



Training on the Inclusion of Persons with Disabilities in EU Development Cooperation

Course Notes

Module 6: Key stakeholders to achieving disability-inclusive development

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Development Cooperation.**

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Module 6: Key stakeholders to achieving disability-inclusive development

The United Nations referenced in module 7 discusses the need for a no gap policy in order for success in achieving disability inclusive development. It recognised that achieving inclusion of persons with disabilities in development does not solely come through one entity rather there is a need for a variety of actors to be involved. This module focuses on civil society as one of these actors and the role it plays in inclusive development.

Civil society is comprised of a wide range of groups these include disability groups, human rights group and allies from different social justice movements. To-date civil society has played an instrumental role in the development of the Convention on the Rights of Persons with Disabilities and since its adoption, it continues to feature under a number of different roles e.g. advocacy, service providers, human rights monitoring. Article 32 on International Cooperation along with other articles identifies clear roles for civil society in working for the implementation of the Convention. The following sections introduce the different kinds of groups working within civil society with a focus on disability. These include (1) Disabled Persons Organisations (2) Organisations working on behalf of persons with disabilities and (3) Human Rights organisations with a focus on disability.

1. Disabled Persons Organisations:

A Disabled Persons Organisations (DPOs) has no universal definition however they are recognised as organisations where the leadership comprises of persons with disabilities. The Disability Rights Fund who prioritize DPOs in their funding portfolio describe DPO's as "representative organizations or groups of persons with disabilities (PWDs), where persons with disabilities constitute a majority of the overall staff and board, and are well-represented in all levels of the organization. It includes organizations of relatives of persons with disabilities (only those representing children with disabilities, people with intellectual disabilities, or the deaf blind) where a primary aim of

these organizations is empowerment and the growth of self-advocacy of persons with disabilities”¹

Disabled Peoples' International (DPI) a global disability organisation considers the role of organizations of disabled people to be the most fundamental issue for the disabled person's movement.² The reasoning behind this is two-fold. Firstly that DPO's represent and voice the concerns and needs of people with disabilities. Secondly, DPOs play an important role at local, national and international levels for people with disabilities, governments, service providers and the general public.

In many countries, DPOs are the first point of contact for any agency or organisation wanting to find out more about barriers facing persons with disabilities. Also they are point of contact for agencies that want to consult with people with disabilities. After all, disabled people, from their own personal experiences best know their needs, aspirations and abilities. Additionally, the presence of DPOs at consultation or meetings brings legitimacy as discussed above they represent the voice of persons with disabilities (discussed in Module 7). See Annex I for tips on how to ensure access and inclusion for persons with disabilities in meeting and consultations. See also Box 6.1 below, which gives details on how AusAID supports building DPO's.

Box 6.1 AusAID providing support to build strong effective DPO's³

An important early initiative under Development for All has been assisting DPOs to strengthen their capacity to deliver on their

¹ See the Disability Rights Fund <http://www.disabilityrightsfund.org/node/35>

² See The Role of Organizations of Disabled People: A Disabled Peoples International Discussion Paper

³ See the Development for All – Towards a disability inclusive Australian Aid programme 2009 – 2014: Achievement highlights – the first two years
<http://www.ausaid.gov.au/Publications/Documents/disabilityachievementhighlights.pdf>

mandate to drive more equitable development.

1. In 2009, Australia provided \$150 000 to people with disability and their representative organisations in Cambodia to strengthen capacity in rural provinces and provide opportunities to develop leadership skills. Around 80 people with disability received leadership training in 2009–10, including provincial members. More than 60 people with disability are enrolled in English language courses, which will enable them to apply for Australian Development Scholarships in 2012.

2. Australia has partnered with the Government of New Zealand to support the Pacific Disability Forum, the Pacific region's umbrella DPO. Since 2009, Australia's support of \$450 000 is enabling the forum to increase the scale and effectiveness of its activities. These include strengthening members' capacity to raise awareness of disability rights and to provide advice to governments on policies and budgets to ensure equal access and full participation by people with disability.

There are a wide variety of different types of DPO, ranging from 'impairment specific' groups, whose members share (or are concerned by) a particular impairment, to cross-disability organisations with members with a wide variety of impairments. They can exist at different levels, from grassroots to global and can sometimes be concerned with specific issues such as gender, youth, sport, entrepreneurship or HIV for example. See Box 6.2 below for examples.

Box 6.2: Illustrated examples of the range and scope of different types of DPOs:⁴

Impairment specific – national level	Uganda National Association of the Deaf (UNAD); Psychiatric Survivors Association, Fiji
Impairment specific – global level	World Blind Union / World Federation of the Deaf
Cross-impairment – national level	Federation of Disabled Peoples' Organisations of Malawi (FEDOMA); Nuanua O Le Alofa (NOLA - Samoa); National Union of Disabled Persons of Uganda (NUDIPU); Cambodia Disabled Peoples' Organisation (CDPO)
Cross – impairment – regional level	Pacific Disability Forum (PDF); Southern Africa Federation of the Disabled (SAFOD)
Cross – impairment - global	Disabled Peoples' International
Grassroots / self-help groups	Kandal Steung Disabled People's Development Organisation (Cambodia); Protibondhi Narider Jatio Parisad (Bangladesh)
Parents organisations	Silent Voices (organisation of parents with deaf children in Uganda);
Women with disabilities	Association for Women with Disabilities, India (AWWD); Association des Femmes Vivant avec Handicap de Bouaké (AFevHB), Côte

⁴ Adapted from Make Development Inclusive Material, see <http://www.make-development-inclusive.org/tools.php?spk=en>

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Example of DPO Activities

DPOs engage in a wide range of different activities many of which bring direct benefits to their members (or impairment groups). The methods they use however tend to be fairly similar.

Core activities include:

- *Psycho-social support* to members and their families (providing a sense of identity and a space in which key problems can be talked about);
- *Impairment based support* – ranging from sign language and mobility training to provision of sunscreen and access to information on potential medical interventions;
- *Awareness raising and sensitisation* – with families, communities, leaders and service providers (especially education + health) on the need to respect people with disability;
- *Mobilisation* – with people with disability themselves to enable them to understand they are members of communities with rights (CRPD is providing a natural focal point for this);
- *Branch development* – training in basic leadership, financial stewardship, planning, reporting and fundraising;
- *Annual events* across the country in support of specific issues like International Day of Disabled Persons (December 3rd).

Along with the variety of the activities of DPO's there is also variance in how they function ranging from weak to strong. In some contexts (such as Uganda, or Philippines) there are relatively well developed DPOs that are used to working with government and development agencies. However in many cases DPOs are quite weak, even in comparison to other civil society organisations and may require a more targeted approach to help bring them into development discussions. In terms of creating opportunities for discussion with DPO's, issues such as access must be considered. See Annex 1 to this module, which gives guidelines on this. The benefits are considerable however, because once the agency establishes a trusting relationship with DPOs they will open up the possibilities for connections to people with disabilities across a whole range of sectors.

1.1. (2) Organisations working on behalf of persons with disabilities

- 1.2. Along with DPO's there are a variety of organisations that work with or on behalf of persons with disabilities. These include Pro-Disability Organisations (PDOs) and disability focused agencies.

1.3. Pro-Disability Organisations (PDO):

- 1.4. The main characteristic of a PDO is that they work alongside people with disability and focus their activities on issues, which are directly relevant to them. These are not membership organisations (which is what distinguishes them from DPOs) but operate as NGOs providing services, information or training for example to people with a disability. Many are staffed and managed by people with disabilities themselves often as volunteers who have particular skills and experiences, which they are keen to share.

Some of them are impairment related in the programs they offer – for example organisations that provide Community Based Rehabilitation (CBR). Others are issues or skills-based such as those providing specialist legal services, education facilities or research and information.

They can be important supporters of DPOs helping to build organisational capacity, raise awareness over rights and help accompany them as they lobby government for inclusion. In situations where DPOs are small and struggle to secure funding, PDOs act as intermediaries to help channel resources. For an example of such an organisation see Box 6.3 below which gives details of a foundation in Finland established by persons with disabilities which provides small grants to DPO's and self help groups of persons with disabilities in the Global South.

Box 6.3: The Abilis Foundation⁵

The Abilis foundation operates through granting small grants to grassroots/self help disabled people's organisations in the South and currently has over 280 projects in 43 countries. The foundation receives its funding from the Ministry of Foreign Affairs in Finland. The projects funded by Abilis are split between (1) income/poverty reduction and (2) advocacy and awareness raising on disability rights (3) Organisational Development.

(1) Income generation (poverty reduction) including different types of employment projects; projects with vocational training followed by some type of business. Abilis annual report 2008 indicated that 42% of projects were linked directly to poverty reduction.

(2) Advocacy and awareness raising including awareness raising campaigns and events material production on advocacy; Human Rights projects including basic human rights training, the UN convention, translation of material, training on the Convention trainings and seminars on advocacy work for DPOs lobbying activities.

(3) Organizational development including establishment of Disabled People's Organizations or Self Help Groups empowerment of disabled persons; international seminars and conferences

Disability Focused agencies:

These are agencies such as NGOs, faith based organisations or even private companies that provide direct services to people with disabilities and increasingly, also provide support to disability organisations so they can become more effective advocacy agents. They can provide specialised services (such as hearing assessments, rehabilitation or prosthetics) or inclusive services (such as livelihood programs, health or education programs) that are designed to be

⁵ To see more about the Abilis Foundation, please go to http://www.abilis.fi/index.php?option=com_content&view=article&id=9&Itemid=18&lang=en

accessible to people with disabilities. Many are also involved in helping build the capacity of organisations of disabled people (DPOs) as well as helping to raise awareness, challenge discrimination and support advocacy initiatives.

The key roles of these agencies are to reduce the impact of impairments (through support to the provision of healthcare, rehabilitation, educational or livelihoods services, improving environmental accessibility, research and development, advocacy) and to support persons with disabilities to access their rights.

See Box 6.4 below highlighting the work of a disability focused agencies⁶

CBM:

With its partner organisations, CBM seeks to build and promote an inclusive world in which all persons with disabilities enjoy their human rights and achieve their full potential. This is to be achieved in three ways (1) working together with partner organisations, CBM supports health care for existing disability and prevention of condition with can lead to disability (2) CBM seeks to improve access to health care, education and rehabilitation and (3) CBM aims to mainstream disability into all aspects of development and empower persons with disabilities to take an active role in their communities through inclusion in development projects and involvement in community initiatives.

Light for the World:

Light for the World provides access to treatment and rehabilitation for persons with disabilities by supporting local partner

⁶ Information adapted by cbm website <http://www.cbm.org> and Light for the World <http://www.light-for-the-world.org>

organisations. We also commit ourselves to the task of creating new opportunities for persons with disabilities, to increase mobility with the help of devices, to start initiatives that will provide education and income, and to support people with disabilities to exercise their rights

In addition, Light for the World is committed to raising awareness of the situation of persons with disabilities within their family, communities and national contexts, as well as within the wider development agenda. This is an important basis for social inclusion and for the autonomy and self-determination of persons with disabilities.

1.5.

(3) Mainstream Organisations with a Disability Portfolio

Over recent years since the adoption of the CRPD there have been a number of mainstream organisations that include a disability focus. A good example of this is Human Rights Watch who appointed a staff person on disability rights and advocacy in 2008. This person is responsible for monitoring developments in the field of disability rights, investigating and reporting on discrimination and human rights violations against persons with disabilities worldwide, and carrying out global advocacy initiatives. See Box 6.5 below, which gives details on Human Rights Watch work on disability and the variety of reports, which have been published on disability rights.

Box 6.5 Human Rights Watch Reporting on Disability Rights⁷

⁷ Reports from Human Rights Watch on Disability Rights can be found at <http://www.hrw.org/topic/disability-rights>

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"Like a Death Sentence"

Abuses against Persons with Mental Disabilities in Ghana



"I Want to be a Citizen Just like Any Other"

Barriers to Political Participation for People with Disabilities in Peru



Futures Stolen

Barriers to Education for Children with Disabilities in Nepal



Annex 1: Access and inclusion of people with disabilities in meetings, consultations and events⁸

2. INTRODUCTION

As discussed in module 2, a number of barriers exist that prevent the inclusion of people with disabilities in mainstream work. The most basic of these is giving effective access to meetings, consultation processes and events to people with different impairments. This information sheet contains practical advice on how to ensure access happens in these processes.

PREPARATION: setting the scene in meetings

Know your audience – check beforehand whether anyone with an impairment – mobility, sight, hearing, speech or understanding – will be coming and make necessary provisions.

Assess physical access – is the venue close enough for people with mobility impairments? Is it accessible to people who find it hard to walk or who use crutches or a wheelchair? Is it on a slope or hill or with rough paths? Is it on the ground floor? Are there many stairs? Will they be able to use facilities like toilets, cafeteria and discussion rooms independently?

Assess sensory access – for lip-readers, ensure there is enough light in the room and seating is arranged accordingly. Make sure sign language interpreters are booked in advance and are accepted by the Deaf participants. Use of drawings and written word can help clarify and confirm points made. For people with visual impairments, make sure they are familiar with the venue. Always ask people to state their names before talking so everyone knows who is speaking.

⁸ Authors: Sue Coe & Lorraine Wapling.

Describe verbally any visual aids used.

Assess cognitive access – ensure people with mild to moderate intellectual impairments are also included. The key is simple language, short messages, patience and repetition as necessary.

Adapt sessions – think about any activities and exercises that rely upon the ability to move around, see, hear or speak. Consider how someone with a physical, visual, hearing or intellectual impairment will participate. Usually, you'll be able to find ways of adjusting the activity with a little creativity. The important thing is to ensure everyone is included and can participate.

Connect locally – locate any representative organisations of disabled people (DPOs). Could they help you contact disabled people in the area? Consider employing local disabled people. They will encourage others to participate. Identify and support disability champions at all levels. If unsure about whether your plans are accessible, ask DPO representatives for advice.

PROGRAMME DESIGN: activities for all

Identify disabled people – the percentage of disabled people in any programme, activity or consultation should aim to match – and arguably exceed – the estimated percentage of disabled people in the community. It is important to establish the numbers of disabled people in the project area from the outset.

Consult stakeholders – locate disability services and schemes to establish links for referrals of support. Find out if there are community-based rehabilitation (CBR) programmes in the area, as you may be asked for help with these services. Accessing aids, appliances or services can be an important part in enabling disabled people to participate.

Budget for inclusion – ensure a standard line for costs of disability access/inclusion within all budgets as a fixed percentage (two to five per cent) of activities or overall costs to cover interpreters, guides, transport, materials, adaptations to premises/facilities/equipment, etc.

PRACTICAL ENGAGEMENT: removing stigma

Ask about disabled people – when you first go to a village and ask leaders about disabled people, don't be surprised if you're told there are none or very few. This is a typical response. People may be embarrassed and consider disability a source of shame. The key is patience, perseverance and persistence. You may need to come back and talk to the village chief again. You may need to call a community meeting. Appoint a disabled staff member to help in introductory meetings.

Visit homes – make house-to-house visits, introducing yourself and your organisation's plans. When asking whether any family members are disabled, at first you may be told "no". Often it will take several visits before you've earned sufficient trust. All of this behaviour is typical. Superstition, suspicion and scepticism mean many families don't want others to know about disabled people – or think because nothing can be done for them, there is no point in trying.

Build confidence – disabled people often think no one wants to hear their opinions and their views don't matter. It takes more than one or two short meetings to overcome a lifetime of being ignored. One way of challenging negative attitudes and mobilising disabled people is using other disabled people in your work – ideally within your own staff but also as external resources.

Take time – patience, understanding and sensitivity are needed, particularly at the beginning. However, it does get easier once staff acquire the skills and confidence to interact – and as disabled people

see others like them actively participating and benefitting from your programme.

CHECK LIST FOR EVENTS⁹

1. Publicise your event in places familiar to disabled people, for example through local Disabled People's Organisations (DPOs).
2. Provide interpreters and communication support workers with papers and information on meetings in advance so they are prepared.
3. Pay attention to contrast and type size in visual advertisements for people with low vision- it needs to be larger font and good colour contrast.
4. Choose a venue centrally located and easy for people to reach.
5. Consider arranging transport for disabled participants as inadequate public transport could prevent their attendance.
6. If disabled people coming to the meeting require personal assistance support, offer to pay for the time and travel costs of the person attending with them.
7. Have someone waiting at the main entrance to direct people to the meeting room.
8. Make sure the event meeting space is accessible for all participants.
9. Make sure staff and volunteers know what accessible features are available in the building (ramps, toilets etc.).
10. Ask all presenters and participants what accommodations or modifications they require.

⁹ Authors: Sue Coe & Lorraine Wapling.

11. Make sure there are no obstructions – such as chairs, tables – blocking major pathways to and in the room.
12. Have good lighting in the room especially for those with low vision and hearing impairments.
13. Prepare alternative formats of materials – for example provide handouts on a memory stick or CD in Word format. Make visual aids tactile by using string.
14. If using sign language interpreters, make sure they're positioned in a good place – check with the Deaf participants if their location is suitable.