MODULE 13 Transcript

RICHARD: Welcome everyone to this online presentation on Module 13, building DPOs, campaigning and increasing our voice. And to help us with this today we have got myself, the General Secretary, Richard Rieser, of the Commonwealth Disabled People's Forum, acting Chair Sarah Kamau from United Disabled Persons Kenya and also we have on film we have Sruti Mohapatra CEO of Swabhiman, and our Vice-Chair in East India and Steve Estey from Canada also on film, who is on the Commonwealth Disabled People's Forum Executive, and Nathalie Murphy from Dominica who is our Caribbean Rep on the Commonwealth Disabled People's Forum Executive. Now, to deal with this issue of representation we have to go right back to make sure everybody understands the key principles of the disabled people's movement, so Sarah is going to start us off on that.

SARAH: Hello everyone, and welcome to this module on DPO building, and I also want to thank you for your resilience for having been part of this course up to this end, we're about to come to the end of it. So I will start by introducing and by talking about disability as an individual problem. Most non-disabled people especially doctors and disability professionals think disability is an individual's problem. So if someone who uses a wheelchair cannot get upstairs to a meeting, people blame the wheelchair and not the stairs. People think we are limited in what we do, because we're not the same as the rest of society. This is often called the medical model of disability. It has been around for a long time. Then disability as a societal problem. The disabled people's movement has developed a very different way of looking at disability. We have learnt that disability is not caused by us, it is caused by society. This is often called the social model of disability. What stops us is the fact we live in a world which ignores our needs for access, understanding, transport, education, employment and so on. The building was built with no lift and the people organising the meeting didn't move it to a ground floor room so a person who has mobility problems is not able to access such a meeting. I will share definitions, one on impairment, which is described as the loss or limitation of physical, mental or sensory function on a long-term and permanent basis. Disablement is the loss of limitation of opportunity to take part in the normal life of the community on an equal level with others due to physical and social barriers. This according to Disabled People's International in 1981, that's where this description comes from. Again we have the UN Convention on the Rights of Persons with Disabilities who have also defined who are people with disabilities? And in Article 1 on Purpose, the purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and to promote respect for their inherent dignity that is one purpose of the Convention. In the Preamble under (d), "Recognising that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others". Article 1 again of the UNCRPD says that, "Persons with disabilities include those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others".

RICHARD: Thank you Sarah.

SARAH: Thank you Richard, over to you.

RICHARD: I have put up a cartoon showing barriers within our society, I will read this out. There's a man there talking to a woman with a stick, "When we talk about barriers what do you mean?" "Anything that stops us from joining in with the rest of society, for example, we would call something like a flight of steps a physical barrier", she says pointing at steps. "Where information is only in standard print and not in formats this creates information and communication barriers so it's not available on CD, tape, large print, Easy Read, Braille and so on". Then the man says, "But I often find that it's other people who stop me joining in with the rest of society". There's a sign-up on the wall saying 'no nutters allowed' which is a slang statement for someone with mental health issues. "Well that would be an attitudinal barrier", says the woman, "when these sort of negative attitudes exist in organisations they result in policies, practices and procedures that disadvantage us. So we would call this is an institutional or organisational barrier". Last little picture, "So when we see these barriers not our impairments are the problem, yeah we can all work together to remove them from society". It's that working together that is important here. We need to take pride in ourselves. Once we realise that it's society, and the way it's organised that disables us and not our impairments, we can take pride in ourselves again. We are not the problem. If disability is caused by physical and other barriers and organisations and attitudes it's possible to get rid of it. If all the barriers which face people with impairments were removed we would no longer be disabled, we would still have our impairment but we wouldn't be at the disadvantage we've been placed in by society. The disabled people's movement understands disability as society's problem and works to take down the barriers which prevent us from taking our full and equal part in society. Just to digress it's for that reason that the Commonwealth Disabled People's Forum sticks to the language of calling ourselves disabled people, we are many people with many different impairments, but we're united by a common oppression of disablism, the barriers, the unthinking often barriers against us. We are united as disabled people, in breaking those barriers down. Another area which has caused many problems over the years is charities which continue to patronise us. There's another cartoon here with a group of people, all non-disabled, one dressed up which people who do fundraising like to do. Called '24 Hour Patronisathon', and on the floor is a sign saying, 'Raising money for the disabled'. In the door comes a woman holding a sign saying, 'Nothing about us without us', and a young man in a wheelchair. The person from the organising committee says, "You're in the wrong room, this is the organising committee!", and it's very much that attitude that other people will solve our problems, that causes us problems. So, even today working in the international field, we have major problems with big charity organisation. Yes, they say the right things, people like Sightsavers, people like Leonard Cheshire, people like CBM, people like Handicap International or Humanity and Inclusion as they prefer to call themselves, or Light for the World, these are some of the big NGOs who fund, work with DPOs. We have to ask them these questions which we raised earlier on in the course but are very relevant at this point. Do they accept the leadership and thinking of Disabled People's Organisations? Do they do everything they can to empower and build the capacity of our DPOs? Do they reject the charity and medical model in favour of the social human rights model? Do they put their organisational, financial and training resources at the disposal of disabled people and DPOs? If the charity provides welfare services and treatment, which many do, treating working rehabilitation, working with impairments, do they still empower the disabled people they work with? Lastly, do they allow disabled people and their organisations to lead, 'nothing about us without us', and not consult us, but lead and we find the answer to those questions are not generally in the favourable. Therefore we have to organise to persuade, cajole, these events to do these and of course because they are self-fulfilling organisations that have a balance sheet that they have to deliver on, and are beholden to the governments that give them money. Only organisations of their size can hold that money and many of our organisations can't, and this a major problem in the world today. Now, it's been a long struggle 120 years at least to speak for ourselves. 130 years ago, speaking for ourselves, in the 1890s the British Deaf Association and National League for the Blind were formed. Similar organisations of sensory impaired people started in the United States and across Europe about this time. These were the first organisations run by disabled people for themselves. Fights for sign language against the eugenicist banning of it, fights for decent wages, and against charity in workshops for blind people, and then later on a second wave of Disabled People's Organisations fighting for human rights, from about mid-70s onwards. It was the Union of Physically Impaired Against Segregation formed by disabled people in the UK wrote a paper called "Fundamental Principles of Disability", and in this paper the social model was first mentioned. Since then many more organisations run by disabled people have been set up, they are known as 'of' organisations because they represent us. And at least half of their management committee must be disabled people to set them apart from groups run by non-disabled people for disabled people. Many of these organisations were set up for the best of reasons, by parents, who felt their children were not included, by adults who wanted to support disabled people with significant impairments, but throughout we have to fight for the voice of disabled people. Our first contribution will be from Steve Estey, who will talk about how they put these principles into practice in Canada.

STEVE: Hi, my name is Steve Estey, I am from Canada. I live in a city on the Atlantic Ocean called Halifax. I'm really happy to be here to talk but little bit of the DPOs in Canada. I have worked for many years, 25 years I suppose with Disabled People's Organisations here in Canada and around the world. The national peak organisation, cross-disability organisation, in Canada is called the Council of Canadians with Disability, and I was for many years the volunteer Chair of the International Committee on the Council of Canadians with Disability, or CCD. CCD is an organisation that was founded in 1970, and it was founded at that time because disabled people didn't have a voice of their own, in any way at all. There were charitable organisations, Rotary Club, March of Dimes, Jerry Lewis telethons down south in the United States, all of that kind of thing and a few disabled people realised that we need to have a voice to speak for ourselves. So we founded what was called at the beginning, the coalition of organisations, I'm sorry, the Coalition of Provincial Organisations of the Handicapped, which was the nomenclature of the day and COPOH, Coalition of Organisations of the Handicapped founded in 1975, brought together cross-systems organisations from all 10 Canadian provinces. Because there were grass roots organisations, that were founded in all of our provinces from the Atlantic to the Pacific, and these cross-disciplinary organisations were working to give disabled people a voice at the provincial and local level. We decided we needed to organise at a national level to give us a national voice so that we did in 1975. We have worked together as national disability organisation since that time and we achieved many, many things. We have also had many, many frustrations just like every other organisation. But in terms of the things we have achieved, I think that really the key thing in the beginning was in 1982 when we repatriated our Constitution from the British. Previous to that there was no Canadian Constitution, the British North America Act, and I'm sure that many other Commonwealth countries have similar experience. In 1982 our Prime Minister of the day Pierre Trudeau, decided to bring the Constitution home, and it's part that he enacted a thing called the Canadian Charter of Rights and Freedoms which enshrines [inaudible] rights in our Constitution and there was a huge, huge effort at that time to ensure that disability was made reference to in the Constitution that the rights of freedoms of people with disabilities were guaranteed in the same way they were for indigenous people [inaudible] or people who were LGBT, or whatever. There was a lot of resistance to this at the time, those of us who are old enough to remember, realise and recognise that there wasn't really much of an understanding of disability as a human rights issue at the time. But we were successful and that was a key, the beginning of the disability rights movement here in Canada in 1982 and from that we achieved a number of other things. I think the next big thing I would point to is the Mine Ban Treaty. I think many people who would be watching this would be in countries that are landmine affected. I can remember working with Disabled Peoples International which was based here in Canada in the 1990s when we drafted the Mine Ban Treaty. The key provision in the Mine Ban Treaty, Article 6, talks about the rights of landmine survivors. I became very involved in all of that work in the 1990s through my work with CCD, and CCD worked with other disability organisations that were engaged in the Treaty, to ensure that the rights of mine survivors were part of the Landmine Treaty and in 1996 when the Landmine Treaty was signed here in Ottowa, in Canada, in Ottowa, that provision was part of it. That was another key success. From that, we went on to work with the drafting of the UN Convention on the Rights of Persons with Disabilities and that work took place from 2002-2006. I myself was involved in that work as a staff person at DPI. I was also an advisor to the Government of Canada because and interestingly, because all of the clever lawyers that came together to negotiate the Treaty, understood human rights, but they didn't have a clue in hell about disability. To be blunt about it. They understood what the right to education was, what the right to life was, what the right to health was, but they didn't understand anything about accommodations necessary to achieve your right to education, or provisions put in place to ensure that people with disabilities have the right to life on an equal basis with other. So that was the work that we did from 2002 to 2006. We kind of breathed life into the CRPD and making something that was actually useful for people with disabilities. So we did that here in Canada, in New York city and Canada ratified the conventions in 2010, and since that time, we have worked as DPOs to ensure that the Convention is implemented, we're just at the beginning of our second review on the CRPD and our organisations are working on the parallel report, because the parallel report is an absolutely essential part of reporting on the UNCRPD, because governments file the reports and they talk about all the grand things they do, and I don't deny that governments do do some good things, there's no question about it, but no Government is perfect. Not even the Canadian Government. I think that the important role of the DPOs is to point out where those shortfalls are, you know, the gaps, we implement the right to education here but there are lots of problems with that and that's what the parallel report talks about.

RICHARD: So that's really useful from Steve. Note that we talked about Canada before earlier in the series, when there was an international conference held, Rehabilitation International and out of that came Disabled People International with a founding conference. It was very largely down to the Canadians and the fact they had done that work and organised themselves nationally and those in the UK, people who had organised themselves in Zambia and Zimbabwe and also South Africa and that organised themselves in Malaysia, that helped to set a world international disability movement on the go. Let's go down to the beginning, how do we start to build these organisations. Well, all over the world there are groups of people in every society who do not achieve all that they could because of a history of being interested as an inferior members of that society. Not just disabled people, can be gay people, can be women and self-organisation has become an essential part in a democratic society of fighting for your rights. Disabled people have the same needs and rights as non-disabled people, these include social life, education, food, money, dignity, respect, access to community services, access to specialist services, forming relationships, sexuality, having a family to name some. Increasingly in the last 50 years disabled people all over the world have come to realise they need to develop their skills to be all that they can be, that they must begin to make decisions and take control of their lives. Doing things alone doesn't always work. We can all point to people who, despite all the barriers, have succeeded on non-disabled people's terms, and there are always these super achievers. But most disabled people cannot do that, because of the barriers that are around, and it's not right to just allow those who can make it through. We need to remove the systematic barriers so everyone has the chance to make it through. No-one has all of the answers. Being a member of a small group of disabled people, talking about experiences and developing respect for each other is a good step forward to develop self-respect and independence. It's certainly a lot better than being on your own and these days, social media can really fulfil that role. But social media is limited, in the end we have to organise ourselves on the ground in order to achieve these things. So finding the first members. Two or three disabled people, talk about what matters to you and what you have in common. Each of you may be able to bring someone else along. Ask to contact disabled people through your health centre rehabilitation, local community, field representatives of non-government organisations, stop people in the street if necessary, leafleting, visiting and so on. Talk to your local newspaper, community radio, local government, use social media, religious and community organisations. Once you know where disabled people are, go out and talk to them and their families. Discuss the problems disabled people in your area face and your ideas for the future. Families of disabled people can play a really important role in this. As long as you have at least two or three interested people, you can share out the work and encourage others to take their different responsibilities and you can make a start. Good ways of finding new members are important throughout the life of the organisation. Too many organisations have become bureaucratic and often even the people who led them have become incorporated into Government, so new generations of disabled people are not brought forward. We need to renew ourselves as organisations, bringing new generations in. It's equally true that people will say oh well we don't need to do those battles anymore, you did them for us. That's not true because the price of democracy as they say is eternal vigilance, the price of disability rights is actually continually being active. So then we need to have a public meeting, or public face. The core group of four or five people need to organise small meetings, internet meetings. The aim of the first meeting to talk about problems for disabled people in the community, to discuss some possible solutions, to get more people to join, to get people with different impairments, experience and skills to take part. The place is really important, remember to pick a time and date when people are likely to be able to come along. Where will you hold the meeting? Can you hold it outside, if the weather is good. Many groups when they first start, meeting in someone's house. Sometimes you can ask people who own or run a community centre, village, church hall, to use their premises but many of them may not have the right access issues, the lighting, the sound environment might not be ok for some people. There might be too much interference from other things going on around. Make sure disabled people can get into it, and it's the right place for them. The access issues need to be there from the beginning. The major problem for everybody, and the many of our movement started with wheelchair users because we were most visible. Many of us had to learn sign language so we could incorporate disabled people. We had to learn to put our ideas simply in easy language and produce documents in Easy Read so people with learning difficulties could take part. We need to allow enough breaks for people who have hidden impairments and metabolic problems or people with mental health issues so they can be included. It's important to think about who is coming, and what barriers any to be removed in our own organisations. We have to be in charge, this is the key of the disability movement, it's where things have gone wrong in a lot of places round the world at the moment. We're not in charge. For far too long non-disabled people have made decisions about our lives. In the last few decades the disabled people have found a strength and confidence to say yes, we need to speak for ourselves, make decisions about our lives because we are the experts when it comes to disability. We achieved that in the UNCRPD, but in the 12 or 13 years since then, we had not been the people in the driving seat. Many non-disabled people's organisations have moved in because there's money available are really taking over and stealing our clothes. We have to fight back against this and say no, self-determination and independent living, choices and rights means that we're in charge. Independent living means having choices about how your life will be, and how to control over your life and having control over the decision taken about your life. So what are our aims, we need to decide the aims of the organisation, there are hundreds of things we can campaign round, and we can't start by campaigning on everything. So you have to decide the basic aims and guiding principles, this should involve everyone who wants to take part. As membership grows there may be different and more things. Ask people for their ideas, encourage them. Short-term aims, for instance, to start with. Form the organisation. Get funding. Develop one project, which you can actually win. So you look for easy gains first. One major aim of an organisation of disabled people is developing the skills and confidence of its members. This is achieved through building a sense of solidarity, by members taking part in the group activities, and by improving the status of disabled people but providing training on self-esteem and understanding their position in the world. Longer term aims might be to improve the situation of disabled people in the community. Getting disabled young people who are not in school into school is a good one. Work with the Government and others in power to change legislation policy, protect the rights and meet the needs of disabled people, say getting them into work. Many governments have quotas but the quotas tend to take the people with minor impairments and not look at the challenge of involving people with more significant impairments, we can do work around that. Develop ways to improve the social and economic chances, as I have just said. Access to health as well. Conduct outreach programmes to find disabled people, particularly in rural areas and in many areas where traditional ideas we have covered earlier in the course, may still hold sway, these people maybe hidden away. We have to bring them out, we have to change the community using street theatre as we've seen in the programme on education, and many other methods so that parents become strong allies of their disabled children rather than being ashamed of them, develop self-help projects for the organisation, eg wheelchair workshop, a market stall that sells craftwork made by members, food crops that we as a collective use. Explore idea for income generating, organising to have money to run well. Encourage people with different impairments to take part, including those with intellectual and psychiatric impairments and other groups of disabled people who get left out. Encourage people with power to improve disabled people's lives through national and local programmes that serve their needs. So there are many things we can do, but we should have some principles as we go through this. Whether they are income generating schemes, service providing or campaigning organisations are all three which many DPOs are, most organisations of disabled people are concerned with dignity, justice, equality, and full participation of all disabled people. To help us with that we need to have a charter, or a statement of principles, which outline these things, and they need to include accountability. The organisation, its services, programmes and policies would be for the benefit of all disabled people, or some programmes are clearly defined groups such as women, disabled members or people with particular impairments. Accessibility, the organisation, its services must meet these principles. Control, the organisation and its programmes should be controlled by disabled people themselves. This is crucial and it really distinguishes between DPOs and other organisations which are not 'of us' but are 'for us'. Dignity, the organisation should be based on the idea of rights, not charity. In some countries you may have to be a charity for legal reasons in order to just get money but that doesn't mean we have the charity ethos. Flexibility, the organisation should be flexible to meet the changing needs and demands of disabled people. Such as in COVID, a big issue has been getting disabled people online as the only means of actually getting education and information. The organisation should promote a positive public image of disabled people and the organisation in the media by advertising campaigns, postering and public speaking, and all sorts of media. Inclusion, the organisation's activities should aim to encourage and enable disabled people to live inclusive lives in the community. We are against segregation. Monitoring and evaluation, the organisation should include a good monitoring evaluation system, which will help to make sure that the work is accountable and is achieving its aims. Personal development, the organisation should help members to take part in the life of their community and should encourage a sense of independence and self-esteem. Who can join? Well, organisations of disabled people are usually defined by those controlled by a majority of disabled people, at least 51%. We, ourselves in the Commonwealth Disabled People's Forum, do not allow people to member organisations unless they can show that the majority of their management committee are disabled people. That is generally the principle, some put the figure at 100% or 80%, we say a majority. Both the Board and member membership level. If disabled people are not in the majority, they cannot control the policies and decision making. We find many of the NGOs or old charities now offer membership to disabled people but their Boards are not run by disabled people and that is a major problem. Some organisations do have relatives or other supports of disabled people as members. They impact in valuable and important ways to support the views, but it's disabled people who must be the majority and in control and remember that everyone has the right and the ability to make choices. Those who feel they represent the interests of people with severe intellectual impairments can best empower, liberate and develop them by letting them make an active part in the programme, policy making activities. Everybody can express an opinion. If we put it across in the right way with the right amount of time. We need to do that, rather than taking the easier option of being an advocate for those people. We need to develop self-advocacy. In some organisations the workforce paid or unpaid are members so they cannot also be on the management committee. The management committee is really looking at the running of the organisation, and making sure it's fair, looking at safeguarding rules, making sure there are means of discipline and grievance and so on, and that the money is spent properly and not squirrelled away by people with corruption. The Annual General Meeting is when all the members are entitled to ask the questions about what the management committee has been doing and check the money has been spent for what it was intended to. We're helped here a great deal by General Comment No 7 from the UNCRPD Committee about how disabled people are meant to relate to the Convention and what our organisations are. So, we find that if we look at the history of the last 50 years there are different forms of organisations that in isolation, solidarity and struggle that DPOs face. Stage 1. People are often isolated from each other, and the world, locked in institutions, segregated by inaccessible housing, hidden away in their families, cut off from the world without the right means of communication and access, and have no power. So that's still in many countries, the majority. Stage 2, sometimes as a result of being managed in groups by medical and rehabilitation professionals, and sometimes due to families of disabled people forming organisations, groups of people with the same or similar impairments begin to come together. Stage 3, disabled people with different impairments realise how some of their experiences are similar. In fact in most cases the majority of our experiences are similar, we're on the outside of the oppression of disability, outside of the barriers. Stage 4, the single impairment and issue organisations join together to campaign to change attitudes, law policies and services more widely. Stage 5, oops sorry, change comes quite rapidly. The community is more aware of disabled people, see them on the streets, at work, on television programmes and policies change, and legislation is passed. Technology advances and mobility access and information improve. Many preventable diseases disappear, disability becomes a human rights issue. We use the social media much more. That's where a lot of countries are in the Commonwealth Disabled People's Forum but not all of them. Stage 6, despite positive changes there are still problems and new dangers, disabled people everywhere are still the poorest group, most vulnerable to violence in all its forms, particularly gender-based violence. The search for cures for impairments means that some non-disabled people seem to think there needs to be no more disabled people. There are still in place many eugenicist measures to abort disabled foetuses, ie up until term to try to genetically engineer us out of existence. The threat of NGO funding and NGOs stealing our clothes is a major issue in the world today for us to maintain our independence. Stage 7, which we have not really reached yet but is the future we fight for. The worldwide disability movement grows in strength, more and more disabled people free themselves from despair and segregation, decide to work together in local groups, and at the national, regional and international levels. As a result, more non-disabled allies understand that disability is a human rights issue and add their support. Commonwealth Disabled People's Forum movement is part of this movement, to universalise the principles that we're fighting for and get universal implementation of the Convention. We are a long way to go on that, but we are there and we will keep fighting for it. A lot of this was drawn from the Disability Awareness in Action Resource Kit which you can find here and it's more than 20 years old but it's still very relevant and there are 6 of these kits, and in the coursebook we will say where you can get them from. We need good self-evaluation tools to decide wherever we are, and SWOT analysis of your DPO, when you have your AGM or other meetings is a good one. What are your strengths, advantages, what do you do well, who do other people see your strengths? What are your weaknesses, what could you improve on? What you do badly, what could you avoid. What are the opportunities, what are the good opportunities facing you, Government initiatives, funding? What are the interesting trends you are aware of, things in the media? Obstacles, what are the threats, what gets in your way. Does your group have all the required skills to do the job? This sort of analysis periodically is really useful to take us forward as DPOs at whatever level we are. And another little analysis here, human rights campaign activity. You can run through this, take any one of the objectives of the Convention, and see what we need to do. What is the change we want, what will you do, to achieve it, who we will recruit to this campaign? How will we research and publicise our campaign? How will you know if you have succeeded? And which parts of the UNCRPD would we use for this. So put it in a diagrammatic form, who will you recruit to the campaign, how will you search research it, what will you want to change, how will you do that, and how will you know that you have succeeded. This basic outline we can use in all the campaigns that we set about doing. Here Nathalie Murphy will tell us more about how in Dominica, a small Caribbean island, they used these ways of thinking to set themselves up.

NATHALIE: Good evening, good morning whatever time zone you're in. It's my pleasure to share with you the development surrounding Disabled People's Organisation in Dominica which we call the Dominican Association of Persons with Disabilities. In 1983 Reginald Rolle was invited to Barbados to participate in a Caribbean forum we called the Caribbean Encounter, and one of the objectives of that programme was to discuss the formation of organisations of persons with disabilities in the Caribbean. He went in July of 1983, and on October 26th 1983, a few of us assembled at [inaudible] to discuss the possibility of forming this organisation. In attendance were friends, family members and supporters of persons with disabilities, and when they listened to what Mr Rolle had to say, they thought it was a good idea. They said, well you should go ahead and start your organisation, nothing should stop you and this we did so we established a steering committee, they were given a one-year mandate to put the structures in place including the development of a constitution, or draft constitution, and that they would have had to present when we held our first annual meeting, Annual General Meeting and one year later that organisation was born in Dominica. It was headed, first President was Reginald Rolle of course, there were nine other members. I was also elected on the Executive Committee, so I am a founding member and I have been with the organisation ever since, I have held various positions, and right now I am almost getting ready to retire and putting measures in place for a successor. A small island, 289 square miles, less than 75,000 people, so it's what you would call it's a closely knitted island, we're almost, everybody knows everybody if you live in a village, you know me I know you, we are relatives, we are family, so it was not difficult really to get interest from other sources, other individuals and to use community centres. We used the homes of the members of the group to hold meetings, there were times we would have some kind of unsavoury remark or negative comment but that did not deter us, of the movement of persons with disabilities is one of advocacy and inclusion then. That was our mission, that was our vision and we did get quite a bit of support. We started with a development agency, local development agency by the name of Small Projects Assistance Team. They assisted us to go round the island, we have public education campaigns, [video distorted] all programmes, we were able to convince and attract some funds not only locally but externally because the proposals that the projects we came up with really impressed donors, friends, supporters and so we were supported at the initial stage, we were supported at the initial stage we eventually opened our office in 1987, we received Government subvention a few years later, then we started thinking of establishing our own facility which we dubbed the Multipurpose Development Centre because we wanted to have conference facilities, we were also thinking of a dormitory hostel because coming, living in a country, rural area, lots of persons with disabilities come from the rural areas, then transportation is a problem to have at night, it will be difficult for them to get back home. So we conceptualised this centre and which also included an auditorium and then we worked steadfastly to ensure that that goal would be realised, the completion of this Multi-Purpose Development Centre we had secretariat and we had the conference room and the dormitory. Now we're building the auditorium [video distorted] we have non-governmental organisational support. We have external donor agencies' support and we have been able to attract quite a bit of support from these institutions and agencies that I have mentioned.

RICHARD: That sounds like -

NATHALIE: Well the impact has been tremendous, you have quite a few persons or disabled persons joining the organisation because we not only do education sessions for the public, we have all public education programmes, we have our 5-year plan, but we have our members themselves. We use them to bring all the message because we have quite a few disabled persons who are talented so they showcase their talent, they are dancers, we have persons who are amputees who dance with other kids, we have [inaudible] and a household name in Dominica. Only recently about up to months ago we held a meeting with a health commission that the Government -

RICHARD: Ok we'll move on. So Sarah is going to tell us a bit now about building their organisation in Kenya.

SARAH: Thank you Richard, I want to talk about the organisation United Disabled Persons of Kenya which is an umbrella body of DPOs in Kenya. These DPOs are from different counties and different types of disabilities, all included. The membership is by subscription and therefore not all the DPOs in the country have been able to subscribe to become members of the umbrella body, but that does not mean that United Disabled Persons doesn't work with even those who are not their members. They reach out to everyone, and the target is to reach out to everyone, so that they are able to also join and become part of the body, the bigger voice so that they speak in one voice. To increase our objective to increase the authenticity and capacity of DPOs and persons with disabilities to effectively represent and advocate for their rights at national and country levels. Where we have had a lot of engagement with DPOs and bringing them to workshops, training them on skills, and economic empowerment programmes which they do now to help themselves, become economically viable, and to be fit, to fit in society. To have a way of life, their livelihoods are changing because of the capacity and the work that they are doing, the skills they have got from being trained by UDPK. An organisation also whose objective is institutionally to strengthen those DPOs so they can also be able to meet their mandates of advocating and demanding for their rights and services from service providers, that we have given them capacity and skills to be able to speak and understand what their rights are and demand for them from duty bearers and other service providers. We also have built those DPOs and strengthened them to effectively monitor their rights, like I said they know what their rights are and demand for them. Because of the trainings and skills that they have gained from being educated and being sensitised by being under UDPK and its affiliates. There's also advocacy work but UDPK had been able to do in inclusive policies, making sure that policies in this country are speaking to their rights of persons with disabilities, like in education, making sure that the policies in education are also including rights and issues of persons with special needs who need an education on how those issues can be brought out in policy and also the way environments, especially in schools or in hospitals, have to also be inclusive of putting in place that when a person who has a disability or an impairment is not denied access or cannot be able to fit in that sphere because of their impairment. So we are also speaking to non-disabling environments to make them, persons with disabilities fit in all spheres of life in every aspect that they need, so there's a lot of awareness raising and creation on disability rights, both to the DPOs, members of the DPOs and even the service providers, the Government, the non-governmental organisations to be able to understand what disability rights are, and this has been happening mostly in one-to-one meetings, they have been happening when this even DPO members are trained on skills to be able to have an economic empowerment on their end and fit in society.

RICHARD: Thank you very much Sarah.

SARAH: Thank you.

RICHARD: Thank you. Now we have another example from Africa up but I am not going to spend time going through it because we had someone actually speaking to it, but it's a similar history for NUDIPU from Uganda, and very similar mission, the needs they identified, and recognition they did, how they did it, the key goals and so on. This will be in the PowerPoint and people will be able to look at this and these two slides I think are really useful. I think the important point I'd make is the philosophy they had is disabled people themselves know their own needs better than anyone else, so NUDIPU believes that they are best placed to make decisions affecting their lives. Agencies intending to work with disabled people should always build on the priorities and the initiatives of those same disabled people. Only this method will help meet the real needs of the target group. So I think we find all over the world, organisations that are growing and putting forward these positions. So I would like to now switch to a different continent, to India. To bring in -

SRUTI: Thank you Richard, I am Dr Sruti Mohapatra, I head a non-profit in India called Swabhiman, we're based in the eastern coast of India. We also have a DPO, Odisha State disAbility Network. Either you need some resources, which can be financial, which can be human, to bring about huge changes whether it's in your own state or whether it's at the national level. Since we were scarce of funding resources in 2003, we thought this is a wonderful opportunity of bringing people together that way we are reaching to large number of people in the remote areas of Odisha and anything we get to know at the national level we're translating back to the villages in just a matter of time. Odisha State disAbility Network was formed in the year 2003, and it has been a frontline change-making organisation, network, which has brought about some significant changes in the state of Odisha, and has contributed as a main, you can say, a frontline organisation in national level changes. At the local level in the state of Odisha, some of the major achievements have been conceptualising a single window approach. We found that those who were disabled, they had to run from one office to the other, then to another to get their different entitlements like a disability certificate, bus concession, or a train concession, or their income certificate or their assistive devices and then I thought why not one platform, and with this in the year 2003, with the help of the senior most officers in Odisha's bureaucracy, we did this, ensured that it's possible and today it has become one of the flagship programmes of the Government of Odisha called as the Bhima Bhoi Abhiyan. The second and very important thing was the political visibility of the disabled by organising the first ever political convention and bringing all political parties aboard talking to them about our issues, with about a thousand people from across Odisha coming in and finally ensuring that we, our issues are mentioned in the political manifestos of all political parties. We considered an appointment of a disability commissioner as one of the major highlights of our achievements because without access to justice, the laws and policies make no difference in the life of the disabled. So though we had a law from 1995, until the year 2010 Odisha did not have an independent Disability Commissioner and it was our united effort at the level of every district, and at the state level that brought in huge media response from national level television channels to local television channels. Our issue got highlighted then we got to meet everybody from the Chief Minister to the Chief Secretary to the leader of the opposition, explaining them our issues and finally the first Commissioner was appointed in the year 2012. Another highlight is the census campaign of India where we played a significant role, hand to hand with National Disability Network in ensuring that the question on disability moved from question number 30 to question number 9 and Odisha did an amazing work because of the Odisha State disAbility Network and the exhaustive four rounds of travel across the 30 districts reaching out to Government authorities, non-government organisations, families of people with disabilities, saw that Odisha has higher disability percentage of 2.9%, if you compare it with the national average of only 2.21%. We have played a significant role in getting the new Disability Rights Bill converted into the new Disability Act, and again Odisha State disAbility Network with its 150 NGOs, more than 300 parents with about 200 young persons with disabilities, brought this change, made this change possible. SASHAKT campaign is till date the only successful campaign in the state of Odisha in India, which created awareness across the state of Odisha, over 45 days reaching out with 314 blocks, the 30 districts to Government, non-government, civil society, to a multi-pronged approach. We were partners with the Government, with the corporate houses, with philanthropic organisations like rotary clubs, like Lions Club, and the media and our goal strengths were these Odisha State disAbility Network partners, who brought about young students as volunteers from their district and we were able to reach close to 5 like of people creating awareness with the help of a bus called the SASHAKT [name], colourful posters, public meetings, public exchanges and conversations, multimedia shows, street theatre, and a lot of folk artforms of India, Odisha, were used in dramatising singing, taking it to people so they would be interested to listen what the law said about the rights of people with disabilities.

RICHARD: So one of the greatest campaigns which perhaps unites us all in our slogan 'nothing about us without us'. And it resonates with the philosophy and the history of the disability rights movement, a movement that is embarked on a mission parallel to other liberation movements and is still unfolding. The disability rights movement demand for control is an essential theme that runs through all its work. Control has universal appeal to disability rights movement activists because the needs of disabled people and the potential for their meeting these needs, are everywhere conditioned by a dependency born of powerlessness, poverty, degradation and institutionalisation. The dependency saturated with paternalism begins with the onset of disability and continues until death. The condition of dependency is typical for hundreds of millions of people throughout the world. Only in the past 35 years has this condition begun to change. Although little noticed, affecting only a small percentage of disabled people, this transformation is profound and continues. So to conclude really, Disabled People's Organisations play many roles at the local national and international level for disabled people, Government, service providers and general public. In many cases, the organisations of disabled people are the best vehicle to carry out the aspirations of disabled people. After all disabled people from their own personal experience, best know their needs, aspiration and abilities. Government programmes should continue to work closely with the NGOs and community-based organisations to strengthen DPOs. This could include undertaking training, building technical capacity, in a running society, building in running society and lining them with appropriate NGOs. But most of all DPOs have contributed significantly to the liberation of many disabled persons. Decision makers and professionals need to acknowledge the importance of the role played by DPOs, and Sarah, last word from you to end up on, why you think DPOs are so important please.

SARAH: Thank you Richard. I would like to say that DPOs are quite important in speaking, bringing persons with disabilities to speak in one voice, to be able to advocate for their rights to challenge duty bearers, and even for themselves to capacity build each other on what their rights are and how they need to fight for them because they don't come easy so therefore let us encourage those who are not in DPOs to encourage DPOs formation in their localities so their voices can be heard as one. Thank you.

RICHARD: And thank you everybody for that, thank you.