

# Module 2: Organising for Disability Equality and the Struggle for Equality - Plain English

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# Module 2: Organising for Disability Equality and the Struggle for Equality

Introduction by Sarah Kamau, Chair of the Commonwealth Disabled People's Forum:

"I come from Kenya in East Africa and represent the United Disabled Persons of Kenya organisation. We are a national umbrella organisation. This means that there are over 300 organisations, led and controlled by disabled people with different focus and interests, such as local organisations, disabled women's, youth networks and organisations that focus on different specific impairments such as blind, Deaf or Albino.

We have found by uniting and listening to each other we have much more chance of influencing the National Government to improve things for disabled people, across Kenya.

(Influencing = talking to people, helping them understand or change their mind)

I would like to welcome you to this second module of our online course aimed at developing Disabled Youth Leaders around the Commonwealth.

Our theme today and this Month is: **Organising for Disability Equality and the Struggle for Equality**

The language we use in the Commonwealth Disabled People's Forum CDPF.

**Disabled people:** In the Commonwealth Disabled People's Forum (CDPF) we call ourselves '**disabled people**' because society disables us. This means it is the world we live in that stops us from doing what we want or being where we want to be.

Last month we focused on the Paradigm Shift (Recap)

Paradigm (sounds like 'para dime') means really big. So there was a really big change in thinking.

This means moving away from

a) **ideas and attitudes** where people think impairment is a punishment, or from evil spirits or Gods

b) **Charity ideas based on pity** (where people feel sorry for us)

c) '**Medical model**' ideas that just look at our impairment and healing us. The problem is often medical science has no answers and makes us feel different from 'normal'. Of course we need medical support, but we don't want to be made to feel different or alone.

**Impairment:** long term or permanent loss of something in our bodies.

We use the **social model of thinking** that means it's the world around us that stops us doing what we want.

**We have to do it together-collectively.**

We realised that we know what is needed to include us which is why we say: **Nothing About Us Without Us.**

Based on this understanding, disabled people and our organisations campaigned and won at a global level at the **United Nations (UN)** the need for **Human Rights** to be extended to all Disabled People.

This was finally achieved in the **United Nations Convention of Persons with Disabilities (UNCRPD)** in 2006.

**The Social model/human rights approach promises real change to full equality for disabled people around the world.**

Sarah gives examples from Kenya:

'We have organised ourselves in the grassroots level. (Grassroots means 'at the most basic level', or common people). We used the Government structures that are there and they have been able to help us to access services and goods from the Government as well as other providers.

We also have the household levels. We go and reach out to the households, where we look at the eldest of the households, and we use them to help us organise our way of fighting for this inclusion.

The village levels are where we have village elders or heads who are also helpful in getting the people on board who would like our support.

We have more levels of groups and then we have the national level, where United Disabled Persons of Kenya are able to talk to the Government.'

**We could say this is our Dream. But how do we make it real?**

**Making Progress and influence**

Change happens every day.

From small beginnings, any organisation can grow. It learns from the experience of its members, listening to everyone's ideas, and grows from the energy of new members. **Each generation will need to change and build these organisations until we have what we want.**

As the world around us changes, some problems are solved, and new ones come. We will need to find new ways to new problems and new challenges.

Change is not always for the better, but it keeps us alert and active. (DAA 1996)<sup>i</sup>

This booklet is taken from some booklets produced by Disability Awareness in Action. This was set up and run by Board Members of Disabled People International to develop the Disabled People's Movement around the World [See end note 1 for links].

**(Clip 1 Rita Kusi of Ghana Federation of Disability Organisations.)**

### **Link with future Modules**

Let us have a look at the steps we go through to build our own organisations. We will look at diversity (women, youth, types of impairments) in Module 3.

Our organisations must be set up and run in a proper way. Module 4 in January 2024 will look at this.

## **Progress of the Disability Movement: From Isolation – Solidarity – Struggle – Equality**

### **Social and Political Change and Influence**

Society (the world we live in) won't change on its own. It only changes when lots of people want change. As disabled people, we want to bring about social change, so we can join in properly.

We know best what we need and can help make it work well. Social change can happen in two ways: through changes in the attitudes and behaviour of individuals and through changes in laws, policies and services.

### **To change attitudes and behaviour,**

people need to know about us, our needs and what we have to offer our community, our society, our world. Using social media and the traditional media (radio, television, newspapers, posters) has proved a good way of doing this.

To change how things work, we need to make sure that the people who make the laws know about our needs and our ideas for solving problems. The framework of the UNCRPD helps us with this.

The UNCRPD has now been signed by nearly all Commonwealth countries. Only **Tonga and Cameroon** haven't. If you want to know when your country ratified the UNCRPD go to [https://tbinternet.ohchr.org/\\_layouts/15/TreatyBodyExternal/Treaty.aspx?Treaty=CRPD](https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/Treaty.aspx?Treaty=CRPD)

### **Awareness: Changing Minds**

In many cases, public education and awareness campaigns have been making the public change its attitudes and actions towards disabled people. One of the easiest ways to help somebody understand is to tell them about yourself.

Everybody is different and difference can be frightening. When you tell someone about yourself - about your daily life, your thoughts and feelings - you make it easier for them to understand you. As individuals, disabled people can tell the community about their needs

and what they have to offer. We need to talk to other disabled people and their friends and families, as well as people who don't have much experience of disability.

Use internet and social media, local radio, local TV and newspapers

**Meeting face to face is far more powerful than on social media.**

### **As an Organisation**

The first step towards change is getting together with other disabled people. If you aren't a member of an organisation already, find out about local groups. If there isn't one, why not start one?

Decide on what you want, and get to know each other.

**The next stage is to tell the world about what your members want.**

To make an issue widely known, you can write letters. You can send out press releases (specially written pieces for newspapers) to newspapers. You can set up blogs on social media and put up posters. You can hold public meetings, ask members to talk to relatives and friends. Do things in the street to make people see you, hold peaceful protests or speak at public meetings.

It's very important to show that your organisation is doing something - providing a service, helping members have an income (money), helping make access better. Tell people why it's good for the whole community to make disabled people's lives better.

### **Having an Effect on Laws and Policies**

Legislation, which means Laws and policies, helps disabled people get their rights to go to schooling, find employment and be able to access community facilities. They also help to remove cultural and physical barriers and make it illegal to discriminate against disabled people. Some of this was happening before UNCPRD was signed. Check that the current legislation is in the requirements of the UNCPRD. [Contact public interest and human rights lawyers to help you with this. They often will do free work for DPOs].

Sometimes, the best way to help change laws, policies and services is by the kind of public awareness described above. In some cases, legislation that changes behaviour, like access laws, can help change attitudes, as people begin to see the benefits of the legislation.

Changes in laws are very important because, even if you persuade the head teacher at the local school or the boss of a big company to support education and employment for disabled people, that teacher or boss may change jobs.

**We want improvements to last and be made law, not temporary and based on the odd kind person.**

If it is OK to do this in your country, you might want to make contact with an official whose work could help with disability policy - a minister or one of their assistants, for example.

**You can help this person hear the views of disabled people at the grassroots;** they can offer you and your organisation a part in decision-making. Many governments have seen why it's good to include certain groups in the policy and law-making processes. This has been particularly true for businesspeople, religious leaders, the military and trade unions. Our cooperation, skills and votes are also important. A number of Commonwealth countries have set up National Disability Councils. It is important that the Disabled Representatives on these Councils are chosen properly. They have to be disabled people. Changing this can be a campaign!

**(Clip 2: Steve Estey, Canada)** sadly has recently died. He started in 1970s. All 10 provinces in Canada developed DPOs that formed the Council of Canadians with Disabilities. **This led to the DPI (Disabled People International)** being formed.

**Developing a unified voice** is important. This means everyone has to come together and agree. Otherwise, some people stop change from happening. There are different stages we can go through in building our organisations.

**Stage One:** Disabled people are often isolated from each other and the world: kept in special homes, or in inaccessible housing, hidden away by families who are ashamed and frightened of them. They have no money, no power, often no way of moving about or communicating with each other.

**Stage Two:** Sometimes, groups of people with the same impairments begin to come together. They talk about what their lives are like. They realise that they are not alone, that they share the same problems. Then, as they become confident because they are helping each other, they see that things can change. They form their own organisations to make sure the services that they need are available.

**Stage Three:** Disabled people with different impairments realise how some of their experiences the same. So then many disabled people realise that their problems are because of non-disabled people's fear. That the world around them has been set up as if disabled people didn't exist. Some organisations are formed for certain reasons, such as access or independent living. These organisations often have people with different impairments as members.

**(Clip Three:** Maataafa Faatino Utumapu, Manager of Nuanua Ol Alofa, our National affiliated Organisation in Samoa.)

**Stage Four:** The different organisations join together to campaign to change attitudes, laws, policies and services. They try hard to make changes. They show the world who they are and what they can do - by being out on the streets, stopping traffic, writing letters, singing, shouting, dancing.

**(Clip 4:** Ganesh Singh, Guyana Council of Organisations for Persons with Disabilities).

**Stage Five: Change comes quite rapidly.** The community is more aware of disabled people, sees them on the streets, at work, on television. Programmes and policies change and laws are passed in some countries. Technology, access and information get better. Many diseases (that can be stopped) disappear. In some parts of the world, general health life expectancy (how long someone lives for), also gets better for disabled people. Disability becomes a human rights issue.

**(Cip Five:** Abia Akram from Pakistan, Special Talent Exchange Program STEP and CDPF Executive)

**Stage Six: Even though there are positive changes, there are still problems and new dangers.** Disabled people everywhere are still the poorest group. They are the most vulnerable to violence of any kind. (This means violence is more likely to happen to a disabled person). The search for cures for impairments means that some non-disabled people think there need be no more disabled people at all.

**'Genetic engineering'** (looking at and changing what human beings are made of and the way their bodies and minds work) means 'eugenics' - "purifying the race". Examples include aborting babies that may have impairments, letting disabled babies die, euthanasia (legal killing) for severely disabled people. Because people live longer, there are more older disabled people, who are kept apart, in special homes or their own homes.

**Stage Seven: The future?** The worldwide disability movement grows in strength. More and more disabled people free themselves from despair and segregation (being kept apart) and decide to work together. They look at the ways their groups are organised. They try harder to bring in more disabled people and to improve communication among members and with the wider community. Then more non-disabled allies (people who are on our side) understand that disability is a human rights issue and add their support.

Threats

**Apathy (where people stop caring)**

**Economic (money not fairly given)**

**Attacks on Human Rights**

**Lack of funding for Development Issues**

**Social Media broadcasting spreading lies and untruth (ie Anti Vax and Covid).**

**The need to find people to blame**

**Why Start an Organisation?**

There are groups of people in every society who do not go as far as they could or do all that they are able to, because of a history of being considered as not as good as others. They might be women, workers, indigenous people or gay and lesbian people; because of their race, religion or culture.

For hundreds of years, groups of people with something in common have come together, to make them feel stronger, improve their situation in the local community, in their country, in the world.

Disabled people have the same needs and rights as non-disabled people. These include a social life, education, food and money, dignity and respect, access to community services, access to specialist services, forming relationships, sexuality, having a family. We have always had decisions about these things made for us by other people; we have always had other people speaking for us. This has to change and together we can make it change.

More and more in the last fifty years, disabled people all over the world have come to realise that 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. No one has all the answers. Being a member of a small group of disabled people, talking about experiences and developing respect and support for each other is a good step towards self-respect and independence. Only when we have a strong sense of ourselves as a group can we begin to do something about society's negative view of us.

**(Clip Six:** Patience Ogolo-Dickson, Executive Director: Advocacy for Women with Disabilities Initiative (AWWDI) Nigeria)

## Building an organisation or Campaign

- 1) Finding the First Members** Find two or three disabled people and talk about what matters to you and what you have in common. Each of you may be able to bring in someone else.
- 2) The Place** 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 meet in someone's house. Also now online which helps, but access can be expensive, for example Sign Language.
- 3) Access** The major problems for everybody trying to organise a meeting are how to get people there, finding the right place to meet and making sure that everything that happens can be understood by everybody.
- 4) Transport** Can non-disabled supporters, families of disabled people, and other disabled people help provide transport to the meeting?
- 5) Alternate Media** Arrange for Sign Language interpreters and personal assistants. Make sure anything written down is read to blind people or available on tape, in braille or Easy Read and Plain English. Ask your supporters to help in taking notes for those who do not understand Sign Language or cannot write down their own notes.
- 6) Publicity** Invite people in a way that works for them, in plenty of time. Communicating with someone is much better than just a leaflet. If necessary, pick them up and bring them along.



## Issues for Disabled People Campaigns

**Campaigning on the UNCRPD** (letting everybody know about disabled people; changing laws, policies and services) Globally, 186 countries ratified, and 54 from 56 countries in the Commonwealth. Implementation (making it work in country) is the Key.

Here are links to the [Commonwealth Disabled People's Forum](#) and [International Disability Alliance](#) who are the 2 biggest organisations interested in the UNCRPD

Here is the link to the [Sustainable Development Goals SDGs](#) (which includes disability) which were only 12% of the way there at the half-way mark September 2023.

**Environment and Impact of Climate Change** – Disabled People are most at risk from Climate Emergency, Global warming and Geophysical events. Campaign to be fully included in what happens in an emergency and finding solutions.

**Getting National Legislation compliant with UNCRPD** E.g. Australia, New Zealand Pakistan, Canada, India, Kenya, Nigeria, Ghana, Guyana South Africa. Many other countries do not have, or stuck in Parliament - Sri Lanka.

**Organising empowerment for certain groups to claim their rights.** E.g Women, Youth, Mental Health Survivors, Learning Impaired or Neuro-diverse.

<https://commonwealthdpf.org/cdpf-womens-forum/>

**Economic** (getting enough money to live) E.g Opposing 42 types of Benefit Cut UK due to austerity Measures [DPAC](#).

**(Clip Seven** Linda Burnip from UK Coalition Disabled People Against the Cuts DPAC)

**Independent Living** - getting information and support; making choices; self-determination E.g Closing Institutions-[European Network Independent Living](#)-Joshua Malinga, Zimbabwe led the occupation of the Home for Disabled People where he lived. Union of Physically Impaired Against Segregation (UPIAS) came out of protests, inhabitants at Leonard Cheshire Home Le Court in Petersfield Hampshire led by [Paul Hunt](#)

**Inclusive Education** [Alliance for Inclusive Education](#) Needed to develop coalitions (joining together) recognising we cannot bring change on our own.

**(Clip 8** UK Alliance for Inclusive Education Micheline Mason)

**Challenging Portrayal in the Media** [1 in 8 Campaign](#)

**Access** such as removing copyright on items for blind people [Marakesh Treaty](#)

[WFD campaign](#) to get Sign Language recognised as a language.

**Getting all public Transport Accessible** [Transport For All\(UK\)](#)

Canada <https://www.disabled-world.com/disability/transport/cta.php>

**Subsidised vehicles** for disabled People Motability UK Disabled Drivers Ass.

See <https://ukdhm.org/ukdhm-2020-broadsheet/>

Social (meeting other people and sharing experiences) **Deaf Clubs**

**Recreational** (taking part in leisure and sports activities) Paralympics/Integrated Games [We the 15%](#)

[UK Disability History Month](#) from 2010 to 2023 with a different theme each year, Learning from Disablism of the Past, Challenging Discrimination Today, Aiming for Equality in the Future.

**Benefits to an Individual** [Disability Benefits Coalition](#) ( organisation of over 100 DPOs, Charities and NGOs campaigning for better disability benefits in the UK )

**Developing Disability Equality Training**

**Clip Nine** Changing Non-Disabled Peoples Thinking and Disability Equality Training  
Micheline Mason

**Challenging Employment practices/quotas etc**

**Improving chances for employment. ILO/ Trade Unions Reasonable Accommodations at Work** [ILO Trade Union Action for Disabled Peoples Rights at Work](#)

**Proving to the wider society that disabled people can be active members of society.**

**Taking cases to court. Disability Arts and Drama. Making Films featuring disabled people and themes.** [GRAEAE Theatre](#)

**Disability Relationships and Sex** [Undressing Disability](#)

**Disabled Parents** [Disabled Mothers Campaign](#)

Such campaigns end isolation (the feeling of being alone), develop a sense of identity (being proud of who you are) and solidarity (feeling strong together). They lead to learning skills through the group, including leadership skills. Working together to improve or provide services for all disabled people in the area.

**DPOs (also now called Organisations of People with Disabilities OPDs) and championing Human Rights**

The role of DPOs includes making people feel strong and proud. It helps people find out what they need most, and making sure people know about it. They help them get better at asking for help and change, and sharing information. They are very important.

**United Nations Convention on the Rights of Persons with Disabilities**

**Article 1: Purpose**

The Convention was made to make sure disabled people have their human rights and dignity.

## Eight Principles

- (1) Respect for dignity, including the freedom to make choices and have independence
- (2) Not to treat disabled people differently
- (3) To be included properly in society;
- (4) Respect for difference and acceptance of disabled people as part of humanity (human race).
- (5) Equality of opportunity;
- (6) Accessibility;
- (7) Equality between men and women; and
- (8) Respect rights of disabled children

Article 4.3 and 33.3 in the UNCRPD say that DPOs are the voice of disabled people and should be asked by governments making the UNCRPD laws in their countries. Last year the [CDPF ran a campaign based](#) on this, and a survey of our members to get funding from Governments so these DPOs can carry out this consultative function. This is something to still campaign on (fight for) in many Commonwealth countries.

### Article 4.3

In making the Convention, and while they make decisions about disabled people, countries that have signed shall properly involve persons with disabilities (including children) through their DPOs.

Article 33.3 National Monitoring (monitoring means properly and often checking on something)

Civil society (a community of people), **in** particular persons with disabilities and their DPOs, shall be involved and properly take part in the monitoring process.

[https://tbinternet.ohchr.org/\\_layouts/15/TreatyBodyExternal/Treaty.aspx?Treaty=CRPD](https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/Treaty.aspx?Treaty=CRPD)

Making and using the UNCRPD came directly from the Disabled People's Movement making the Paradigm Shift. Many struggles have led to this.

In the Netflix Series "Sex Education", Series 4, Programme 7 there is a good example of a struggle in a college for access, with a sit in and solidarity with disabled students.

Convention in full <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities>

Some UNCRPD papers, not all! in Plain English or Easy Read: [Documents in plain language and Easy Read versions | OHCHR](#)

## Conclusions

If you have not challenged the way you are treated, do so.

If you have done it on your own, join up with other disabled people.

If you are not in an organisation committed to struggling for change, join one.

If you are in an organisation, put yourself forward to lead in new aspect.

Stand for election to Office.

Find new ways to tell and help everybody in your community to bring about disabled people's human rights.

Don't just read about it, do it.

## Follow up Activities:

<https://commonwealthdpf.org/training/disability-equality-capacity-building/module-13/>

may be useful to help your understanding in this area.

1. Find out where there are disabled people in your country who are not members of a DPO. Write and design a leaflet to convince them to join a DPO.
2. Disabled people are often expected to personally be strong about their impairments and access needs. Design a poster or letter giving the main reasons why such a disabled person should join a DPO and join in.
- 3.i Find an area in your country where disabled people's rights are not properly there. Make an action plan to bring in disabled people and their DPOs into the campaign.
- 3.ii List the main points you need to think about.

## Appendix 1 Who to influence

Anyone in charge of anything should make it accessible to disabled people.

### Local Level: Who, Why

A. Local authorities: To talk about local laws and budgets and to make change official. Speak to their officers, civil servants, etc. National Level: Village elders, Town planners

B. Professionals: education, health, welfare, business, law, medicine, media, etc. For awareness-raising through community leaders and for specific action: accessible schools and churches, a local radio programme on disability. This can lead to examples of good

practice which will help change the minds of the people in group A. Trade unions, Religious leaders.

C. General public support in campaigns from people who will also benefit from change (e.g. parents and friends, users of local facilities, mothers carrying children). This shows the policy-makers that changes are supported by a large part of society.

### **National Level: Who, Why**

A. Ministers To influence national laws and regulations. Civil servants

B. Other state authorities: health, housing, transport, etc. To help change their policies and practices and for actions, such as community-based rehabilitation, accessible housing and transport systems.

C. Other (voluntary) bodies: charities, NGOs, aid agencies, trade unions, media. For support in campaigns.

D. Associations of professionals: To change their policies and structure to include the real needs of disabled people. To get their support in getting people to know about it.

E. General public: To make people know about disability issues and to show that we are part of the general public. As at local level, show how change benefits all.

### **Regional Level: Who, Why**

A. National representatives to regional bodies: Contact with representatives of your own country means that they will support the right regional policies and programmes. If you can make the contact regular, your influence will be greater.

B. Committees of regional bodies: Contact can also be made formally through petitions and letters. Use International Disability Alliance (IDA) and CDPF briefings.

C. UN regional commissions such as UNDESA and UNDA: Send these bodies copies of your own policy documents and plans. Ask to see any material they have produced on disability.

### **International Level: Who, Why**

A. United Nations. Each member state of the UN has a set of people called a Mission that represents it at the General Assembly in New York. Make contact and inform them of the views of disabled people in your country.

B. Other international groupings of countries. Your country may have a representative on one of the important committees. Your influence with them can affect policy. Shared programmes on disability with countries with the same language, legal system, etc., can be very useful.

C. International non-governmental organisations have some of the same interests and it is good for them to share information. Each organisation should speak on its own behalf at the UN, while recognising the benefits of speaking with one voice on some issues.

D: Multinational companies These have a major influence on employment and the economy in any country. They need to be aware of disability issues. They may be able to transfer examples of good practice from one country to another.

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#### End notes

<sup>i</sup> This booklet draws on and updates a series of booklets produced by Disability Awareness in Action DAA in 1996. DAA was set up and run by Board Members of Disabled People International to spread best practice and develop the Disabled People's Movement around the World. They are worth reading if you want more advice and a deeper understanding of the various aspects of the dynamics of building effective Disabled People's Organisations.

Tool Kit 1 Media Influencing <https://www.independentliving.org/docs2/daakit1.html>

Tool Kit 2 Consultation and Influence <https://www.independentliving.org/docs2/daakit21.html>

Tool Kit 3 Campaigns <https://www.independentliving.org/docs2/daakit31.html>

Tool Kit 4 Organisation Building <https://www.independentliving.org/docs2/daa4.pdf>