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Commonwealth Disabled People's Forum Disabled Youth Leadership

Course Module 3

Building DPOs -Ensuring Equity within the Disabled People's Movement – Impairment, Sex, Ethnicity, Age, Class, Rural/Urban, etc.

Introduction

by Kerryann Ifill, Vice-Chair of the Commonwealth Disabled People's Forum. "I come from Barbados in Caribbean and am also President of the Barbados Council of the Disabled. We are a cross impairment Organisation representing the views of our members to Government. We are a national umbrella organisation. Meaning that in our membership are 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, neurodiverse or learning difficulty.

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

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

Our **theme today** and this Month is:

Building DPOs -Ensuring Equity within the Disabled People's Movement – Impairment, Sex, Ethnicity, Age, Class, Rural/Urban etc

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**'.

RECAP

We focused in September on the Paradigm Shift (Recap). As you now know, this means the transition away from:

a) **negative culturally based ideas and attitudes**, 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 'powerhouse' of our transforming our lives.

We have to do it together, collectively. This was the theme of October.

We looked at the dynamics of building campaigns together from in the local village or town right up to National, getting disability rights-based legislation and implementing it.

These campaigns have led us to the 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.

From Isolation to Solidarity.

A summary of what we are examining today could be from Isolation to Solidarity. What is essential for all of us with different impairments, life experiences and backgrounds to come together to be the most effective as DPOs in achieving our aim **to bring about implementation of the UNCRPD and developing Disability Equality.**

Disablism is the oppression that still dominates the world where disabled people (people with a wide variety of impairments) are disabled by the cultural norms and attitudes, organisation of society and the resultant environments all make us less than we could be. We call this oppression Disablism. Though it is worldwide it manifests in different forms. We as people with impairments whether we are born with them or acquire them, whether they

are physical or mental, whether they are visible or invisible, we experience these individually.

‘From the moment a child is born, he/she emerges into a world where he/she receives messages that to be disabled is to be less than, a world where disability may be tolerated but in the final instance, is inherently negative. We are all, regardless of our status, shaped and formed by the politics of disablism’.

Our socialisation, in these circumstances leads to our internalising these negative views:

“Internalized oppression is not the cause of our mistreatment; it is the result of our mistreatment. It would not exist without the real external oppression that forms the social climate in which we exist. Once oppression has been internalized, little force is needed to keep us submissive. We harbour inside ourselves the pain and the memories, the fears and the confusions, the negative self-images and the low expectations, turning them into weapons with which to re-injure ourselves, every day of our lives.” Marks¹

Our first job in building our Movement has to be to help each other overcome the impact of our disabling world on how we view ourselves. **Our confidence and self-image** are often disempowered. Overcoming isolation, we have to empower each other.

Let me tell you the ways we have done this in Barbados through our Barbados Council of the Disabled.

“Ways we have done this in **Barbados** through our **Barbados Council for the Disabled (BCD)**. First, BCD is made up of member organisations. We have over 20 organisations under our umbrella which cover the spectrum of impairments. From among these members, we elect a Board of Directors which advises and governs the policy of the BCD. These members cover the ambit or cross section of impairments as well as being reinforced by Ex-Officio (non-voting) representatives of Government institutions. Next, we have a network of Sub-Committees made up from our Board and our very qualified Secretariat (who are disabled and non-disabled people) all work together to expand our programmes and change the lives of disabled people. We carry out surveys, conduct public engagement activity. We work to develop services for ourselves to empower ourselves. When the Government in 2017 passed legislation making it illegal to park in disabled parking places without a permit, the BCD became the body that issued parking permits. Hold regular meetings with our members, sit in and share how they are developing. It is not just a top-down or bottom-up approach, but it is a cross-sectional approach where we understand what happens in each organisation where others can show -up and assist each other. Where for example, we come to understand what is happening in the community of the Deaf people, as Blind people and

¹ Marks, D. (1999). *Disability: Controversial debates and psychosocial perspectives*. Taylor & Francis/Routledge.p25

can mutually support each other. This leads to a collection of voices speaking together. All of this is important and we do it through training so we can all understand what we do and how we do it”.

My impairment is Blindness. Let me tell you the things I need. **Good Manners or Disability Etiquette** to include **Blind and visually impaired people** in your organisation.

1. Ensure if you are inviting me as a blind person to your activities that you provide accessible information, whether it is electronic, Braille or large print, whether I ask for a Reader or a support aide. These are the things I need to participate in your meetings having come informed. Make sure you share that information with me ahead of time, so that I can read in up in my preferred format.
2. Greet me at the door. Explain to me where I am going. Where I am sitting. Who is sitting beside me. What the room is like. Ask me if there is anything else I need. So that I can feel comfortable and confident in the room. If I don't know where I am, if I don't know who is around me, then I am vulnerable.
3. If you are holding an event with ushers/attendant/support workers around the room make sure they are trained and understand how to facilitate the needs. Make sure you get the lighting right for example with low vision. Don't see the same in every situation.
4. Make sure you have proper lighting, clear pathways without bags/coats on the ground or sticking out that might be an obstruction. As I use my cane, I want to be able to navigate. Yes, it helps me get around, but you too can help me by making sure those obstacles are not there.
5. Most importantly ask what I need. Don't assume.
6. Don't grab hold of my arm or my cane, or any walking aid.
7. If I happen to be using a service animal, do not approach animal.
8. Do not speak to the person who may be accompanying me. Speak directly to me.
9. Involve me in your activities.
10. Do not hold activities and programmes and make me feel I am an after-thought. Don't say 'Oh dear I forget to get it in Braille, we will send it to you afterwards.'
11. Don't create activities that I can't participate in equally.
12. Always remember persons who are blind or visually impaired have a voice. Often a strident one. Let us share amongst the meeting.

Now over to Richard Rieser, our General Secretary, to unpack the other essential ingredients to building successful cross impairment Disabled People's Organisations, with the help of contributions from a range of disabled people across the Commonwealth.

We need to make any coming together of Disabled People a positive experience.

Experienced campaigners and others new to trying to act collectively, to change and improve our position as disabled people in society.

Respect This means treating each other and ourselves with respect.

The internalised oppression many of us have grown up with often reduces how welcome we are of difference. Many disabled young people end not wanting to have anything to do with other disabled people, or if they have hidden impairments 'passing'. Disablist society says 'overcome your impairments'-They also make not ask for what we need. E.g., fear of being helped. Fear of being in a wheelchair, for ambulant impaired people. As Micheline Mason puts it:

"Internalized oppression is not the cause of our mistreatment, it is the result of our mistreatment. It would not exist without the real external oppression that forms the social climate in which we exist. Once oppression has been internalised, little force is needed to keep us submissive. We harbour inside ourselves the pain and the memories, the fears and the confusions, the negative self-images and the low expectations, turning them into weapons with which to reinjure ourselves, every day of our lives." ²

The idea of being 'normal' is really strong, even when it is obvious we have physical or mental differences to the majority population. As I used to think as an infantile polio survivor that it is easier to walk around with a lopsided gait, to fall sometimes and stand in pain for long periods than have a chair or in my earlier days even a walking stick. I remember I was in my 30s, when my partner said why are you in such a state and I replied, "Well I'm standing here". And she said, "Why aren't you sitting down". I said, "Well it doesn't look very manly." And she said, "Don't be ridiculous. You need a chair and that's what you need." And she then went on to convince me that I needed a wheelchair and I'd been brought up to overcome my impairment. That's what the Physios and Rehab experts told you. And of course, they are completely wrong because a wheelchair, a stick, crutches or a cane is an aide³. So we need to be happy about using our aides and appliances and reasonable accommodations. Under the UNCRPD these are now a Human Right for Disabled People.

'ASKING FOR YOUR ACCESS NEEDS IS AN ACT OF PERSONAL LIBERATION'

If you aren't asking for your own access needs, you are hardly going to change the world for other disabled people. It means ensuring equality by analysing what the impairment-based access accommodations and supports that disabled participants need to function. In any group of disabled people, it means becoming familiar with each other's access needs and if possible, learning how to accommodate and where possible meet them.

The In from the Cold Collective in the UK 45 years ago had to challenge isolation and learn to accommodate each other's needs, whether wheelchair users, Deaf People, Blind people, Mental Health Survivors, Neurodiverse, coming physically together, so that we can really

² Micheline Mason p 28 in R. Rieser & M. Mason (1990) Disability Equality in the Classroom, ILEA
http://worldofinclusion.com/res/deinclass/text_only.pdf

³Disability Oppression How it Seems to Me' R. Rieser in Disability Equality in the Classroom R Rieser & M Mason, 1990 ILEA, London <https://disability-studies.leeds.ac.uk/library/author/rieser.richard/>

form the unity we need to challenge and change the oppressive disablist society we live in. When resources are scarce, particularly when starting up, we can use each other's collective skills, such as non-deaf people learning signing or at least finger spelling.

Later we shall go through examples of access needs for different impairment groups. We also, as in **Appendix to these Module 3** course notes, will list some common key points of Disability Etiquette for different impairment groups.

All our organisations should seek to embed the principles of the UNCRPD into the way we build and develop our organisations:

- Respect for inherent dignity and individual autonomy.
- Non-discrimination.
- Full and effective participation and inclusion in society.
- Respect for difference and acceptance of disabled people as part of human diversity and humanity.
- Equality of opportunity.
- Accessibility.
- Equality between men and women.
- Respect for the evolving capacities of disabled children and respect for the right of disabled children to preserve their identity.

This doesn't mean treating each other equally. It means ensuring equality by analysing what the impairment-based access, cultural, religious, language, social and economic differences might be that are internalised by people and come out in their discourse.

One way to handle this is by jointly creating **Ground Rules** or more formally **Standing Orders** that ensure these differences are addressed. So, for instance:

- One person speaking at a time.
- Not speaking again until everyone who wants to speak has spoken.
- Taking speakers to ensure gender balance.
- Allowing sufficient time for people to use their chosen means of communication.
- Confidentiality so that participants can talk about their experiences and not have them spread around.
- Respecting each other's experience and views, whilst amicably arguing different perspectives.

Some of the barriers we face are societal:

The language we converse in. We use English in CDPF as the official language of the Commonwealth, but we must recognise the first language of participants and find ways of including them. Translation using the expression and idiom of the local culture. The nearer we get to the grassroots the more we need to use the language of the people whether it be Urdu, Hindi, Bangla, Swahili, and a whole range of other languages. We need translation, not just off the web, but reflecting local expression and idiom.

Caste/Class Example in many parts of South Asia, caste is seen as pre-determining of people's social status. We must work against this to create forums where all can communicate their views and ideas on an equal level.

Sexism is deeply dominant. Embedded in most societies, where boys and men have been used to seeing themselves as superior to girls and women, objectifying them to satisfy their sexual desires.

Creating a space for Disabled Women and Girls to meet together without men and boys, is a necessary way for disabled girls and women to work out their views, demands and give non-oppressive solidarity to each other.

However, women and girls need to function within the wider Disability Movement with disabled men and boys in cross sectional umbrella DPOs or local organisations. The males need to take responsibility for their sexist behaviour such as speaking over women, treating them disrespectfully or in sexualised/abusive manner. For much more detail on the issues and inclusion of disabled women and girls go to:-

<https://commonwealthdpf.org/training/disability-equality-capacity-building/module-10/>

CDPF has an active Women's Forum and they have put forward the **CDPF Women's Declaration**

https://commonwealthdpf.org/wp-content/uploads/2023/03/CDPF-WOMEN-DECLARATION-Version-1-24_03_23-1.docx

which CDPF Women's Representatives used to make presentations at the March 2023 [Commission on the Status of Women.](#)

2023 13th Commonwealth Women's Affairs Meeting in the Bahamas in August 2023

<https://thecommonwealth.org/events/13th-commonwealth-womens-affairs-ministers-meeting>

(Clip 1: Patience Ogolo Dickson, Nigeria.)

How the society is stratified by caste, tribe or cultural group or social class will vary, but some things are dominant like **Sexism** we briefly examined above.

Racism Power and prejudice based against those with skin colour and other bodily features and ethnic differences has a long history of exploitation, de-humanising, and subjugation.

Racism in post-colonial countries with a significant settler population of Europeans, racism and devaluing first peoples is a major issue that needs addressing centrally, especially because levels of impairment are higher due to their treatment. This is true in Canadian First Nation, New Zealand Maori, Australian Aborigines and Torres Strait Islanders, where first Nations need their own organisations and umbrella DPOs need to make accommodations and welcome their participation. The Umbrella DPOs members need to challenge their own racist thinking which they may have imbibed from the dominant views

in society, including the British slave trade started by the Stuart Kings which ran for 400 years. At a similar time, the Spanish did the same thing in Latin America, Caribbean and so did the French.

Due to Indigenous People's social situation, as well as psychological impact of being on the receiving end of racism, often leads to alcoholism and mental health issues.

We're going to see a clip now from First People's Australian Network which is an Australian DPO, an associate of ours, and I think makes a lot of these points.

Clip 2: First Peoples Network Australia, June Reimer, the experience of First Nations disabled people in Australia.

Where tribal/racial differences exist, effort needs to be made to include tribal and ethnic minorities or in post racist societies such as South Africa effort needs to be made to make DPOs reflective of the majority population. There's much to be done to challenge these divisions in our society, and other countries, such as tribal groups in India, need to be thought about, in Kenya, many places across the Commonwealth.

To find out more about this watch the presentation

<https://commonwealthdpf.org/training/disability-equality-capacity-building/module-11/>

Youth Let us turn to including Youth first with a clip from Kihembo Wilbert. Kihembo is non-verbal and relies on using information technology, which he has a diploma in, to communicate with a support worker voicing for him.

Clip 3: Kihembo Wilbert, Voice of Youth Uganda & Youth Representative on CDPF Executive.

As we have said before, the Commonwealth Disabled People's Movement is dominated by older people. We need their experience and wisdom, but also need to create space for Disabled Youth Fora, Empowerment Groups and Networks; to provide training, such as on this course and more intense Training the Trainer Courses, where disabled youth learn to train on the paradigm shift and develop such courses with their own input of experience and understandings.

- Young disabled people need to be made to feel welcome.
- Have their needs met.
- Be given space on the mainstream DPO agenda.
- Have their experience, ideas, and interests (especially environmental) respected.
- Often it is useful to support the setting up of separate Young Disabled People's Networks and Associations.
- To exercise positive action to make sure representatives on the Umbrella DPO Boards or Executives.

The CDPF Youth Forum has deliberated and put forward a Youth Manifesto for Commonwealth Year of Youth

<https://commonwealthdpf.org/manifesto-for-commonwealth-year-of-youth/>

To help us understand the dynamics of this, I turn to Doctor Miro Griffith who is a disabled activist but also a post-doctoral researcher at Leeds University.

He is a policy creator, currently working on disability youth across Europe as a project, so let's have a look at what Miro has to say. You will need to listen carefully to this, because he's more academic than some of the other explanations.

Clip 4: Dr Miro Griffiths, Leeds University.

Miro mentioned *intersectionality* and many young people using Post-Modernist thinking based on Foucault and others favour a model of multiple identities and oppressions. Such as sexual orientation (i.e., Lesbian, Gay, Bisexual), Transgender and 'Black Lives Matter'.

In the CDPF our respect will include those who identify with these experiential movements, but we are fundamentally a **Social model organisation** that is about building a Social Movement of all people with impairments-long term loss of physical or mental function and disabled by the social, cultural, attitudinal, communication and organisational barriers in our countries, who as a result of having an impairment identify as disabled. Today 55 of the 56 Commonwealth countries have ratified the UNCRPD which gives us a wide agenda to organise on for **full implementation of the UNCRPD and for disability equality**.

We heard from Kerryann at the beginning about what Blind and visually impaired people need. Now we shall hear from Rachel Chomba, a CDPF Executive member representing Africa from Zambia on the needs of Deaf People.

Clip 5: Rachel Chomba (CDPF Executive) on Including Deaf People.

A group that has been particularly marginalised within the Disability Movement are DeafBlind we will now hear Simate Simate, a DeafBlind activist from Zambia, on what you need to do to include DeafBlind people.

Clip 6 Simate Simate, DeafBlind Activist Zambia.

There are too many different impairing conditions for us to go through all their needs and accommodations, but as a basic way forward ask the person what they need and don't just accept if they say nothing. Many people need more time, rest breaks, plain language, dietary needs, supportive relations, especially those with hidden impairments where because we cannot see their impairment, we assume they don't have needs.

Neurodiversity has only in recent years been identified as a group of impairing conditions such as Autism, Attention Deficit Disorder, Attention Deficit Hyperactivity disorder, Dyslexia and Dyspraxia. Let us now hear from Dr Emile Gouws CDPF Executive Officer for **Intellectual**

Disability and under-represented groups and a self-advocate for disabled people and some colleagues with autism in South Africa.

Clip 7: Dr Emile Gouws and autistic colleagues South Africa.

Psychosocial conditions coming under the label of Mental Health issues are an example where the '**Medical model**' approach is still predominant, reinforced by traditional stigma. Here in particular many countries are finding it difficult to introduce **assisted decision making** in line with Article 12 of UNCRPD. Rose Umutesi from the CDPF Exec. and National Organisation of Users and Survivors of Psychiatry, Rwanda will fill us in.

Clip 8: Rose Umutesi Mental Health Survivors.

Overcoming traditional prejudices is nowhere more serious than when it comes to disabled children and their parents. Convincing parents to stand up for their disabled child's right to education, health and other rights, is clearly shown here in Dharavi slum in Mumbai, India, the largest in Asia. Here ADAPT/ Mumbai Inclusion centre filmed their methods to challenge parental attitudinal barriers; going door-to-door, convincing parents that their child can do things, would benefit from education and using street theatre and other methods, to convince residents in the community.

Clip 9: Mil Julke Dharavi, Mumbai, India <https://m.youtube.com/watch?v=vCG8HZXxmZk>
Community Based Rehabilitation (CBR) based on the UNCRPD can be a powerful stimulus for action on including children and debunking their so called 'special needs' which often acts to keep them separate. See the diagram below⁴.

Rural Areas in Majority World Countries

Though there have been some improvement where particular NGO led projects have been, research has established disabled people in rural areas are characterised⁵ by:

- Disabled people are often left out of rural development strategies and programmes, which leads not only to their exclusion from initiatives but also their marginalization in community decision-making.
- Policies for disability inclusion do not always exist, and where they do exist, they are not always implemented. For example, staff of rural training centres and employment programmes and services may lack the capacity to serve disabled people. Disabled people may also lack access to information about community services and programmes, or about their rights to participate.
- Many rural disabled people have limited or no access to transportation, and rural roads and buildings are often not accessible to those with physical or visual impairments.

⁴ 23 Disability and community-based rehabilitation in Setting up Community Health and Development Programmes in Low and Middle Income Settings (4 edn), Oxford University Press <https://doi.org/10.1093/med/9780198806653.003.0023>

⁵ https://www.ilo.org/wcmsp5/groups/public/---ed_emp/documents/publication/wcms_159006.pdf

- Rural disabled people are largely excluded from existing disability services, such as vocational rehabilitation services, which tend to be located in urban areas.
- Rural schools and training centres are scarce, they lack the necessary assistive devices, and their training approaches are often not geared for diverse learners.
- Disabled People are often excluded from basic education and therefore do not meet the entry requirements of formal vocational training programmes, such as literacy skills. This affects their chances of finding decent jobs.
- Negative attitudes and stereotypes about the abilities of disabled people emanating from society and sometimes the family can lead to discrimination. Community development schemes often disregard disabled people because of negative, mistaken assumptions about their ability to participate.

Disabled People's Organisations in rural areas need to develop the confidence and capacity to address the above disparities.

1. Develop a small cadre of disability activists who understand disability rights from 'social model' perspective.
2. Learn to meet each other's communication and access needs.
3. Educate the local community to challenge stigma and show what disabled people can do.
4. Recruit family members and local community to support your campaign aims as long as the disabled people stay in control.
5. Campaign to get resources into the area for inclusive and empowering projects.
6. Put forward representatives for local public decision-making bodies/elections.
7. Use radio and other media to get your message across.

Challenge notions of special needs with inclusive approaches as in diagram below.

CBR is a strategy that can be useful focusing on providing equal opportunities to disabled people so they can participate in community life.⁴ Ensure local DPOs are empowered to be powerful partners in this process working with health and education workers. In doing this, CBR enhances quality of life. When CBR was first developed in the 1980s, it centred on providing access to community-level health and therapy. CBR has since evolved to address access to education, employment, and social services. To achieve such changes, we must engage at multiple levels with the following groups:

- Disabled people and their families.
- The local community and their leaders.
- Government departments and health services; and
- Educational and employment institutions⁶.

⁶ <https://academic.oup.com/book/25049/chapter/189171800>

Any CBR-inspired programme should be based on the principles outlined in the UNCRPD ⁷.

The picture below says, 'A disabled child growing up has the same needs as other children' and then illustrates the following points: for play, respect, friendship and love, helping and work, adventure and testing of limits, school and other forms of group learning and taking part in community activities.



Rural and Urban: Sarah Kamau, the CDPF Chair, from United Disabled Persons Kenya now tells us how they set about overcoming the divide between rural and urban groups of disabled people.

Conclusion

I hope from all of that you have got more of an understanding of how we build

⁷ United Nations. *Convention on the Rights of Persons with Disabilities*. 2006. Available from: <http://www.un.org/disabilities/convention/conventionfull.shtml>

cross-impairment DPOs as clearly our strength is greater together than being in separate impairment only organisations.

Because disability and disablism is created by society, the consequence of picking out one group from another by impairment, is a recipe for divide and rule. We have to be united as cross impairment disability groups.

The history of disabled people organising is that when we get together, we can achieve great things. I was lucky to be part of the Disability Caucus during the latter years in New York when we made the UN Convention(2001 to 2006). It was only because we had 80+ different organisations from round the world working together as DPOs, to put forward amendments to what the diplomats were thinking of putting in that Convention, that we have a Convention that is fit for purpose. It's not perfect, which is why you need to look at the General Comments, which keep coming from the UNCRPD Committee.

<https://www.ohchr.org/en/treaty-bodies/crpd>

Nevertheless, it was a real paradigm shift as we have said. We also need to learn from the organisation of some impairment groups, particularly blind and deaf people, who got organised long before other people and did get priority treatment because of that. Now we have to address impairment world-wide and unite.

We need in disabled people's organisations to function democratically (which we will examine in Module 4) but be impairment friendly. So as Kerryann said if she doesn't feel comfortable in the room, she can't really participate. We need to make sure that each person's impairment needs are being met. For that reason, at the end of the notes, there will be much more detail of the type of etiquette or good manners to different people with different impairments you need to know and practice.

We need to challenge prejudice and abusive behaviour, amongst our members. We can't allow the normative views of women, race, of even indeed in many of our countries' homophobic views, which are not really conducive to allowing all people to come together in our movement.

We also need to reverse the hierarchies in society, inside our movement.

We can't just reintroduce them, because for instance high caste people have always run things in India, so they are the only people who run disability organisations. Social relations are important. We are not primarily social clubs, but political organisations and when I mean political it's with the small 'p'. We're not party political, but we are about changing the world and that is about making our will felt and therefore it is political.

We should have clear aims.

We should never lose sight of our objectives, be deflected, be co-opted into Government because they offer us nice jobs.

We need to beware of setting ourselves up as a silo, we need to be open to the constituency we represent.

For umbrella organisations, it is all disabled people in that country/district/region.

We need to think about groups we have not yet got in touch and brought in, we need to find ways of bringing them in. Beware of silos!

We may also become service providers, as you heard the Barbados Council officiates parking places in Barbados, but we need to keep our **independence** from Government.

We can work with Government, but we need to be a separate voice for those we represent and not be coopted into Government.

Remember!!!

“If you always do what you have always done, you will always get what you have always got... Be the change.”

Or as Gandhi said, "Be the Change You Want to See in Society".

Module 3 Tasks

After studying the presentation, this text and the Appendix, try and complete the following tasks:-

- 1) For a DPO you know in your country, find out and briefly write answers to the following:
 - a) How did it start?
 - b) When did it form and who was involved?
 - c) What were the main aims?
 - d) Who does the DPO represent?
 - e) What has it achieved?
 - f) What are some difficulties the DPO has faced?
 - g) What should the DPO do to develop its influence and membership?

- 2) Put forward a set of 6 ground rules for DPO meetings and for each ground rule briefly say why you think this is important enough to be included.
- 3) You arrive in a new part of your country and after enquiring, find there are no DPOs to represent disabled people.
 - h) What 3 actions would you undertake to set up a new DPO and why?
 - i) You are organising the first meeting with few resources, other than a free community centre. What would be your key considerations to set up a successful meeting for a cross impairment group?
 - j) How would you judge if the meeting was successful?
 - k) What would be the next things you should do to build a representative DPO?

Appendix: Good Manners to Disabled People or Disability Etiquette⁸.

Involving people with mobility impairments

- When talking with a wheelchair user, either get a chair and sit down or ask if they prefer you to stand or crouch. If you do stand, do not tower over people – looking up can result in a stiff neck. Stand a little way away so that you can have a conversation eye to eye, on an equal level.
- Prior to inviting wheelchair users to a building, obtain information about the access to that building. Provide the wheelchair user with the information, so that they can make a decision about whether or not the building will be accessible to them as an individual. If the building is not accessible, you should not use it.
- A wheelchair is part of the “body space” of the person using it. Do not lean on it unless you would usually lean on the person themselves.
- If you wish to speak to the Personal Assistant of the wheelchair user, request permission and make sure that you do not place yourself in a position that excludes the disabled person from the conversation.
- In public places or offices, ensure that items are not left lying around on the floor. Make sure there are adequate spaces for people to get around and that access is safe for everyone.

Crutch or stick users:

- For some stick or crutch users, stairs may be difficult. Where you have alternative access for wheelchair users, consider asking if when using sticks or crutches they would find this more convenient.
- People who need sticks or crutches may find it hard to use their hands when standing up, for example, to count money, or to fill in a form.
- At events where people are standing, provide chairs and stools so they can choose to use them if in pain or fatigued.

⁸ User Involvement Tool Kit – Disability Etiquette Guide Mary MacManus (2011) Dorset County Council

Involving people who are D/deaf, deafened and hard of hearing

- D/deaf culture describes the social beliefs, art, literary traditions, history, values, and shared institutions of Deaf people who use a sign language. When used in this cultural sense, the word 'deaf' is often capitalised in writing, and referred to as 'big D Deaf'. Culturally Deaf people tend to/may often view 'deafness' as a difference in human experience rather than a disability. Deaf culture therefore does not automatically include all people who are deaf or have a hearing loss. Like most cultures, the exact boundaries of Deaf culture are contested. For example, perennial questions arise as to where hearing people who have Deaf parents and sign fluently fit in.
- Some people with hearing impairments are not BSL users. They might use a combination of lip reading / lip speakers or might wear hearing aids. It is therefore important to make sure you establish what each individual's preferred method of communication is and ensure that this is made available prior to activities/meetings.

General Etiquette

- The usual etiquette for getting someone's attention is to tap them lightly on the arm, between the shoulder and the elbow. We suggest you take guidance from the SL interpreter or the Deaf people at the event as to the best way to call people to attention.
- Always speak directly to the person, never to a third party.
- Speak in a natural, conversational tone. It is not necessary to speak loudly or to over-enunciate.
- Be aware that effective communication via written notes has limitation; SL has a very different structure from English or the Community Language, and D/deaf people may therefore have limited literacy skills in English or the Community Language.
- Make direct eye contact. Natural facial expressions and gestures will provide important information to your conversation.
- When talking, do not allow your face and mouth to be obscured. Avoid holding things near your mouth - eating, smoking or waving your hands in front of your face - these things can be distracting.
- Bright and dark places can be a barrier to clear communication. Good lighting is important, but keep in mind the glare factor and do not stand in front of a bright window.
- Ensure that background noise is kept to a minimum.
- If a person is lip reading, speak clearly and slowly but do not exaggerate your speech. Be aware that lip reading has its limitations, as many words look the same on the lips, and even the best lip reader would only be able to lip read 50-60% of what is being said.

- If a word or phrase is not understood, rephrase it by using different words with the same meaning.
- Changing the topic of conversation abruptly can cause confusion. Use transitional phrases between topics, such as “let’s talk about exams now”.

Working with Sign Language interpreters and lip speakers

- If a person uses a Sign Language (SL) interpreter, address your comments and questions to the Deaf person, not the interpreter.
- Always speak in a natural, conversational tone. The interpreter will tell you if something needs to be repeated or if you need to slow down.
- Normally, the SL interpreter sits opposite the Deaf person. Depending on the situation, however, the Deaf person will be able to advise on the best arrangement for effective communication.
- Interpreting is physically and mentally demanding so plan for frequent breaks. Generally, a SL interpreter working alone should have 10mins break in every half hour. However, this may vary for individuals and type of event, so do discuss this with the BSL interpreter beforehand.
- It is useful to provide any written material to the interpreter in advance of a meeting so that they can familiarise themselves with details about the meeting.
- Find a suitable place to talk, with good lighting, away from noise and distractions.
- Remember not to turn your face away from a D/deaf person. Always turn to your listener so they can see your face.
- Check that the person you're talking to can follow you. Be patient and take the time to communicate properly.
- Use plain language and don't waffle. Avoid jargon and unfamiliar abbreviations.

Involving people who are visually impaired

- First of all, identify yourself clearly, and then introduce anyone else who is present and where they are placed in the room.
- Ask the person if they require any assistance and, if so, how best this should be provided.
- When offering a handshake, say something to indicate that you wish to shake hands.
- When meeting someone out of their home or in their workplace, ask what central point they are familiar with and arrange to meet them there. Please ensure you arrive at the agreed time and make your presence known when they arrive by introducing yourself.
- When offering a seat, speak to the person through the process (chair on right, left, back of you, etc) and place the person's hand on the back or the arm of the chair, so that they are aware of the position of it.
- At the end of a conversation, do not just leave. Say when you wish to end a conversation, or when you are moving away.

- If you are running a meeting or an activity that visually impaired people will be attending, make sure that materials are prepared in advance in accessible formats so that everyone has the same access to the information available. Ensure that you ask the attendees what format they would like it in, for example, large print, Braille or if it is helpful to have the information emailed to them in advance.
- Always say what you want, as gestures are useless communication tools to most visually impaired people.
- Always talk to the visually impaired person and not to his or her guide or support worker.
- If a visually impaired person attends a meeting or an event without a guide or support worker, then ensure that assistance with refreshments and locating the toilets is offered even if they do have a guide dog/white stick.
- Do not interact with a guide dog without prior agreement of the visually impaired person. These are working dogs and some people prefer that you do not pet them.

Making information accessible to people with visual impairments

Some designs can be unclear, confusing and difficult to read for many people, including people with visual impairments. The Royal National Institute of Blind People (RNIB) has produced 'Clear Print Guidelines'⁹ to help avoid this. Top tips for achieving Clear Print:

- Document text size should be 12-14 point, preferably 14 pt and capable to expand to 16-20 point.
- The font you choose should be clear, avoiding anything stylised.
- All body text should be left aligned.
- Use bold sparingly, only highlight a few words rather than a paragraph.
- Keep the text layout clear, simple and consistent.
- Don't use blocks of capitalised letters and try not to use any italics or underlining.
- Text shouldn't be overlaid on images.
- The substrate or coatings should not be glossy or reflective.
- The contrast between the text and background is as high as possible.
- All text should be the same orientation on the page.
- Space between columns of text is large enough to be distinct.
- Any information conveyed in visuals or colour use Alt text or audio description.
- Word processed documents save as a Word Document, not a PDF, so Screen readers can work.

Involving people who have learning difficulties

- Don't make assumptions.
- Position yourself at the same level.
- Position yourself so that the person can see your face.

⁹ For further information about Clear Print, see RNIB's See it Right book, contact: accessibleinfo@rnib.org.uk or visit www.rnib.org.uk

- Keep your hands away from face.
- Never shout.
- Use simple words and sentences.
- Always check information has been understood.
- Minimise background noise wherever possible.
- Don't use jargon.
- Don't talk too fast.
- Take time to listen and understand.
- Explain things very clearly.
- Speak to the person and not their support worker.
- Don't be afraid to ask people to repeat themselves. Tell them that you did not understand.
- Don't pretend that you have understood what was said when in fact you didn't.
- Don't assume that people will be able to find another point of advice. You might need to give some extra support.
- Go back over the information. Say the main points again.
- Use a variety of information support tools, such as pictures. For example, draw a clock with time when arranging a meeting or talking about a start, open or close time.
- Documents should be Easy Read in plain language with pictograms.

Involving people with speech impairments

- Make eye contact and be especially attentive with a person who has difficulty speaking or who uses a communicator.
- Wait quietly and listen whilst the person talks.
- Resist the temptation to speak for the person, or to finish their sentences.
- Some people may prefer to be asked questions that require either a short answer, or a nod or shake of the head. Offer this option if it is appropriate to the situation or ask if they will write down words or phrases you are having difficulty understanding.
- Be sure you understand fully what the person means before making any assumptions.
- It can be helpful to say what you have understood and ask the person to confirm or clarify.
- If you don't understand what is being said, don't be afraid or embarrassed to ask the person to repeat it, maybe several times.
- Don't make assumptions about the person's hearing or intellect just because he or she has difficulty speaking.
- If the area is noisy, take account of this and, if possible, move to a quieter area.
- Lack of time is often the biggest barrier.

Involving people who have mental health issues:

- Do not make assumptions.
- Ask people what is the best way for them to work with you?
- Do not have events or meetings in the early morning.

- Ask people if they require a reminder about your meeting.

Making information accessible.

All people benefit from information that is in plain English and concise. However, as mentioned above, it should be noted that medication and fatigue issues linked to some long-term health conditions can sometimes limit concentration span, and some people may also feel overwhelmed by an excess of information.

- Send information in advance so that groups can meet to discuss the issues you need help with.
- When planning your activity, think about regular breaks.

Accessibility for autism¹⁰

When presenting information to autistic people, be mindful that not all autistic people have the same accessibility needs. Some autistic people experience sensory overload more than others and in different ways.

Common causes of sensory overload in autistic people include:

- Too many noises being made at the same time.
- Bright colours or extreme colour clashes e.g. bright yellow on a white background.
- Getting too much information at once.
- Too many things happening in the background.

Many of these apply to websites, printed and digital documents. Some of those examples can also happen in phone calls, video calls and face-to face meetings.

Websites and apps

To make a website or app autistic-friendly, these steps are worth taking:

- If possible, use a pastel background colour for each page of your website or app.
- If you can, install an accessibility plug-in that will let users change font size and background colours. For WordPress.org websites, WP Accessibility is widely-used.
- Have a clear drop-down menu where all the main pages on your website are just one click away.
- Have panels on homepages and landing pages leading to key pages e.g. to any referral form pages you have.

¹⁰ Making information accessible for neurodivergent people Leeds Autism AIM part of Advonet
<https://www.wypartnership.co.uk/application/files/3716/4735/6437/making-information-accessible-for-neurodivergent-people-final-v2-20.04.21.pdf> With lots more information and links about access for different forms of neuro diversity.

- Use a sans-serif font for your body text. These are easier to read. Century Gothic, Arial, Calibri and Verdana are good examples.

Digital documents – PDFs, Word docs, spreadsheets

For any written documents, PDFs, spreadsheets and slideshows, these steps are worth considering:

- Pastel backgrounds work well.
- Clear, concise language is a must. This is especially true if trying to explain something that is complicated like making a membership form.
- Make your documents easy to navigate. For longer documents, please use page numbers and headings.
- For documents with different sections, set them up so when clicking on a Contents page item, they go to that point of the document.
- Tick/check boxes for forms are useful to save time for the person filling them in.
- Line spacing of at least 1.15, spacing between paragraphs is useful for breaking up text.
- For spreadsheets, have the top row or first column frozen so it appears when scrolling.
- In spreadsheets, it is worth using alternating colours for different columns. This makes it easier to find the stat or number needed.

Print documents – leaflets, posters, flyers

These steps are worth bearing in mind for producing any printed resources:

- Where possible, using pastel-coloured backgrounds can make text more readable. If you can, use these colours for printing out notes, newsletters and so on.
- Increased line spacing of at least 1.15 can make it easier to read text.
- For A4 newsletters, use no more than three columns per sheet.
- For A5 leaflets and flyers, use no more than two columns per sheet. If possible, stick to one column.
- If you are making a folded leaflet, make them bi-fold. Tri-fold leaflets can be confusing for some people to navigate.

Verbal information – phone calls, video calls and face-to-face meetings

When speaking to autistic people in person, on the phone or via video call:

- Be clear and concise. Try not to talk too much.
- Use concrete language – say what you mean e.g. “The COVID vaccine comes in two doses.”

- Do not expect the person to maintain eye contact throughout. For some autistic people, eye contact can be quite painful to make.
- Make sure there is little to no background noise when you are speaking. If there is background noise, it can be hard for them to filter out what you are saying.
- For appointments, please give a specific time for when you will speak. Then, the person you are calling will be less surprised and taken aback when you call.
- Find out what works for the person you are speaking to. Give them a choice – video call, phone call, face-to-face meeting or text chat.
- Try not to come across as patronising or condescending when speaking to an autistic person via video call or on the phone.
- If you are going to be late to a meeting, keep the person informed. This is useful in case they are anxious that you won't be there.