

## **4. DPOs in the Promotion and Protection of Human Rights**

### **Learning Goals**

The participants will gain a basic knowledge of:

- The role of organizations of people with disabilities in processes of individual, social and community empowerment

### **4.1 Role and Values of Organizations of people with disabilities**

#### **4.1.1 An organization as a voice for people with disabilities**

*The process of change in the reading of disability developed over the past 30 years, thanks to the growth of the movement of people with disabilities in awareness and their ability to represent their own needs and rights. The process was extremely rapid and it transformed cultural approaches, policies, social services and appropriate technological solutions. This process was made possible in large part by the development of organizations of people with disabilities and their parents. Creating one's own organization, which is independent, united and able to represent all disabilities, is an important step towards achieving the goal of social inclusion.*

#### **4.1.2 An organization based on human rights**

*Organizations of people with disabilities and their parents must be able to create and develop associations that, even in their internal dealings, operate on the basis of human rights principles. Many organizations base themselves on the direct leadership of people with disabilities and their relatives (where the people with disabilities are unable to represent themselves), by guaranteeing that these people are the majority in leadership bodies and among the members. Internal democracy, representation, respect for gender and minority equality, the direct participation of people with disabilities, the empowerment of members and people with disabilities, capacity for dialogue with public and private institutions, competence in various fields, freedom of information, forms of protection, the continual education and training of leaders, care for people: the more the values and principles of human rights can be brought to life within the organization, the more it will be able to protect human rights in all initiatives. In recent years umbrella organizations have been formed by associations and/or their coordinating organizations, aiming to bring together with a single voice the plethora of organizations that protect people with disabilities. The aim is to face the institutions and forces of civil society with greater negotiating power.*

*This path surpasses corporate models of representation and enriches discussion and the ability to put forward new ideas. Networking thus becomes important both within and outside the organization, including connections with international networks. The Convention itself produces a new type of action for the organizations, because the human-rights based approach is universal and includes all the different disabilities: all leaders of organizations of people with disabilities will need to be competent in human rights.*

## **4.2 Empowerment of Organizations of people with disabilities**

### **4.2.1 Organization and democracy**

*Building an organization of people with disabilities and their families means being based on principles of democracy and representation, which consists of shared rules, transparency and the balance of powers. It is important that the people with disabilities are themselves the key players in the life of the association and, where they cannot represent themselves (because they are minors or are not in a fit condition to represent themselves), that their parents are their representatives. For centuries other people have spoken in our name, creating a society that has excluded us. At the same time it is equally important to guarantee the independence of the organization from political parties and institutions, to ensure that choices and decisions can be made free of inappropriate ties. The protection of human rights can in fact be contradictory to the management of certain services; it is however compatible with information, education and consulting services. Another important consideration is the need for an organizational structure that can act effectively, bearing in mind the different institutional levels that must be dealt with (many states have national, state, provincial and local governments, so dialogue must be carried out at all levels).*

### **4.2.2 Action plans**

*To achieve effective action and assess the results achieved, it is important to draw up an Action Plan for the organization, which identifies priorities for action, deadlines, methods and tools for pursuing aims. The Action Plan is drafted using democratic procedures that involve the members and, if possible, also friends of the organization. The Action Plan is also a tool for public awareness-raising, gathering together social forces that can support our efforts and involving civil society. It is important to link the Action Plan to the country's general development strategies, with particular attention - in the case of developing countries - to PRSPs, which are designed to eradicate poverty. The Action Plan will also be more effective if tied to the MDGs.*

### **4.2.3 Fundraising**

*To ensure the organization's independence and autonomy it is necessary to develop effective and ethical fundraising activities and sustainable initiatives. To this end, as well as the traditional support from membership fees, organizations must know how to carry out intervention projects and programmes using public and private funds.*

### **4.2.4 Organizational development strategies**

*Organizations need to develop the ability to monitor and assess their abilities, by identifying strengths and weaknesses and developing a strategy for strengthening and developing the organization and its planning mechanisms. It is useful to do a SWOT analysis of the organization involved in the course. The development strategy will be more effective if it is able to make the most of the organization's strengths and deal with its weaknesses. The more the organization views itself as a single organism able to grow and adapt to new needs, the more its activities will be effective and self-aware.*

### **4.2.5 Monitoring activities**

*To make the realization of the Action Plan and the organization's activities effective it is important to develop internal systems for monitoring the progress of the plan and the activities, tools and methods chosen to support it. Having clear aims makes the monitoring process easier. Monitoring shall be carried out while keeping in mind the organizational structure of the association, the contents of its Action Plan, the everyday operation of the organization, the tools available, and national and local working methods. This can be done while making all levels of the association aware of the monitoring activities, through periodical reports, organizational meetings, internal audits and performance indicators.*

### **4.2.6 Networking and information**

*To allow the organization to act swiftly and appropriately in all areas it is vital to create good networks and exchange information. Networking is not just another area of action, but a strategic playing field for strengthening organizations of people with disabilities and their families. Networking allows an organization to activate all its available resources and make them effective in protecting human rights. It is important to find ways to continually stimulate the network, both within and outside the organization. The circulation and spread of information is an important tool in this regard. Constructing an information system capable of gathering information on human rights protection at the local and national levels and spreading it among members and beneficiaries is vital.*

*The stimulation of the network must facilitate the direct participation of the entire organization, by provoking the members to become active and skilled in the area in which they work. It is equally important to keep up to date with what is happening at the international level by keeping in touch with the network of international organizations. It is therefore essential to educate people in languages and provide appropriate instruments for communication and working.*

#### **4.2.7 Education and training**

*It is also important to provide ongoing education and training for the association's members and leaders. Indeed, teaching about rights and evolving opportunities for their protection and promotion, good practices, innovative projects and new regulations is a good way to ensure the effectiveness of the organization's activities. Education and training must of course be focused and coordinated with the organization's monitoring system, Action Plan and development policies.*

### **4.3 Empowerment of People with Disabilities**

#### **4.3.1 The concept of empowerment**

*There are various interpretations of the concept of "empowerment" in a liberal context and in social sciences. The word itself has two meanings: the strengthening of capacities and the acquisition of power. The social impoverishment that people with disabilities have undergone must be counterbalanced by actions that offer growth in awareness and abilities, the reacquisition of a recognized social and political space and the acquisition of the power to confront institutions and propose solutions. Empowerment can occur at the level of individuals, communities or societies.*

#### **4.3.2 Action for individual empowerment**

##### **4.3.2.1 Advocacy**

*One typical individual empowerment action is advocacy, which involves informing, orienting and supporting the rights of people with disabilities. Advocacy can be carried out through services such as information counters, the formation of groups of experts on various topics in support of sufferers of human rights violations, panels of lawyers specializing in disability for legal action.*

*Advocacy requires the presence of experts in the various areas who are familiar with the relevant subject matter and can offer people with disabilities information, protection mechanisms and connections to community resources in support of their rights. Advocacy activities must be closely linked to other social and individual empowerment activities.*

#### **4.3.2.2 Networking**

*Networking lies on the border between individual and social empowerment. Having started out as a way of linking people interested in the same areas of action and knowledge, it has progressively transformed into a tool which - when used appropriately - is a motor for building the organization, developing joint activities and adding value to the resources of the individual and the network. The swift transfer of information, exchange of experiences and good practices, enhancement of skills in the network and teamwork are the most important aspects of networking. This strategy increasingly requires the training of specialized workers in the stimulation and development of network abilities and skills, who are constantly kept up to date.*

#### **4.3.2.3 Peer counseling**

*The action of raising people's awareness of their own condition can be developed almost exclusively by people with disabilities themselves. This means that more self-aware, adequately trained people with disabilities who are included in society can support the path to awareness of other people with disabilities: this activity is known as "peer counselling" and has become an essential tool for action and a genuine political and technical occupation. A central role in empowerment is played by peer counselors: people with disabilities who support other people with disabilities on their path to autonomy and self-determination. Theoretical references go back to humanistic psychology and, in particular, Rogers and Carkhuff's "client-centred therapy." These authors identified self-help among peers as an extremely effective tool. By "peer" they meant someone in the same situation, of the same age, culture and background or with the same life experience. In the case of people with disabilities a "peer" is someone who has a disability. Originating in the United States of America, peer counselling spread first to Europe and then to other parts of the world, adapting to different cultures and situations. Many organizations of people with disabilities have developed skills in this field, producing books and manuals.*

## 4.4 Social and Community Empowerment

### 4.4.1 Community based rehabilitation

*The CBR strategy was conceived and promoted by the WHO and other UN agencies towards the beginning of the 1980s for the rehabilitation of people with disabilities in developing countries who lacked access to services; since these countries had limited resources for ensuring high-quality institutional services, emphasis was placed on developing a method that could broadly cover needs at limited cost. Having originated within the WHO it was clearly health-focused; the WHO recommended that CBR be made a part of basic health care and focused its energies on the recovery of functional abilities so that individuals with disabilities could be integrated back into their own communities. However, CBR arose just after the Declaration of Alma-Ata (1978), which radically changed the concept of illness and health by highlighting the importance of the individual and the community in policies and in carrying out health-related action. The WHO has a broad view of the concept of health, which is not simply the absence of illness. In consequence, CBR came into contact with the new concept of rehabilitation, which was not limited solely to medical rehabilitation. The new concept of rehabilitation highlighted the importance of coordinating medical, social, educational and professional training aspects for the optimization of the abilities of the person with disabilities within the community. CBR currently presents itself as a development strategy based on the respect for human rights; it considers the individual as a whole and complex being in order to achieve equal opportunities and the full participation of people with disabilities in their families, communities and societies. "CBR is a strategy within general community development for the rehabilitation, equalization of opportunities and social inclusion of all people with disabilities. CBR is implemented through the combined efforts of people with disabilities themselves, their families, organizations and communities, and the relevant governmental and non-governmental health, education, vocational, social and other services. The main objectives of CBR are (1) to ensure that people with disabilities are able to maximize their physical and mental abilities, to access regular services and opportunities, and to become active contributors to the community and society at large; (2) to activate communities to promote and protect the human rights of people with disabilities through changes within the community, for example, by removing barriers to participation." (Joint Position Paper, WHO, ILO & UNESCO, 2004).*

#### **4.4.2 Public awareness campaigns**

*To modify the negative view of people with disabilities that society has built up, public awareness campaigns can be organized on general and/or specific topics. These campaigns must be based on simple and effective messages in order to change prejudices and stereotypes. It is necessary to identify the target audience for these campaigns and choose the tools to use accordingly, while bearing in mind the available resources and appropriate methods. Within the campaigns, special events (such as meetings, concerts and conferences) can increase the attention of the public and the media. It is useful to give some examples of campaigns.*

#### **4.4.3 Lobbying**

*Focused lobbying activities can be a useful tool for the achievement of concrete objectives. Lobbying consists of organized activities that put pressure on influential people, public and private institutions and political and social decision makers. It is based on an analysis of decision-making processes on topics and objectives of interest to the organization in order to carry out concrete action and initiatives (meetings, presentation of documents, television and radio appearances, etc.) aimed at influencing decision makers and advising them according to the goals of the organization. Lobbying also makes use of public awareness campaigns.*

#### **4.4.4 The use of mass media**

*In recent decades it has become particularly important to be able to make use of the mass media (newspapers, magazines, television, radio), which are tools for information and communication that directly reach millions of people, thus influencing public opinion. To achieve this result, it is necessary to raise visibility via significant action (protests, public awareness campaigns, conventions and seminars, special events etc.) and to know how to influence people working in the media industry. Each mass medium has its own language which must be appropriated in order to be effective. Writing a press release or an article is in fact quite different from taking part in a television programme or giving an interview. It is important to build up contacts in the media who work in the disability and human rights areas. Where the resources are available, it is important to appoint a press officer.*

#### **4.5 The Human Rights Strategy for People with Disabilities as a Contribution to the Construction of Inclusive Societies**

*The contribution of the social and cultural action of the movements of people with disabilities does not stop, however, with the application of the human rights paradigm to the 10% of the world's population who live with disability. It is much more significant, because it broadens and enhances the individualistic concept of human rights, traditionally focused on the inalienable rights of individuals, towards a view that gives society responsibility for ensuring the social inclusion of all citizens, whatever their differences. Human rights protection is in this way not just linked to respect for individual freedoms but also to the social and cultural construction of inclusive societies, in which prejudices and barriers are eliminated and all can live without social, legal or practical stigma.*

*This opens up a new area of cultural and political action that affects society as a whole: how to include human diversity within society and within economic and social development models. The specific theme of the reformulation of the social and cultural view of disability thus becomes a paradigm for confronting myths and ideologies that have become accepted as common sense, built on age-old practices of segregation and exclusion that are no longer acceptable. The reconstruction of society must be based on a universal approach to the construction of environments, goods and services, equal opportunity for all citizens, and the elimination of all forms of discrimination. It is an extraordinary contribution which brings human rights in the individual and social spheres together, placing the responsibility for action and behaviour on both people and institutions.*