

## Contents

Introduction.....	2
In this Module we will unpack the principles of Democracy, its link to human rights, the rule of law and freedom of information and how these relate to disabled people achieving our human rights in practice.....	2
The General Secretary of the United Nations on his guidance notes on Democracy (2015) says:.....	3
Scader Louis, Malawi FEDOMA (Federation of Disabled Organisations in Malawi).....	4
Progress of a Social Movement: Isolation - Solidarity - Struggle.....	5
Activity A: how would you characterize the Disabled People’s Movement in your country?..	6
Making decisions collectively.....	7
Activity B: What would be your criteria for characterising a disability organisation as a DPO and Why?.....	7
<b>Independent Living</b> .....	7
Deciding Your Organisation’s Aims.....	8
Some important considerations in deciding your aims!.....	9
Membership and involvement.....	11
Example of a (SWOT) Strength -Weaknesses-Opportunities-Threats analysis.....	13
Activity C. Carry out a SWOT analysis on a Disabled Person’s Organisation you know.....	14
Rasanjali Pathirage – Disability Organisations Joint Front, Sri Lanka.....	14
Mohua Paul, Chair person Access Bangladesh Foundation.....	15
Leadership Training.....	16
Activity D. What do you consider the most important features of Leadership in the Disability Movement and Why?.....	18
Activity E. Consider what you can do to get your Government to support the Commonwealth Disability Inclusion Protocol.....	19
UNCRPD Article 29 – Participation in political and public life.....	20
Activity F. What are the barriers in the electoral system that reduce the power and voice of disabled people and how might they be changed in your country?.....	20
Activity G. Suggest ways that the methods set out here in a Council in a high Income country based on the principles in the UNCRPD could be adapted to working in your locality.....	21
Full report as submitted to Cabinet.....	21
Videos from Hammersmith and Fulham.....	21

Appendix 1: New Zealand DPO Coalition Attributes..... 24

# CDPF Course Disabled Youth Training for Leadership

## Module 4: Democracy, and Disabled People's Organisations

### Introduction

We as humans face threats - an unequal world where the gap between rich and poor is widening both between countries and within countries; where multi-national corporations often operate for their profits alone; where the urgent need to seriously tackle human-led climate change is being talked out; where increasingly autocratic political leaders choose competition, confrontation, war rather than peace and collaboration. This means that we live in the most globally unstable period since the Second World War.

We do have increased opportunities, while colonialism has been replaced by a far greater number of nation states who have generally supported a 'rules based' international order, far more people both as a percentage and in total live outside poverty. Globally, more young people, especially girls have access to education. Health provision has massively improved. Despite these and other important gains for humanity the threats and opportunities both make implementation of human rights much more difficult, especially for traditionally marginalised groups, such as disabled people.

Without a 'rules based' democratic system the chances of implementing our human rights as disabled people are lessened and as standards of health, education and living improve without full implementation of disabled people's rights, gaps between disabled and non-disabled people will increase due to stigma, discrimination and lack of reasonable accommodations.

**In this Module we will unpack the principles of Democracy, its link to human rights, the rule of law and freedom of information and how these relate to disabled people achieving our human rights in practice.**

These principles are laid out in both the Commonwealth Charter and the United Nations Declaration of Human Rights and subsequent charters. One of the unifying forces that hold the Commonwealth together is a commitment to this approach when dealing with civil and political rights. This has led to various members being temporarily or permanently excluded from the Commonwealth for breaches of these principles. Currently Gabon for not following free and fair elections. Previously the Maldives, Fiji for coups or Zimbabwe on a longer-term basis.

But despite all but one of the 56 Commonwealth countries, (Tonga), having ratified the United Nations Convention on the Rights of Persons with Disabilities, the aspirations contained in this legally binding Treaty are as far away as ever from being implemented at the grassroots level for the majority of the 450 million disabled citizens of the Commonwealth.

The process that led to the formation of the UNCRPD (2006) started more than 30 years prior, when disabled people began to view themselves as human rights holders rather than objects. Essential to this process was the transformation of organisations representing disabled people moving from charitable organisations set up 'FOR' us by the non-disabled world, to self-representation and empowerment with our own organisations run and controlled 'BY' disabled people.

The importance of developing an ever-wider range and diversity of disabled people in our organisations we covered in Module 3. In Module 4 we will examine the ways we can make our decision making as inclusive, representative, and democratic as possible. In doing this, we strive to represent the diversity of disabled people, our wishes and aspirations, as the fundamental change motor in all our countries.

The General Secretary of the United Nations on his guidance notes on Democracy (2015) says:

**“Democracy, based on the rule of law, is ultimately a means to achieve international peace and security, economic and social progress and development, and respect for human rights – the three pillars of the United Nations mission as set forth in the Charter of the UN.** Democratic principles are woven throughout the normative fabric of the United Nations. Indeed, the first three words of the Charter itself are **“We the peoples,”** followed closely thereafter by important references to essential democratic underpinnings such as **“human rights,” “fundamental freedoms,” “the equal rights of women and men”, “life in larger freedom,” “self-determination,” and the removal of distinctions on the basis of “race, sex, language or religion.” [or disability].**

The General Assembly, in “The Universal Declaration of Human Rights” elaborated on the general human rights provisions of the Charter **including the obligations of non-discrimination, equality before law, freedom of movement, thought, opinion, information, expression, assembly and association** - recognized as rights necessary for democracy.

The Declaration contains explicit provisions declaring that **“the will of the people shall be the basis of the authority of government; this will shall be expressed in periodic and genuine elections which shall be by universal and equal suffrage and shall be held by secret vote or by equivalent free voting procedures”** and guaranteeing everyone **“the right to take part in the government of his country, directly or through freely chosen representatives [and] the right of equal access to public service...”**

If our organisations are to be representative and we claim them to be in line with points 4.3 and 33.3 of the UNCRPD, we must make every effort to represent wider layers of empowered disabled people.

We will also look at how our organisation can maximise the development and accountability of leaders in our Movement.

However, to ensure democracy, as laid out in the quote from the Secretary General of the UN, we must also examine how we can enhance the participation of disabled people in the general political process, both in voting and as being representatives at every level of the system. [Article 29 – Participation in political and public life](#)

### Scader Louis, Malawi FEDOMA (Federation of Disabled Organisations in Malawi)

“I represent FEDOMA and we are an umbrella body of Disabled People’s Organisations in Malawi. Structurally the organisation has 11 affiliates, different disabled people’s organisations from diverse groups. We have a Board of Directors and we also have a National Executive Council, NEC. The Board provides oversight of the work that the Federation does while the NEC is comprised of representatives of leaders from the affiliates of FEDOMA. In terms of how we ensure our members views are incorporated and included in the decisions the organisation is making because the NEC is made up of representative DPO leaders they make sure decisions in collaboration with the Board are presenting the thoughts and interests of the people they are representing.

In addition to this, we ensure that the selection of the Board members and the selection of NEC is done at the General Assembly where we allow members to come together and make decisions on how they want the organisation to be led and to function. As an organisation we are also intentional in including Disabled Women and Youth. This is illustrated even in the selection of leadership at Board and NEC level, where there is equal representation of women, acknowledging the double discrimination that women face. We also ensure that Youth are part of the leadership team. This not only at the NEC level but at the Secretariat where the day-to-day administration and management of the organisation is done.

FEDOMA operates on values and principles borrowed from what the UNCRPD is providing, ensuring that there is non-discrimination within the Federation, but also the Movement, equality and also respect in terms of the views of diverse groups of disabled people that the organisation works with and receives.

In terms of the key issues that we are campaigning there are a lot of issues. As Malawi the Disability Movement has made a lot of progress. Recently we saw Parliament passing the Persons with Disabilities Bill that has been waiting for the last five years, replacing some old views that we had, that contained discriminatory language and other things that are not in line with the UNCRPD provisions.

Currently we are advocating much for inclusive electoral processes in line with Module 4 because next year in 2025 Malawi will hold a General Election. This year and next year there will be a lot of campaigns, including the President, so we are advocating that electoral processes, starting from the registration up to the actual voting, are inclusive. Also we are encouraging disabled people that are interested to join politics to do so and link them to appropriate civil society organisations that can support them to represent other disabled people. Currently, in Parliament we only have one disabled MP and he is someone with albinism but in 2025 we would like to see more disabled people get to Parliament and be part of the decisions being made.

In Malawi we still have archaic discriminatory laws around participation in fair elections for example, although our Constitution (Section 40) is providing for political rights for all, but the Local Government Act is denying the participation of people with psychosocial disabilities, denying the right to vote and stand for election. Even last week in the papers, this has been one of the things that the Disability Movement is fighting for, to make sure that in the upcoming election even people with psychosocial impairments are allowed to participate and stand for election.

Lastly, for me it is high time we added inclusive to the word democracy to Democracy itself. I was thinking as I was preparing for this, a definition of Inclusive Democracy would be:

**Removing all undue barriers to allow every citizen to engage in the civic and political discussion. It means ensuring that the political decision tables reflect the diversity and voices of all citizens.**

So until that is achieved Democracy will still be a far-fetched dream, especially for countries that are way behind in ensuring equal participation of citizens, particularly those who are disabled!”

### **Disabled People’s Organisations**

[Disability Awareness in Action, Organisation Building, Resource Kit No. 4](#) although nearly 30 years old still gives us some very useful pointers on some of the key issues that need addressing.

### **Progress of a Social Movement: Isolation - Solidarity - Struggle**

**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.

**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 business people 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.

**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.

**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.”

### Activity A: how would you characterize the Disabled People’s Movement in your country?

All of these stages of development of our Movement can still be found. Stage 5 is probably where we were in 2006 and in some places and countries we are nearer to stage 7, but how would you characterize the Disabled People’s Movement in your country?

#### Making decisions collectively

**The key change is how we make decisions collectively. How we involve more disabled people and how we can impact change amongst the wider non-disabled society.**

**The New Zealand DPO Coalition** IN 2015 developed a checklist of attributes an organisation should have to qualify it as a Disabled Persons’ Organisation. It is important to note that these attributes were developed for the New Zealand context, and not all may be applicable a particular COUNTRY CONTEXT but could be useful in developing a similar list here. This is reproduced in a useful Irish National Disability Authority Document (1921) called [A review of Disabled Persons Organisations and their participation in implementing and monitoring the UNCRPD](#). See Appendix 1 at the end of this document for the New Zealand criteria.

#### Why We Have to Be in Charge

For far too long, non-disabled people have made decisions about our lives. In the last few decades, disabled people have found the strength and confidence to say: "We need to speak for ourselves, make decisions about our lives, because we are the experts when it comes to disability." By forming organisations, we show that we are not people to be pitied but people with rights, skills and duties who demand a place within our community, not banished to the edges of it. By working together for the good of a group, we show that we can run things and take charge of our own lives. (From [DAA Kit 4](#))

### Activity B: What would be your criteria for characterising a disability organisation as a DPO and Why?

#### Independent Living



**A key area for all DPOs is Independent Living and working for all disabled people to have access to their choices and rights being properly considered.**

## **Self-Determination & Independent Living: Choices & Rights**

Independent Living means:

- having choices about how your life will be
- having control over your life

Independent living isn't about living on your own and doing everything for yourself. It is about 'self-determination': having control over what happens to you. It is having the right and the opportunity to follow a course of action by choice. And it is about having the freedom to fail - and to learn from your failures - just as non-disabled people do. Whatever the severity of someone's impairment (this includes intellectual impairments or learning difficulties) independent living means having every chance to make decisions and to be as self-sufficient as possible.

Barriers to independent living include lack of accessible environments, housing, education and employment; lack of recognition and respect for Sign Language; lack of accessible information; non-disabled people's misunderstanding and prejudices about impairments; institutionalisation and inflexible service provision. To have independent lives, disabled people have to overcome these barriers. This has most often been achieved by working together, finding our own solutions to our problems.

These principles run through the [UNCRPD](#) are exemplified in Article 12 Equal Recognition before the Law which promotes assisted decision making and Article 19 Living Independently and in the community.

## **Deciding Your Organisation's Aims**

First you have to decide the organisation's basic aims and guiding principles. This should involve everyone who wants to take part. (As the membership grows, there may be different or more things to aim for.) Ask people for their ideas and hold a meeting to encourage discussion.

### **Examples of Short-Term Aims**

- Form the organisation.
- Find funding.
- Develop one project (for example, income generation or access to local transport).

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's activities and by improving the status of disabled people within the community.

### **Examples of Long-Term Aims**

- Improve the situation of disabled people in the community.

- Work with government and other people in power to change legislation and policies to protect the rights and meet the needs of disabled people. [Implement the UNCRPD]
- Develop ways to improve the social and economic chances in disabled people's lives (education, employment, health, information, etc.).
- Conduct 'outreach programmes' that find disabled people, particularly in rural areas, and ask them about their needs.
- Develop self-help projects for the organisation, e.g. a wheelchair workshop, a market stall that sells craftwork made by members or food crops grown by members.
- Explore ideas for income-generating projects, so that the organisation has 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.

## Some important considerations in deciding your aims!

### **i) Remember Equal Opportunities covered in Module 2**

A major aim of any organisation of disabled people is to overcome discrimination against disabled people. Within the organisation and the general community, members work for the equal rights and participation of all disadvantaged people. Stronger members must not discount those who do not think as quickly or speak as loudly or fluently as themselves.

Having recognised our own discrimination, we must not discriminate against others. Disabled people cannot gain true self-determination in the wider community if they oppress other people in order to do so.

### **ii) Participation**

An organisation of disabled people is a people's organisation. It has no need for great bureaucracies, huge numbers of offices and different departments. In that case, it would be taken over and run by the staff in the way that service organisations are. There would be a wide gulf between the leadership and the grassroots members. In a self-help organisation, staff are just people who carry out the wishes of the people who make up the group. This is often organised through committees made up of members.

### **iii) Development, Liberation, Empowerment: Change**

Used in the context of poverty, discrimination, superstition and fear, the word development can be interpreted as liberation (becoming free) and empowerment. As this affects disabled people, it includes freedom from community and institutional oppression, as well as from

hunger and poverty, and empowerment to use the rights and gain the skills and confidence to make choices that affect our lives.

People can only liberate, empower or develop themselves if they are able to understand the things that discriminate against or oppress them. People will use different words and different ways of expressing what these things are. A very important part of developing an organisation is encouraging individual members to identify for themselves the things that need changing.

#### **iv) Principles for Equality & Growth**

Whether they are income-generating schemes, service-providers, campaigning organisations or all three, most organisations of disabled people are concerned with dignity, justice, equality and full participation for all disabled people.

It is useful to think about and discuss a few general principles which should apply to all programmes and policies throughout the organisation.

#### **v) Accountability**

The organisation, its services, programmes and policies should be for the benefit of all disabled people, or, for some programmes, a clearly defined group (such as women members or people with particular impairments). It must meet the stated aims and must be accountable for its actions and the use of funds to members, fulfilling any legal needs.

#### **vi) Accessibility**

The organisation, its services, the place it meets, its programmes and materials should be available to all its target group of disabled people, where and when they want them.

#### **Control**

The organisation and its programmes should be controlled by disabled people themselves. This means that a majority of its management committee or Board are disabled people but also disabled people who understand the **human rights/social model** approach and have been empowered to put this into practice.

#### **vii) Dignity**

The organisation should be based on the idea of rights, not charity. In some countries, you may have to become a 'charity' for legal reasons - this should not interfere with the organisation's 'rights' issues.

#### **viii) Flexibility**

The organisation should be flexible, to meet the changing needs and demands of disabled people.

#### **ix) Image**

The organisation should promote a positive public image of disabled people and the organisation.

**x) Inclusion**

The organisation's activities should aim to encourage and enable disabled people to live inclusively in their community.

**xi) Monitoring and Evaluation**

The organisation should include a good monitoring and evaluation system, which will help to make sure it works well and is accountable.

**xii) Personal development**

The organisation should help members to take part in the life of their community, and should encourage a sense of independence, self-esteem and solidarity.

## Membership and involvement

**i) Who Can Join**

Organisations of disabled people are usually defined as those controlled by a majority of disabled people (at least 51 per cent) at both the board and membership levels.

If disabled people are not in the majority, they cannot control the policies and decision-making. We become disempowered recipients of other people's solutions to our problems.

Some organisations do have relatives or other supporters of disabled people as members. Their impact is valuable and can support the views of disabled people themselves - but it is disabled people who must be in the majority and in control. Where members have learning difficulty, neurodiversity, mental health issues or communication impairments It Is VERY IMPORTANT THAT they encouraged o become self as advocates.

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 take an active part in the programmes and policy-making activities of the organisation:

allowing them to express what they want and what they think, then acting on that rather than deciding what is "for the best".

In some organisations, the workforce, paid or unpaid, are members, though they cannot also be on the management committee. Membership helps someone feel they belong and may make people act more responsibly. Think about the good effects of having disabled people, with the right support, in salaried posts. Organisations should be providing disabled people with good role models.

The Committee of Management should always have a majority of disabled people. a rule about this should appear in the by-laws.

As we discovered in Module 3 DPOs need to take positive action to recruit disabled people with the fullest range of impairments, from hard to reach groups such as ethnic or tribal / caste minorities, ensure women and youth are well represented and geographically remote areas.

#### **ii) Annual General Meetings**

At an annual general meeting (AGM), you can vote for the management committee or board and officer posts. You can maintain contacts between members, run workshops and seminars to educate and inform them and to discuss particular issues of concern to the main aims of your organisation.

#### **iii) Legal Structure**

Organisations of disabled people are usually covered by the same general laws that apply to all cooperative organisations. Find out about registering your organisation and any regulations on trusteeship and charitable status in your country.

#### **iv) General Membership Participation**

Among other things, involvement of grassroots members includes:

- the ordinary support of the work and ideals of the organisation
- service as committee members
- creating awareness in the wider community.

#### **v) Management Committee**

The management committee is elected by the general membership to formulate policy. Officers of the management committee are elected to carry out specific areas of the committee's responsibilities.

#### **vi) Social media and the internet**

can overcome many of the barriers of travel and allow frequent communication and votes and consultations. It is very important to wherever possible to allow a mixture of face to face and internet meetings and remember many disabled people do not have access to this technology. Every effort needs to be made to get disabled people online provide them with the hardware-switches and software they need to communicate. An excellent example in the last few years has been SAFOFD (Southern African Forum of Organisations of Disabled) collaboration with Microsoft to spread the use of this technology. Social media can particularly attract young disabled people, but it can also isolate and individualise. The essence of Disabled People's Organisations is to develop a strong collective voice and this needs to be achieved by an open discussion listening to each other's views to achieve a consensus which also reflects experience.

- vii) **Structure of the organisation** needs to ensure the democracy of decision making and accountability of those who hold elected positions. These are usually in the

Constitution and there must be a means of changing these rules if the majority of voting members agree.

The structure of the organisation needs to be agreed and made available.

### ***Important Considerations***

- Grassroots structure.
- Decentralisation - the power and decision-making shouldn't belong to a small group at the centre of the organisation: power and responsibility must be shared.
- Drawing up a constitution.
- Registering the organisation.
- Deciding who will do what - the functions of executive, officers and committees.
- Elections - how and how often.
- Collective responsibility - everybody has some responsibility.

### **What is Accountability? - Accountability means responsibility**

The first step in making an organisation accountable is agreeing what it expects of its members, elected officials, paid and unpaid staff. These agreements must be written down in the constitution, by-laws and policies of the organisation. They set out the responsibilities and authority of each position, the limit to that authority and when it can be used.

In theory, each elected official and paid and unpaid staff member should be accountable to members for their day-to-day work. In practice this is impossible. Imagine if every phone call, letter or decision had to be approved by every member of the organisation! What usually happens is that members elect their representatives to the board of management at annual general meetings and these representatives run the organisation on behalf of its members.

The key to accountability is good communication at all levels and support for those who need it most -those with difficult jobs to do. A clear understanding of the policies of the organisation and the responsibility of each member is also very important. Willingness to listen to what other people say, making sure discussions are about issues and not personal differences, respect for the decisions of the majority all contribute to good organisational accountability.

There needs to be a cycle of accountability and elections with Annual or General Assemblies of all the constituent organisations. Organisations, especially at National and International level, need a development plan. In framing these development plans, membership should be consulted, but the elected leadership need to identify what the organisation does well and what else needs to be done.

There are a number of ways of doing this. A useful approach is Strengths, Weaknesses, Opportunities and Threats analysis, or SWOT.

## Example of a (SWOT) Strength -Weaknesses-Opportunities-Threats analysis

### Strengths

Five good strong disabled people, with different impairments and experiences.

Have a place to meet.

Some campaigning experience.

A member who can draw posters.

A member with a car.

Three of our committee members have a lot of time to spare.

### Weaknesses

No deaf members.

Very few women in senior positions.

Transport is a problem for everybody.

No one with financial experience.

None of the committee has much time.

No opportunity for information exchange.

### Opportunities

Talking with the local authority.

Setting up projects.

Funding available in the community.

Leadership training available.

### Threats

Charities attract all the funding.

Professionals resent disabled people's progress.

Lack of assertiveness of members.

Antagonism among members.

If you consider these four aspects to the organisation before beginning a project, you can often anticipate problems before they happen.

**Activity C. Carry out a SWOT analysis on a Disabled Person's Organisation you know.**

These activities can then feed into building an Action Plan.

There is a great deal of further useful advice in [DAA Resource Kit 4 Organisation Building](#) which can give you much useful insight and exemplars of this process and how to ensure your DPOs are representative, accountable and built on a firm footing. We will cover Finance and Project Management in Module 5 and representation to Government in Module 6. One area that the Tool Kit covers which is very important for DPO is **Leadership training** (continued after Rasanjali and Mohua)



## Rasanjali Pathirage – Disability Organisations Joint Front, Sri Lanka

“Hello I am president of DOJF Sri Lanka. I am also an Executive Committee member of CDPF. The DOJF is an umbrella body of persons with disabilities established in 2001. The DOJF consists of 36 organisations spread across the country representing all categories of impairment. Namely Physical, Hearing, Visual, Intellectual. The DOJF is registered as a Disabled People’s Organisation. At National Secretariat for persons with disabilities which the National advocacy body on disability and functions under the Ministry of Social Empowerment. The DOJF works for the protection and promotion of the Rights of disabled people ensuring a barrier free , independent life, equity and dignity. Our Executive Committee’s transparent and gives an opportunity for each type of disability [impairment] to represent as Secretary General and President for every 2 years. So we have opportunity for persons with different impairments to be represented as Vice-Presidents in our Executive Committee.

We also join together for all our advocacy and lobbying on Rights of persons with disability. At the same time we also give respective membership and opportunities for Women with disabilities. Executive committee members are selected from organisations ‘of’ and ‘for’ disabled people who are members at local level. We have quarterly Executive Committee and we discuss and take decisions, collaborate project staff and update the progress during these quarterly meetings. We conduct independent international audit and evaluation. Recommendations from audit and evaluation are adapted to improve our service and implementation. Our finance is very much transparent and accessible to any member organisation. We take decisions during an emergency to the Management Committee(MC) which includes the President, Secretary General, Treasurer and two Vice Presidents. The MC meets every month and evaluates the progress of the Action Plan even during the Executive Committee. We have Women with disabilities and Youth with disabilities representation. There are 5 out of 17 members are Women. We advocate and lobby the Government the Rights of persons with disabilities. We support the Government to coordinate the Parliamentary caucus for inclusion of PWDs. We are represented at the National Council that is the highest decision making body on disability issues in the country. We believe Nothing About Us Without Us,  
No One left Behind,  
Inclusion makes positive changes.”

## Mohua Paul, Chair person Access Bangladesh Foundation

“The aim of our DPO is it is a Leading National Organisation established in 2008. In terms of our organisation, we have a dedicated Executive of 9 members, 6 of who are disabled people, 5 females and 4 males. Additionally, our 22 members in General Committee including 17 disabled people with a balanced representation of 11 females and 11 males. We aim to promote inclusion for persons with disabilities and other marginalised people in all spheres of life right through education, training, employment, implementing art and culture, legal service, health care, climate change, information and communication.

Our Executive committee meets on a regular basis to take decisions on implementation and other aspects of the organisation. Careful levels of opinion are reflected in all decision making powers. Our organisation exclusively works for people with different types of disability in selecting participants for events, training sessions, seminars, workshops and symposium. We ensure the participation of persons with all types of disability such as deaf, autism, physical disability, mental illness, visually impaired, intellectual disability, deafblind, Downs Syndrome and multiple disability. In our organisation the method of the Board Members, including women and youth with disabilities take all decisions of the organisation. Currently the Government is working with the Government on implementation of Rights Act for Persons with Disabilities, 2013, the World Disability Summit 2022, other disability related Laws, Policy and for making the Nation inclusive of people with disabilities. We ensure the active participation of all types of persons with disabilities.”

## Leadership Training.

Leadership should not be tied to one person, though it is usually thought of in that way. Leadership is necessary to keep the direction of an organisation and the goals of its activities clear, and to try to reach the goals by using and developing the resources of the organisation in the best possible way. If leadership rests with only one person, the organisation becomes too dependent on that one person.

An ideal situation within a group would be that everyone takes responsibility for the function of leadership. That is only possible in very small organisations. In most cases, as a group grows, there is a group of people with the special task of watching over the leadership function. This is generally the management committee. Taking an officer role can help people learn leadership qualities. It is better that they do not stay as leaders for too long to allow others a chance.

### i) **What Good Leadership Means**

- A deep interest in the aims of the organisation and the ambition to reach them.
- A genuine interest in the people who make up the organisation.
- An active ambition to develop the organisation; to create and respond to change.

Leadership styles taken on by organisations of disabled people must follow the goals of the organisation: to improve disabled people's image of themselves individually and collectively, without detracting from others, and to enable them to press for their rights without fear.

As a leader in an organisation, you of course have to know the aims of the organisation, but you must also understand the reasons for those aims. You need to ask yourself frequently: "Why does our organisation exist? Are my actions and decisions fulfilling that purpose?"

One of the most important tasks of the leadership group is to communicate the aims of the organisation: to try to get as many members as possible to share the organisation's values and understand the aims of its activities. Remember, however, that those aims should also come from the group itself, not be imposed by the leadership.

ii) **Good Leadership Qualities**

- Charisma
- Personal qualities that influence and inspire people.

iii) **Good Communication**

- Between the leadership and the different parts of the organisation.
- Between the different structural levels of the organisation.
- Between individuals within the organisation.

iv) **Responsibility**

A successful leader gives responsibilities to members, creating new possibilities to find solutions to problems.

v) **Appreciation**

The best way to appreciate people is to show genuine interest in what they do.

vi) **Development**

The leadership must accept and fulfil its role as evaluator and educator.

To summarise, for good leadership:

- Remember the group's aims.
- Remember the people.
- Try to develop.

vii) **Important**

Once a decision has been made, it must be communicated to everyone to ensure that everyone knows how to carry it out. Communication must be effective so that people at all

levels are informed and involved. Communication, as well as knowledge, is power. Good communication is essential if power is to be shared.

#### viii) **Training Tomorrow's Leaders**

One reason that many disabled people's organisations grow weak is because their leadership has had no training. It is important for the leaders of any organisation to gain basic knowledge of cooperation and teamwork, programme planning, calling and running meetings and ways of working effectively through committees. Once this knowledge is available within the organisation, it needs to be shared widely, so that the group will have new leaders in the years to come.

One way to do this is to start "human resource" development workshops and "leadership improvement" seminars to help mobilise the resources and expertise available in the community. Leadership training seminars mean that leadership emerges and develops, rather than allowing the existing leadership to stay in positions of permanent power, putting the grassroots membership in a position of permanent dependence. A membership that challenges and changes its leadership can be a sign of a very well-run organisation.

Leaders themselves need to be trained to listen rather than just to speak. Organisations need to have channels of communication with their members that allow everyone to take part in decision-making processes. The training policy should create ways of teaching members the principles of management by participation and consensus.

#### ix) **Secondment or Exchanges**

Secondment is a good way of developing an organisation, by allowing a staff-member to spend time in another organisation, or by bringing in someone with specific skills to train members within the organisation. It is important that secondment should benefit all members of the organisation not just the person who visits the other organisation or the people who work with the outsider.

**Activity D. What do you consider the most important features of Leadership in the Disability Movement and Why?**

#### **Commonwealth Charter**

[The Commonwealth Charter](#) is a document of the values and aspirations which unite the Commonwealth. Created and agreed in 2012 and agreed by all member countries it expresses the commitment of member states to the development of free and democratic societies and the promotion of peace and prosperity to improve the lives of all the people of the Commonwealth. The Charter also acknowledges the role of civil society in supporting

the goals and values of the Commonwealth. This includes the Commonwealth Disabled Peoples Forum[CRPD].

The Charters preamble goes on to say

“Recognising that in an era of changing economic circumstances and uncertainty, new trade and economic patterns, unprecedented threats to peace and security, and a surge in popular demands for democracy, human rights and broadened economic opportunities, the potential of and need for the Commonwealth – as a compelling force for good and as an effective network for co-operation and for promoting development – has never been greater,

Recalling that the Commonwealth is a voluntary association of independent and equal sovereign states, each responsible for its own policies, consulting and co-operating in the common interests of our peoples and in the promotion of international understanding and world peace, and influencing international society to the benefit of all through the pursuit of common principles and values,

Affirming that the special strength of the Commonwealth lies in the combination of our diversity and our shared inheritance in language, culture and the rule of law; and bound together by shared history and tradition; by respect for all states and peoples; by shared values and principles and by concern for the vulnerable”

“The vulnerable” is an ‘old-style’, medical model concept that refers to ‘old, infirm and destitute’ people. It does not view disabled people as active citizens who are subjects who must have the primary say in how their lives must be improved. It does not take a human right approach to disabled people, though drawn up 6 years after the UNCRPD was agreed.

While of course the CRPD supports the principles of the Charter: Democracy, Human Rights, International peace and Security, Tolerance, respect and understanding, Freedom of Expression, Separation of Powers the integrity of Legislative, Executive and Judiciary leading to the Rule of Law, the promotion and protection of fundamental Human Rights and Good Governance, Sustainable Development, Protecting the Environment, Access to Health, Education, Food and Shelter, Gender Equality, Importance of Young People, Recognition of the Needs of Small States and Vulnerable States and the Role of Civil Society plays in our communities and countries as partners in promoting and supporting Commonwealth values and principles, including the freedom of association and peaceful assembly, and in achieving development goals.

However, since becoming an accredited Commonwealth Association the CDPF has become increasingly concerned that disability equality and rights is mainly paid “lip service” to, with no disabled speakers at Commonwealth events, no disability equality training for staff or

Commonwealth Governments, lack of understanding of reasonable accommodation and accessibility at Ministerial Meetings and Forums.

We considered including disability in a list of equality issues that require a mainstreaming approach to be in the Commonwealth Heads of Government CHOGM Statement to be issued in Samoa in October 2024. Instead, we are promoting and campaigning for Governments to support the adoption of the

[Commonwealth Disability Inclusion Protocol and Strategy](#).

## **Activity E. Consider what you can do to get your Government to support the Commonwealth Disability Inclusion Protocol.**

### **Participation of Disabled People in Politics and Democracy**

Article 29 of UNCRPD is also another area that is vital to disabled people and their DPOs. Not only to remove the barriers and stigma against disabled people exercising their democratic rights in free and fair elections without corruption and intimidation, but also to ensure that representative are elected at every level from local district and regional councils to the national parliament.

UNCRPD [Article 29 – Participation in political and public life](#)

“ States Parties shall guarantee to persons with disabilities political rights and the opportunity to enjoy them on an equal basis with others, and shall undertake:

a) To ensure that persons with disabilities can effectively and fully participate in political and public life on an equal basis with others, directly or through freely chosen representatives, including the right and opportunity for persons with disabilities to vote and be elected, inter alia, by:

i. Ensuring that voting procedures, facilities and materials are appropriate, accessible and easy to understand and use;

ii. Protecting the right of persons with disabilities to vote by secret ballot in elections and public referendums without intimidation, and to stand for elections, to effectively hold office and perform all public functions at all levels of government, facilitating the use of assistive and new technologies where appropriate;

iii. Guaranteeing the free expression of the will of persons with disabilities as electors and to this end, where necessary, at their request, allowing assistance in voting by a person of their own choice;

b) To promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs, including:

- i. Participation in non-governmental organizations and associations concerned with the public and political life of the country, and in the activities and administration of political parties;
- ii. Forming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels”.

**Activity F. What are the barriers in the electoral system that reduce the power and voice of disabled people and how might they be changed in your country? Disabled People and their DPOs need to be involved continuously in Co-Producing State Services for them.**

Where services for disabled people are provided by Government, at whatever level, disabled people need to be involved in **coproducing those services**. A good example of building and putting this strategy into practice come from the London Borough (Local Council) of Hammersmith and Fulham where the Council funded [Nothing About Disabled People Without Disabled People : Working Together To Change Servicicers](#) Report 21017. By involving local disabled people in identifying barriers and finding solutions a co-produced Action Plan was produced that fundamentally improved service delivery to disabled people. This work was led a 10 person Disabled People’s Commission . The role out was negatively impacted both by COVID 19 and Central Government cuts to Council budgets.

Disabled People’s Commission: Who we are and how we work In December 2015 on the International Day of Disabled people, Hammersmith and Fulham Council agreed to work closely with Disabled residents, this means people who live in Hammersmith and Fulham. We took the chance to set up what we believe, is the first local Disabled People’s Commission in the country. We aim to work together to build a culture that values, respects and pushes for the rights of Disabled people living in Hammersmith and Fulham. "Nothing About Disabled People Without Disabled People”. All ten Disabled People’s Commission commissioners are Disabled people who face many different barriers in their daily lives. They all live in Hammersmith and Fulham. The way we carried out this work:  
Stage 1: We looked at research and examples of co-production (working together).

Stage 2: We carried out surveys to find out what Disabled people thought. We also did surveys for Councillors and Council staff.

Stage 3: We ran meetings and events to get information about people’s experience of decision making and co-production.

Stage 4: We used the information that we got to write a report with our findings and recommendations, this means what we think should happen.



Watch the summary video ['Nothing About Disabled People Without Disabled People' - accessible summary video](#)

**Activity G. Suggest ways that the methods set out here in a Council in a high Income country based on the principles in the UNCRPD could be adapted to working in your locality.**

Full report as submitted to Cabinet

- ['Nothing About Disabled People Without Disabled People' \(pdf 2.1MB\)](#)

Videos from Hammersmith and Fulham

- [Click here to watch our three videos](#)

The picture on the next page is a poster from Hammersmith and Fulham. It says the following:

**Key Findings:** Many say the quality of life has gone down; some feel they don't have a voice in local decisions; councillors and staff want to work better with disabled residents.

**Recommendations:** Work in a Human Rights way; agree to coproduction (working together); skill up to work together better; write a communication strategy (plan) for co-production; write a budget (money plan); strengthen DPOs; make services deliver what disabled residents want; monitor (check) the work.

# Nothing About Disabled People Without Disabled People

Working Together To Change Public  
Services In Hammersmith & Fulham.

## Key Findings

Many say  
quality of life  
has gone  
down



Some feel they  
don't have a  
voice in local  
decisions



Councillors &  
staff want to  
work  
better  
with  
disabled  
residents



## Recommendations

Work in a  
human rights  
way



Agree to  
coproduction  
(working together)



Skill up  
to  
work  
better  
together



Write a  
communication  
strategy (plan)  
for Co-production

Strengthen  
Disabled  
Peoples  
Organisations (DPOs)



Make  
services  
deliver  
what disabled  
residents want

Write a  
budget  
(money plan)



Monitor  
(check) the  
work

Report by the Disabled People's Commission  
Hammersmith and Fulham, November 2017.



## Useful Film Clips

Voting is for Everyone Australian Electoral Commission 17.43 2018

<https://youtu.be/H8ISaEn95mg>

Commonwealth Parliamentary Association The Barriers People with Disabilities Face when voting <https://www.youtube.com/watch?v=2KDnhCXxg9E> March 2022

USA Electoral Assistance Commission 2002 <https://youtu.be/8jLH0Ay7R4s>

Kenya Q&A with Stanley Mtoma <https://youtu.be/DKweWhsS900> 2017. 3.52.

IDA Side Event CSP 2022 Disability Inclusive Democracy: Building Participatory Societies

<https://youtu.be/dfXlktzdtr8>

The political rights of persons with [disabilities](#) Parliamentary Assembly of the Council of Europe.

## Appendix 1: New Zealand DPO Coalition Attributes

The New Zealand DPO Coalition developed a checklist of attributes an organisation should have to qualify it as a Disabled Persons' Organisation. It is important to note that these attributes were developed for the New Zealand context, and not all may be applicable in an different contexts but could be useful in developing a similar list here.

1. The organisation has a legal existence i.e. must demonstrate it exists as a group of individuals with certain rules that bind them to a common purpose or goal
2. The organisation has a national structure and focus. If the organisation has a regional focus, it demonstrates that there is no national organisation that speaks on behalf of its members
3. The organisation upholds and promotes the philosophy that people with disabilities have the right to participate collectively in decisions that impact on our lives  
(Nothing about Us without Us)
4. The organisation's primary goal, objectives and operations reflect and support the primary purpose of the Convention
5. The organisation functions effectively and demonstrates it is putting into practice its constitutional requirements
6. The organisation may focus on a single disability or it may be a multi-disability organisation. It is open to all disabled people who meet its membership criteria

7. The organisation must be governed by a significant majority of disabled people who reflect its community of interest and meet its membership criteria
8. Only disabled people who meet the organisation's membership criteria may elect and vote for its governing body
9. A significant majority of the organisation's members are disabled and reflect its community of interest
10. The organisation demonstrates that it has a mandate or authority to speak on behalf of its members and this remains paramount over any other obligations including direct service provision
11. The organisation responds to and is driven by the collective voice of its disabled members who reflect its community of interest
12. The organisation demonstrates that it has strong links to its members throughout the country, or throughout the region for a regional organisation
13. The organisation has a variety of ways to ensure its members are informed of key decisions at both a local and national level