yourself and perhaps one of the most important functions of DPOs is to counter that. So it's not just about an external thing, it's also about realigning the way we see ourselves and this is why so many people in what they've written have said actually coming into a group with other people with a similar experience has helped me feel empowered and more human. So jointly discussing our experience with others, in a similar position, is really important. These are the roles that DPOs can play. Find out the experiences of others with different impairments to us. We always assume other people's experience is the same but the way they experience it is different in each case. A deaf person who is just without any means of communication is very different to a wheelchair user who can communicate endlessly but isn't allowed into the building or to get to the meeting. So we have to find empathy with each other's access needs. The need for people with learning difficulty have simple language. Easy to read. Pictograms. We need to make our organisations the most accessible places on the planet so that we set an example. Develop our understanding of societal explanations of what we each experience. So they are often wrong explanations of our experiences that the professionals will give and there are many of many university courses that still teach them. And so we have to challenge that. We generalise our experiences, that's very important, that we start from our own experience but we generalise them amongst each other. We offer solidarity and support to each other by our organisations. We analyse what is causing our oppression as disabled people, barriers and disablist thinking, in the society. Or putting it the other way, survival of the fittest against us. Market, the market has no room for subsidy for disabled people in a pure market economy. But as human beings we have ever human rights to have the adjustments that we need. So if you have someone who is a pure marketeer they will not see any space for disabled people, except maybe by saying, yes, we should feel sorry for them, pity charity. We don't want that, we want human rights. And, so, really, this ideology has to be tackled from our collective experience and making sense of the world. Develop a culture of resistance and protest. Things will not change if we don't make them change. We've learned that, over the years. Identify easy wins first while systemically advocating wider change so there's no point going to the Government and saying we want all disabled people to have a pension that they can live on comfortably because you are not going to get that. Maybe to go and say we want a subsidy for transport or we want to increase the pension so we're not starving is something we can actually fight on. Recruit and educate many more to the view, the issues as we to. So we need to educate millions of disabled people in the world who do not understand what we're talking about. We have not achieved our objective. We need to grow our organisations for two reasons. There are millions of isolated disabled people out there who need or support and solidarity. We need all of them to be part of the organisation debating and developing their thinking so that we have more power in the world to change things. Publicise and educate the public on what we think and why. It's no good just keeping these views ourselves, we need get both the media and explain why we think what we think and we have the backing of the UNCRPD now. And the SDGs so we can hang our thinking on that. But we shouldn't just be arguing for those, we should be arguing for our thinking right from the start. And we need on push for statutory change, change in the law but that on its own isn't enough. Because we need to implement the change by developing a disability equality culture. This is gone in a way it was there stronger before. That is, with us, educating and training, managers and professionals throughout our society and what we call disability equality training. To get them to see and understand the importance of the changes in the UNCRPD and the SDGs. Secondly, we have understood in increasing numbers what we need to do as disabled people to continue our liberation. We are not liberated yet, I could not because we have a convention. That is a statement of intent. So let us identify what is getting in the way of us achieving what is in that convention. Organisations that say they support our arguments but do not support our control over what is happening to us. Eg governments, rehabilitation professionals, charities and NGOs. They really need to be working for them not to be there at all or to work with us as allies supporting us with us leading. Lack of funding for our organisations and in society to overcome barriers is pap perhaps the number one big thing we have. And interesting to quote back at those governments. The you UN says you should be funding us so we can be representative bodies to give you our views so please get on and fund us. Lack of funding, lack of widespread disability equality training for managers and other professional gatekeepers, delivered by those who utility identify making changes need to happen. in other words we need it turn our understanding off our personal experience into the collective and we then need to explain that in ways that all people who are in positions of power and control will understand that they have to actually change their thinking to. Unless we do that, and this is a way for DPOs to charge for their services, develop professional training and offer it to all managers and gatekeepers throughout their system, that is how change comes about. On we need government funding for that as well. Challenge those of a seeking individual solutions to seek collective solutions. History is litters with disabled people who despite their impairment through their will managed to achieve all sorts of things. It is also littered with millions of millions of people who were rejected and isolated. We must learn that individuals seeking solution isn't the answer. We need collective solutions for all disabled people to really change things. We need to rebuild our movement from the grassroots based on accountability and utilising modern methods to get or messages across and deliver lasting change. How much easier it is now for activists to get their message out there on the internet, on social media, with the emails, than those who went before who had to actually communicate even before telephones, they had to communicate by written messages and leaflets and there's still a place for those traditional means. But we can enhance them by modern methods. Recognise the world he live in requires continual and ongoing vigilance to achieve the outcomes we seek. So it's no good just achieving it in the constitution as you did in South Africa Thandiwe because unless you have strong organisations to keep pushing and delivering you'll not get the policy objectives that you want to. Is that true?

THANDIWE: Yes that's true.

RICHARD: So the price of our freedom is our continual vigilance and continual building of organisations and bringing new generations of disabled people in. It is not done, it is a work in progress and we need to build that progress. That right? Would you agree, Thandiwe?

THANDIWE: I agree with that, Richard. We need to push and push every time.

RICHARD: Okay. Good. So those are, if you like, some guidelines as we come into these last two activities so that's the input and we'll take about 5, 6 minutes on each of these because I want to us cover both. Two scenarios, on I'll read them out twice. Building our movement local. The local organisation charged by the government to accommodate local disabled people is run by an international NGO, ie not a disabled person's organisation. They support disabled people with mobility aid, welfare support and adapted house. So it's an NGO, a service provider. Providing some support to disabled people and funded by the government. Although they have reasonable budgets, most of the money is spent on administration and only a small proportion benefits disabled people. They have set up advisory group of village elders and a few of their satisfied clients, disabled people. So the questions are: what should you do to change this? How will you do it? And what would you like to replace it with? So again I'll read it out (read slide).

Remember this is a local organisation. 1: what should you do to change this? 2. How will you do it? And, 3: what would you like to replace it with? So we'll give you a minute to think about that.

GEMMA: Could you just read the three questions at the end there again please.

RICHARD: What should you do to change this scenario? How will you do it? And what would you like to replace it with? Okay we need to get some ideas because I want to at least share the last one with you. I don't think we will have time for discussion.

GEMMA: I have a few, do you want me to read them.

RICHARD: Read out the ones you've got. I will suggest if people want to put activity four or five in as part of their course work on this module 13 that would be perfectly all right to write a fuller explanation and send it in when you send in other stuff, okay? So they can be included.

GEMMA: Just to say that next week, even early next week we'll put this recording of this seminar on the web. And later on, there will probably be afternoon one that will properly be embedded with subtitles but this one will go up next week as this is. And we could also put up as a separate file this slide, this slide show. Do you think Richard so people can access it easily. Okay. So in terms of what people have written, so we have disabled people should be empowered in the decision making body of the NGO. Disabled people should be employed in the NGO. Disabled people should have decision making power. How you do it, somebody says continuous advocacy and by putting an example that we can do it. Somebody else said firstly set up a disciplinary panel for defaulters that squander funds and strictly monitoring by the funders. Nadia said disabled people involved in the decision making and how the money is spent. Someone said increase representation of disabled persons, online campaign and referendum. Disability people should be decision making by the NGO and be advocate. Persons with disabilities should be required to be employed. Nadia, number two, disabled people should challenge the organisation to ensure disabled people are involved in decision making process. And then there's three answers, so one there should be specific personals of task and upward members in the local organisation. Number two, the RNG should revise its budget for increasing the number of persons with disabilities in all levels of staffing including management and three if requires the constituencies of post‑the local and international organisation should be revised to include the persons with disabilities. If required the top level management should be changed to make it inclusive management. Y right, these are all very good points. I would make two points. It's the Government have given permission for this to happen, the Government is an elected body and therefore is vulnerable to pressure. The campaigning we need to do is at several levels, the structural changes are all right in terms of demands but we also need to put pressure on the government that this is not in line with what should be going on according to the UN consequence. It should be a representative organisation. Secondly, international NGOs are extremely vulnerable because they rely on fundraising across the world, particularly in the more high income countries and therefore bad publicity about what they're doing, they are extremely vulnerable to. So putting forward manifesto for change to the head office of this organisation and arguing why they need to do it, with publicity and demonstrations and other things, using our collective strength. Getting other people to organise it, maybe here, if there are trade unions in the country and they are well organised getting solidarity and support from them, maybe some. People who work for the NGO aren't unionised, maybe she should be unionised so they also get better terms and conditions. And they could exercise a quota to increase the number of people, disabled people who are employed there. So it's a made up situation but I'm sure there are lots of residents there. And this one is perhaps too near the knuckle but thinking about what is happening in India at the moment. But this is a global pandemic and we're not out of it yes. Your national government decides that as a consequence of the COVID‑19 pandemic and that the Indian variant, that's not in India but the current Indian variant is impacting most on younger people, there is not enough vaccine to support young and healthy people and, so, have agreed they will not give the vaccine which is in short supply to anyone over 50 years of age. Or, anyone who is disabled or has a long term health problem. So that's the snow. Very near nightmare scenario, national government decides there is as consequence of COVID‑19 that the current variant is very in infectious to younger people and not enough vaccine to support young and healthy people so they have agreed they will not give the vaccine which is in short supply to anyone over 50 years of age or anyone who is disabled or has a long term health problem. This is a very strong eugenicist policy arguing we need to keep the young healthy because they're the way forward for the country and forget everybody else. What should we do faced that scenario from the Government? How will you do it? And what would you put as alternative? We have three, four minutes for people to come up with ideas about that. This is something I hope we won't face but it could be that we will be facing this formally. Informally it's already happening in many places. So what should we do about it? Okay I think we need to maybe get a few views on this.say I would like, if you want to write more about these, number four and five we will put them up and you can submit them as a written work for your assessment on this module.

GEMMA: Okay we only have a couple so far, they're still coming in.

RICHARD: Read them as question go.

GEMMA: So ideologically it is a wrong decision as a human being we have rights to live. We will go for excessive campaign.

RICHARD: Right.

GEMMA: Rose can I ask you to mute or I'll mute you. DPOs to raise their rights to the Government to see their body. Empower persons with stabilities with structures. Put pressure on government by reminding them of their obligations under the UNCRPD. Physical accessibility is met all vaccination centres with appropriate facilities. Both groups of age must have the same right. Everybody should raise their voice. DPOs should make statistics of age group disabilities and disseminate the information by advocacy to identify the vulnerability of young people with disabilities. I would definitely get a collective effort of DPOs and petition the above because we have equal rights and DPOs work collectively.

RICHARD: Right. Nobody's yet mentioned it's also all people over 50. So we should be contacting organisations that represent senior citizens because they will have a common cause with us on this issue. It's not something you will resolve in your own country. You'll need to bring international pressure in this situation. So we will need to go to UN organisations like the world held organisation which is a UN organisation. The UN secretary general, Security Council, get other governments to put motions through that this is totally in breach of the international human rights agreements that we have. We need to mobilise international voice of disabled people, we need to expose this in television, media, social media, around the world really quickly to stop it happening and, most of all, questions should be asked about why the vaccine is in short supply and this is also something that maybe, if it's a low or middle income country we can ask the questions of why the high income countries have basically cornered the market on vaccines and are not putting enough money into manufacturing vaccines all or the world because as is said so often all over the media, if the pandemic is anywhere it can be potentially everywhere. And, so, the way the world has responded to this, the selfishness of particular countries has not been a good model. And so this gets at the heart of that. That really the world community had need to change and the only way that that will happen is by pressure from the vast majority of citizens around the world. Because it's a slippery slope. You can say, I'm not that group so I'm all right. But then say they have less and they bring it down to 20 or 40 people aged 40. This is ridiculous, it is not a human rights rite it's a borrows abuse of human rights. So I hope that has given you food for thought. But it is unfortunately too near to our experience of where we are, so Thandiwe would you like to say à las word about what you've taken away from today? And then I have à las word.

THANDIWE: That's Richard. The thing that I've taken away today is to say, one, there's still a lack of commitment from our government. Or from our countries. It's neither here nor there. There's no things that are happening that are consistent. There's lack of consistency. Now, we as the DPOs, we need to push further. For example of this one of the COVID‑19, maybe we need to have what we're going to talk about sent out communication out there. And say this is what is happening and this is inspect DPOs or organisations of people with disability, we are saying this is our spend point, especially as Commonwealth DPO. So that we can start to push further and further. Because if we keep quiet and wait and also tart to hold our government accountable, I'm not sure how we're going to do that Richard as Commonwealth. Maybe we need a letter that is going to come from all of us, give it to our President and say, this is what we are saying as Commonwealth, as one of the thinking that I'm having now. I'm thinking on my toes. So we can move forward and make sure that issues of disability, what is happening in India, what are we saying? So if we can be able to push for that, we are going to make them. And the United Nations must tell us how do they account to us? Because also they're yes quiet. Sometimes they are there, sometimes they're not there. It depends on what they need in that moment and we don't want that kind of activities.

RICHARD: Thank you, Thandiwe. So my last point to end, Gandhi, the moving force India and made reforms in South Africa, founder of the ANC who went onto take power 70 years after he was there. But he said, if you want real change in the world you must be the change you wish to see in the world. And I think that really gives us that our DPOs, if we want a better world our DPOs should be modelling that, they should be respectful of each other, they should be dealing with access issues, they should be responsive to our issues and be democratic. And nobody should be left out. So we have a chance of actually showing the world we want which takes account of challenging sexism, racism, disablism and begins to deal in a planned way with the world economy and the environment so we can all live with it. And we can do that in a small way in our DPOs and that's why it's so important that we have our own independent organisations. So I would like to, I'll come out of this. I would like to thank everyone for being on the call today. Next week is our last seminar. And we will be contacting a number of you to give us your views online, on the course but we'll all have a space on the seminars next week to give us your views and those views can be put into a compiling video which we're going take to the United Nations in the third week of June and I'll let everybody know what that meeting, it will be an online meeting, when that will take place and we'll show people's views of this course. We think this course is an important way forward for the world. We think there should be more online training like this during this time. And we want your support to show it's important so you'll be being contacted about that but have some thought ready for next week so that we can record them with the signer and the captioning. So I would like it thank the signers and the captioners, thank Thandiwe who is not very well for joining us and Gemma for organising everything. So goodbye to everyone action thanks very much to you all.

THANDIWE: Thank you, bye.