

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

## Contents

<b>Introduction by Sarah Kamau, Chair of the Commonwealth Disabled People’s Forum: ...</b>	<b>2</b>
<b>A word on the language we use in the Commonwealth Disabled People’s Forum CDPF. .</b>	<b>2</b>
<b>Last month we focussed on the Paradigm Shift.....</b>	<b>2</b>
<b>Sarah gives examples from Kenya .....</b>	<b>3</b>
<b>Making Progress and influence .....</b>	<b>4</b>
<b>Progress of the Disability Movement: From Isolation – Solidarity – Struggle – Equality... </b>	<b>5</b>
<b>Social and Political Change and Influence.....</b>	<b>5</b>
<b>To change attitudes and behaviour, .....</b>	<b>5</b>
<b>The next stage is to tell the world about what your members want.....</b>	<b>6</b>
<b>Developing a unified voice .....</b>	<b>7</b>
<b>Threats.....</b>	<b>8</b>
<b>Why Start an Organisation?.....</b>	<b>8</b>
<b>Building an organisation or Campaign .....</b>	<b>9</b>
<b>Issues for Disabled People Campaigns.....</b>	<b>10</b>
<b>DPOs (also now called Organisations of People with Disabilities OPDs) and championing Human Rights .....</b>	<b>11</b>
<b>United Nations Convention on the Rights of Persons with Disabilities .....</b>	<b>11</b>
<b>    Eight Principles.....</b>	<b>12</b>
<b>Conclusions .....</b>	<b>13</b>
<b>Follow up Activities:.....</b>	<b>13</b>
<b>Appendix 1 Who to influence .....</b>	<b>14</b>

# 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. Meaning that in our membership 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.

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**

A word on the language we use in the Commonwealth Disabled People's Forum CDPF.

**Disabled people:** Why we still choose to call ourselves 'disabled people': In the Commonwealth Disabled People's Forum (CDPF) we call ourselves '**disabled people**' because of the development of the '**social model of disability**'. In the C19th and C20th, a disabled person's medical condition was thought to be the root cause of their exclusion from society, an approach now referred to as the '**medical or individual model**' of disability. We use the '**social model of disability**', where the barriers of environment, attitude and organisation are what disable people with impairments and lead to prejudice and discrimination. So, to call ourselves 'persons with disabilities' is to accept that we are objects and powerless. We also view ourselves as united by a common oppression so are proud to identify as '**disabled people**' rather than '**people with disabilities**'. **When we are talking about the UN Convention on the Rights of Persons with Disabilities** we will use '**people or persons with disabilities**'.

Last month we focussed on the Paradigm Shift (Recap)

As you now know, this means the transition away from a) **negative culturally based ideas and attitudes** based on trying to explain impairment as punishment, the impact of evil spirits or Gods and is expressed by prejudicial Stigma and attitudes;

b) **Charity ideas based on pity** and providing refuge and asylum to those with impairments, outcast or ostracised by society;

c) **Medical model ideas that focus mainly on our impairment** and healing us. The problem is often medical science has no answers and this approach puts the focus on how we are different from 'normal'. Of course we need medical support, but we do not want to be seen through that lens which often leads to our isolation and segregation.

**Impairment** -long term or permanent loss of physical sensory, psycho-social or mental function is part of the human condition. **The issue is how it is responded to.**

We promote the **social model of thinking** that empowers us as disabled people to challenge the barriers in society, in the environment, organisation, communication and attitudes and find solutions that lead to our equal treatment.

This social model thinking has been the 'power-house' of our transforming our lives.

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

It also leads to us understanding we are the experts on 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 explicitly 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 holds out the promise of real change to full equality for disabled people around the world.**

Sarah gives examples from Kenya

'We have organised ourselves in the grass roots level, using 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, who are called Nyumba in Kenya, they call them Kumi, and also the people we engage and use as organising 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 the county assemblies, and we have members of county assemblies who represent issues of disabled people in the legislative assemblies. In these county assemblies we have ward education, bursaries, and we have ward development funds where the representatives of disabled people within them, are able to push for the disability inclusion agenda and disability equality rights.

There is also in the ward level, the ward administrators who are people we engage also as they are concerned with the public participation, on the things that the counties want to put on hold.

We have the national level, where United Disabled Persons of Kenya are able to influence Government on policy, inclusion, and we have in different forum like the disability inclusion co-ordinating committee on the political space. We also have the data, disaggregation where we engage with the Kenyan National Bureau of Statistics.'

### **We could say this is our Dream. But how do we translate it to reality?**

Richard Rieser our General Secretary leads the rest of the presentation.

### **Making Progress and influence**

Change happens every day.

From small beginnings, any organisation can grow, learning from the experience of its members, listening to everyone's ideas and views, profiting from the energy and commitment of new members. **Each generation will need to overhaul and build these organisations until all our objectives have been achieved.**

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

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

This booklet draws on and updates a series of booklets produced by Disability Awareness in Action 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 [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 phases we go through to build our independent organisations. We will examine the need to reflect and champion diversity in Module 3, in November. This will examine this need in terms of women and youth, age, type of impairments and other differences.

Our organisations must be established and run in a democratic and inclusive manner. Module 4 which will run in January 2024 will focus on this theme.

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

## Social and Political Change and Influence

Society won't change on its own. It only changes when large sections of society want change. As disabled people, we want our influence to bring about social change, to allow us full and equal participation.

We know best what our needs are and our contribution to the process of change will make it more effective. 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 has proved a good way of doing this.

To change society's formal structures, we need to make sure that law and policy-makers, as well as service-providers, know not only about our needs but also our ideas for solving problems. The framework of the UNCRPD helps us with this. The UNCRPD has now been ratified by all but 2 Commonwealth countries **Tonga and Cameroon**. 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 launched to educate the public to alter its attitudes and actions towards disabled persons." One of the simplest ways to influence somebody 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 no organisation exists, why not start one?

Decide on your aims 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 and send out press releases to newspapers, set up blogs on social media, put up posters and hold public meetings, encourage members to talk to relatives and friends. Hold stunts, peaceful protests or intervene at public meetings.

It's very important to show that your organisation is achieving something - providing a service, generating income for members, encouraging access improvements. Point out the benefits to the whole community of improving disabled people's lives.

**Having an Effect on Laws and Policies** "Legislation has in many cases been enacted to guarantee to disabled persons the rights to, and opportunities for, schooling, employment and access to community facilities, to remove cultural and physical barriers and to proscribe discrimination against disabled persons." Some of this was introduced prior to the UNCRPD being ratified. Check that the current legislation complies with the requirements of the UNCRPD. [Contact public interest and human rights lawyers to help you with this. They often will do pro bono (free) work for DPOs].

Sometimes, the best way to affect laws, policies and services is by the kind of public awareness described above - by creating the right atmosphere for legislative change. In some cases, legislation that changes behaviour, like access laws, can encourage changes in 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 be permanent and enforceable, not temporary and based on a sympathetic individual.**

If it is accepted practice in your country, you might want to make contact with an official whose work could have some influence on disability policy - a minister or one of their assistants, for example.

**You can offer this person direct access to the views of disabled people at the grassroots;** they can offer you and your organisation a part in decision-making. Many governments have seen the benefit of including certain groups in the policy and law-making processes. This has been particularly true for business people, 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 by the Representative Organisations of Disabled People in your country, not just appointed by the Minister. In some cases, people chosen to sit on these Councils can be not representative or even informed by the

grassroots experience of disabled people. Changing this can be the basis of a campaign in itself.

**(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. Without them the split at the Rehabilitation International Conference in 1980 leading to the founding of DPI the following year would not have happened.<sup>ii</sup>

**Developing a unified voice** is important, otherwise divide and rule tactics can be used by those who do not want change. 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: locked in institutions, segregated by 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 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. They talk about what their lives are like. They realise that they are not alone, that they share the same problems and, with the confidence that comes from supporting one another, they begin to 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 are similar. As a result, many disabled people realise that their problems are not just because of their individual impairments but because of non-disabled people's fear and superstition, and the fact that society itself has been organised as if disabled people didn't exist. Some organisations are formed for specific issues, such as income generation, 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 single impairment and the 'issue' organisations join together to campaign to change attitudes, laws, policies and services. They use their votes and any money that they and their friends or relatives have to put pressure on politicians and businesspeople to make changes. They use their bodies, their voices, their hands or their feet, to show the world who they are and what they can do - by being out on the streets, stopping traffic, writing letters, singing, shouting, dancing. Ratification and Laws to Implement UNCRPD.

**(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 legislation is passed in some countries. Technology advances and mobility, access and information improve. Many preventable diseases disappear. In some parts of the world, life expectancy and general health for disabled people also improve. Disability becomes a human rights issue.

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

**Stage Six: Despite positive changes, there are still problems and new dangers.** Disabled people everywhere are still the poorest group; the most vulnerable to violence in all its forms. The search for cures for impairments means that some non-disabled people seem to 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 that 'eugenics' - "purifying the race" - comes back into fashion. Examples include aborting fetuses that may have impairments, letting disabled babies die, euthanasia for severely disabled people. With increased life expectancy, there are more older disabled people, who are segregated in institutions 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 and decide to work together in local groups and at the national, regional and international levels. They look at the ways their groups are organised and make improvements to draw in more disabled people and to improve systems of communication among members and with the wider community. As a result, more non-disabled allies understand that disability is a human rights issue and add their support.

## Threats

### **Apathy**

**Economic: domination of market economy and profit**

**Attacks on Human Rights**

**Lack of funding for Development Issues**

**Social Media/ unbalanced broadcasting spreading lies and untruth-Ant Vax and Covid.**

**New Populism which seeks scapegoats.**

## Why Start an Organisation?

There are groups of people in every society who do not achieve all that they could because of a history of being considered as inferior members of that society - because they are 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 strengthen their sense of identity and to 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.

Increasingly 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 so not restricted geographically, but access can be expensive -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 for people who can't use public transport?
- 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. Approach your supporters for volunteers to help in taking notes for those who do not understand Sign Language or cannot write down their own notes.
- 6) Publicity** Make all those you want to come to the meeting receive notice in a format that works for them in plenty of time. A personal contact works much better than just a leaflet. If necessary arrange to pick them up and bring them along.

## Issues for Disabled People Campaigns

**Campaigning on UNCRPD** (letting everybody know about disabled people; changing laws, policies and services) Global for UNCRPD 186 ratified 54/56 Commonwealth.

Implementation is the Key [Commonwealth Disabled People's Forum](#) , [International Disability Alliance](#)

**[Sustainable Development Goals SDGs](#)** -12% there at 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 emergency procedures 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 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 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 copywrite 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, develop a sense of identity and solidarity and 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 [disabled persons organisations DPOs] includes providing a voice of their own, identifying needs, expressing views on priorities, evaluating services and advocating change and public awareness. As a vehicle for self-development, these organisations provide the opportunity to develop skills in the negotiation process, organisational abilities, mutual support, information sharing and often vocational skills and opportunities. In view of their vital importance in the process of participation, it is imperative that their development be encouraged." UN World Programme of Action Disabled Persons 1982

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

**Article 1: 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.

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’.

## Eight Principles

(1) Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons;

(2) Non-discrimination;

(3) Full and effective participation and inclusion in society;

(4) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;

(5) Equality of opportunity;

(6) Accessibility;

(7) Equality between men and women; and

(8) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

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

Article 4.3 and 33.3 make it clear that Disabled Peoples Organisations as the representative voice of disabled people should be consulted by states in implementing the UNCRPD. Last year the [CDPF ran a campaign based](#) upon 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 in the majority of Commonwealth countries.

## Article 4.3

“In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with **and actively involve persons with disabilities, including children with disabilities, through their representative organizations.**”

## Article 33.National Monitoring

**3. Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process.**

Ratification Commonwealth only 2 countries Tonga and Cameroon have not ratified .  
Soloman Isles only June 2023. Rest of world 9 including USA.

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

The adoption of the UNCRPD and the process that led to it came directly from disabled People's Movement adopting the Paradigm Shift. Many struggles have led to this.

## Conclusions

The adoption of the UNCRPD and the process that led to it came directly from disabled People's Movement adopting the Paradigm Shift . Many struggles led to this.

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

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 influence 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 read to enhance your understanding in this area.

1. Identify 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 encouraged to personally overcome the disadvantage arising from the social reaction to their impairments and access needs. Design a poster, an info graphic or letter giving the main reasons why such a disabled person should join a DPO and get involved in its activities.

3.i Find an area in your country where disabled people's rights as outlined in the UNCRPD are not being delivered effectively. Develop a campaign action plan to engage disabled people and their DPOs in the campaign.

3.ii List the main points you need to consider and why in carrying out the above activity?

## Appendix 1 Who to influence

Anyone in charge of any kind of enterprise should make it accessible to people with disabilities. This applies to public agencies at various levels, to non-governmental organisations, to firms and to private individuals.

### **Local Level    Who    Why**

A. Local authorities: To influence local by-laws and budgets and to formalise change. 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 influence 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 statutory authorities: health, housing, transport, etc. To influence their policies and practices and for specific action, 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 raising awareness.

E. General public: To raise awareness of 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 appropriate 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 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. Concentrate particularly on issues to be discussed at the UN Conference State Parties and Country Reports at UNCRPD Disability Committee OHCHR, Geneva and High Level Forum on SDGs (July).

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 share many common interests and can benefit from sharing 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.

---

#### 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>

<sup>ii</sup> The 1960s and 1970s saw the formation of wide range of organizations of disabled persons in Canada and across the world. The [Handicappförbundens centralkommitté](#) HCK in Sweden took issue with the medical model of disability, whereby disabled people were unable to fully participate in society as a direct result of their inability to perform certain physical or mental tasks

This new wave of organizations, however, was distinguished by an increasing move towards multi-disability representation and a profound shift in how disabled people defined themselves in relation to society. This redefinition of disabled identity was integral to the founding of Disabled Peoples' International.

In 1979, they united and formed the only national multi-disability organization in Canada, the [Coalition of Provincial Organizations of the Handicapped](#) (COPOH). A headquarters was established in Winnipeg, Manitoba.

[Rehabilitation International](#) (RI) is a worldwide organization founded in 1922 devoted to improving the quality of life of people with disabilities. With member organizations in more than 100 countries, it is comprised of service providers, government agencies, academics, researchers, and advocates both with and without disabilities.

Both the Canadian COPOH and the Swedish HCK were member organizations in 1980, when RI announced it would host its upcoming World Congress in Winnipeg. Many in the COPOH and HCK believed that RI was too tightly focused on a medical model of disability that defined the disabled as sick and needing treatment.



---

RI held its Delegate Assembly meeting on June 20-22, just prior to the start of the formal Congress. At the Assembly, Bengt Lindqvist, a visually impaired member of the Swedish delegation, introduced an amendment calling for a change in the RI definition of “organizations of disabled people”. The amendment stated that at least 50% of the delegates representing such organizations should be disabled people and called for the establishment of a committee to explore the implications of having all member organizations accept a 50% disabled (the language used at the time was “handicapped”) governing policy.

The amendment was defeated sixty-one to thirty-seven. Lindqvist announced the results at a COPOH information-sharing meeting being held at the Congress. Henry Enns, a RI delegate from Canada and member of the COPOH, later said that the feelings of frustration and anger felt at the defeat of what many were calling the “equality amendment” sparked a bond of group solidarity among the 250 disabled people from 40 countries then in the room. The RI vote, he recalled “made it clear that there would be no changes made in the immediate future”.

An Ad Hoc Planning Committee, with representatives from Canada, Costa Rica, India, Japan, Sweden and Zimbabwe, was elected to work out the form that this new organization would take. Henry Enns and Jim Derksen of Canada were both elected to this committee. Over two days of meetings, the committee drafted a proposal for a founding philosophy, structure, and leadership configuration. The COPOH organized another meeting of over 300 disabled delegates on June 26 where the planning committee presented their proposal. The new organization would be composed entirely of disabled people and be multi-disability. The proposal stated that the coalition would “be based on the philosophy of equal opportunity and full participation of handicapped people in all aspects of society as a matter of justice rather than charity”.

The proposal was unanimously accepted. The delegates then elected a formal Steering Committee for the WCPD with two representatives from seven regions of the world. Henry Enns was named Chairperson and Bengt Lindqvist of Sweden named Vice Chairperson. There was much to do. The Steering Committee met again in October 1980, in February 1981, and in August 1981. Throughout these meetings, they made a number of key decisions. They agreed to change the name of the organization to [Disabled Peoples' International](#) (DPI), prepared a Constitution based on that of the International Labour Organization, and decided to hold a World Congress of disabled people to truly inaugurate DPI on the world stage.

The first DPI World Congress would be held in conjunction with the [United Nations](#) in November 1981 in Singapore. DPI was founded as a social movement and represented the social model of disability and a rejection of the medical model of disability. This was an important philosophical principle, which had prompted the split with Rehabilitation International.

“In the world today, there are several international organizations which work in the field of disability”, Henry Enns explained. “Most of them specialize in one particular disability such as blindness, deafness, etc. and represent the interest of professionals and service providers. DPI is the only international cross-disability organization in which disabled people have a decisive control”. Jim Derksen, from the founding DPI planning committee, later contended that, “rehabilitation tries to change the disabled person to accommodate society. Our organizations accept that many disabilities are permanent and tries to change society so that it accommodates disabled people”.

Following on from UPIAS in 1981, Disabled Peoples' International at its founding World Summit in Malaysia adopted the following statement:

**“Impairment** is the loss or limitation of physical, mental or sensory function on a long term or permanent basis.

**Disability** is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers”.

Disabled Peoples' International, 1981

This proved incredibly liberating to many disabled people who had internalised society's negative attitudes and treatment of them, often leading to very low self-esteem and isolation. If they were not responsible for the barriers, they could join together across different impairment groups and challenge the barriers and change society.