

## REVIEWS

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# Organisations of Persons with Disabilities and Community-based Rehabilitation

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### ABSTRACT

*Over the last few decades, there has been a growth in community-based rehabilitation (CBR) programmes in different parts of the world. These programmes are regarded as one way of strengthening the implementation of the UN Convention on Rights of Persons with disabilities.*

*CBR programmes and Organisations of persons with disabilities (DPOs) have developed parallel to one another and are interlinked in different ways. CBR can play a role in the setting up and strengthening of DPOs. On the other hand, DPOs can also initiate and run CBR programmes. Both share similar objectives in terms of respect for human rights of persons with disabilities.*

*This article looks at the historical evolution of connections between CBR and DPOs, analyses some of the areas where their activities are interlinked, and presents 2 case studies - one from Santarem metropolitan area in Brazil and the other from Bidar district in India - to demonstrate those links.*

**Key words:** CBR, DPO, case study, India, Brazil

## INTRODUCTION

CBR is a strategy within general community development for the rehabilitation, equalisation of opportunities and social inclusion of persons with disabilities. It is implemented through combined efforts of people with disabilities themselves,

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their families, organisations and communities, and the relevant governmental and non-governmental health, education, vocational, social and other services (ILO, UNESCO, WHO, 2004).

### **Origins of CBR and DPOs**

Towards the end of the 1960s, in some countries DPOs had started to formulate a new concept of disability (UN, 1994). Disability rights movements which began during that period were inspired by other civil rights movements, such as the women's movement. In 1969, the Independent Living Movement began in Berkeley, USA. In the UK, UPIAS (Union of the Physically Impaired Against Segregation) started in the early 1970s. The first international DPO federation, Disabled Peoples' International (DPI), held its founding world congress in 1981 in Singapore.

The first CBR policy document was developed by the World Health Organisation (WHO) in 1974. Einar Helander, the first rehabilitation specialist to join WHO, described the context in which this document was developed, *"In many countries there were small organisations of parents and of persons with disabilities. Among these hundreds of villages and urban slum areas visited, there were examples of disabled adults who had successfully trained themselves, and of disabled children whom family members had trained"* (Helander, 2010).

It was thus that the initial developments among the CBR and disability rights movements took place around the same time in the 1960s and '70s. From the beginning, CBR and DPOs were linked together in some areas and there were many small CBR programmes run by persons with disabilities or by families of children with disabilities (Werner, 1995).

For example, the 'Three D' CBR project in St. Catherine and Clarendon in Jamaica was initiated in 1978 by the Jamaica Council for the Handicapped. Due to lack of funding, this project was stopped in 1982 and was taken over by the Parent Association for Disabled persons. A key feature of the programme was parent training and development of an organisation of parents (Thorburn, 1990).

On the other hand, a small CBR programme in Guyana was initiated in 1986 by a group of persons including community volunteers, parents of children with disability and rehabilitation professionals. Over the years it expanded to different regions of the country and also created links with DPOs and different ministries (O'Toole, 1995).

One of the earliest examples of a CBR programme managed by a DPO was in Mauritania. A DPO called UNHPM (Union Nationale Des Handicapées Physiques et Mentales) initiated a CBR programme in the country in 1989. The programme gradually expanded and created links with the Ministry of Social Affairs (AIFO, 1996).

Over the past decades, both DPOs and CBR have evolved along lines that have strengthened their early links.

### **DPOs and their Evolution**

DPOs are representative organisations formed by persons with disabilities and/or their family members. For example, DPI, the international federation of DPOs that brings together members from 130 countries, defines an essential feature of DPOs as “a majority of the members as well as the governing body of a DPO shall be persons with disabilities”. In addition, if specific groups of persons with disabilities cannot represent themselves, such as persons with psycho-social disabilities and children with disabilities, they can be represented by others such as the family members (DPI, 1993).

CBR Guidelines (WHO et al, 2010) explain that DPOs can be either “single disability organisations” and represent individuals with a particular kind of impairment, such as a hearing or visual impairment, or they may be “cross-disability organisations” and include different groups of persons with disabilities.

The evolution of DPOs in the developing world was closely linked to some international initiatives. The World Programme of Action concerning persons with disabilities was adopted by the UN General Assembly in December 1982, and the period from 1983 to 1992 was declared the UN Decade of Disabled persons. The first DPOs in many countries came up during this period. Later, roles of DPOs were institutionalised at the international level through the United Nations.

The Standard Rules were adopted by the United Nations General Assembly in December 1993. Article 18 of the Standard Rules focussed on the DPOs. Directed mainly at national governments, the Standard Rules asked for recognition of “*the right of the organisations of persons with disabilities to represent persons with disabilities at national, regional and local levels*” (UN, 1994).

The UN Convention on Rights of Persons with Disabilities (CRPD) also underlined the importance of working together with DPOs in Article 4.3, “*In the development*

*and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organisations “ (UN, 2006).*

## **Roles and Activities of DPOs**

DPI (2012) defines its mission as: *“to promote the human rights of disabled people through full participation, equalisation of opportunity, and development.”* Many DPOs in different parts of the world, who are members of DPI, also share similar mission statements.

One of the earliest manuals providing practical information about setting up a DPO and defining its activities was prepared as part of the UN Decade on Disability at the Economic and Social Commission for Asia and the Pacific (ESCAP, 1991). It provided guidelines on establishing and strengthening DPOs. These guidelines proposed 2 kinds of roles for DPOs:

- (1) Information provision, advocacy and lobbying related activities;
- (2) Providing specific services to their members.

Another manual on management of DPOs by UN-ESCAP, published a few years later (ESCAP, 1997), took note of greater attention paid by DPOs to advocacy and awareness-raising activities. It asked DPOs to play a greater role in service-provision, for the following reasons:

- There are not enough services to enable people with disabilities to participate actively in community services;
- Existing services do not meet the actual needs of people with disabilities;
- Organisations recognise the capability and resourcefulness of people with disabilities as service providers and their aspirations for meaningful participation in community life.

An international survey was carried out by World Health Organisation (WHO) in 1999, in which a large number of DPOs also participated. The summary report of this survey took note of the active role played by persons with disabilities, their families and their organisations in taking care and providing services (WHO, 2001).

## Role of DPOs in CBR

Though inspiration for CBR came from family members working with persons with disabilities in the communities, initially there was no clarity about the possible roles of the DPOs in the CBR programmes. The WHO CBR manual (WHO, 1989) proposed the formation of informal or formal groups to represent persons with disabilities among the CBR activities.

The first version of Joint Position Paper (JPP) on CBR prepared by three UN organisations (ILO, UNESCO and WHO) in 1994, asked for involvement of different community organisations in CBR, including the DPOs, but did not assign a specific role for the DPOs. However, as CBR programmes gained experience, possible roles of DPOs in CBR were suggested:

Which kind of roles can be played by DPOs in CBR? A good place to begin is by encouraging persons with disabilities to take over more of the organisational and service providing roles in CBR programmes. Where possible, disabled people's organisations can lead or advise programmes (Werner, 1998).

DPOs need to take a leading role in CBR programmes in the communities by being pro-active and by asserting their roles as primary actors (Masakhwe et al, 2008).

Thus, the updated version of JPP ten years later asserted that *"today DPOs are prepared to take meaningful roles in the initiation, implementation and evaluation of CBR programmes"* (ILO, UNESCO, WHO, 2004).

During the first Asian congress on CBR, an international workshop on UN Convention on the Rights of Persons with Disabilities and CBR had recommended that *"DPOs and CBR programmes should work together. CBR programmes should facilitate, promote and strengthen DPOs at all levels, with appropriate empowerment activities and instruments. CBR programmes should support networking between DPOs at grassroots level and national level. At the same time, DPOs should support strengthening of CBR programmes"* (Deepak, 2009).

However, to play an active role in CBR programmes at community level, capacity building may be required for DPOs' members. The role that the DPOs can play in the CBR programmes (and in the communities in general) would also depend on the empowerment processes that support skills and competence in the areas chosen by the DPOs (Griffo, 2007).

Increasingly there are examples of closer links between CBR and DPOs. For example, in 2006-07, Mongolia national CBR programme organised training for the National Federation of Association of persons with disabilities on Human rights and CRPD. Later this training was extended to other local DPOs (Griffo & Ortali, 2007).

Research on a district CBR programme in India showed that in areas covered by CBR, 17.7% of persons with disabilities were members of DPOs, compared to less than 1% in the control areas (Biggeri et al, 2012). In an emancipatory research project in the same district, DPO representatives were among the researchers (Deepak, 2012).

Lastly, in 2012, DPI conducted a survey among its members to find out their views on CBR. Almost 79% of the respondents felt that CBR was important for the implementation of CRPD. The survey also found that 15% of DPOs were involved directly in the CBR programmes in their countries (DPI, 2012). Thus, it would appear that collaborations and interconnections between DPOs and CBR programmes are increasing.

### **Conflicts between DPOs and CBR**

There have been occasional problems between DPOs and CBR programmes. One of the theme papers for an international consultation took note that “many CBR programmes do not involve people with disabilities or DPOs in planning, implementing and monitoring the work of CBR. In many places, CBR implementers and DPOs (where they exist) do not work together” (WHO/DAR, 2003).

For example, in 1992 in Uganda, the Government involved NUDIPU (National Union of Disabled Persons of Uganda), the national level federation of DPOs, in drawing up the guidelines for CBR activities in some districts. However, DPOs dealing with specific disabilities were not involved and “they felt left out and unappreciated. Also, at the implementation level in the districts, the local organisations were not actively involved in the management of CBR programmes. This led to some serious resistance by some prominent DPOs” (Ndaziboneye, 2002).

To bridge the divide between DPOs and CBR, it has been argued that DPOs should join the ranks of those (professionals) who are committed to ensuring that rehabilitation becomes accessible to all (Cornielje, 2009).

## **CASE STUDY 1: A CBR PROGRAMME MANAGED BY A DPO IN BRAZIL**

Santarem is one of the major cities in the Para state in the north-eastern part of Brazil. Santarem metropolitan area includes three municipalities - Santarem, Belterra and Mojui dos Campos with a total population of around 300,000 persons.

### **Origins of CBR in Santarem**

A CBR programme was initiated in Santarem in 1996. As part of a research project on implementing CBR in urban slums, a group of Brazilian NGOs including a DPO (ADEFIS - Associação dos Deficientes Físicos) and a state organisation working with prisoners in the local jail (Penitenciária Agrícola de Cucurunã), joined together in an informal network to promote CBR activities involving persons with disabilities and other vulnerable groups.

The research project concluded in 2001. In the years that followed, except for the DPO (ADEFIS) that continues to be active in CBR implementation, the other organisations have withdrawn from the network.

### **Origins of ADEFIS**

ADEFIS is a DPO of persons with physical disabilities who live in the Santarem metropolitan area. It was started in 1992. At present, there are about 500 members, each of whom pays a monthly fee of 2 Real (approximately 1 US Dollar). It is governed by a council of 8 members who are elected every 3 years by the general assembly. According to its statute, no person can be the president of the organisation for more than 2 consecutive terms. At present, the governing council is composed of 3 women and 5 men.

Around 100 persons participate in the general assembly. Difficulties relating to transport and finding an accessible hall where all the members can meet are 2 of the barriers that limit participation of members of ADEFIS in the general assemblies.

ADEFIS has rented an office near the city centre of Santarem. The office has a full-time secretary paid by the municipal government of Santarem. All the CBR activities of ADEFIS are carried out by its members and some community volunteers (mainly family members of persons with disabilities).

## Activities of ADEFIS

ADEFIS defines all its work as CBR, and does not make a distinction between its role as a DPO and its role as an implementer of CBR. The principle activities of ADEFIS are:

**(a) Public awareness on disability issues:** Creating public awareness about disability issues and the barriers faced by persons with disabilities are the most important objectives of ADEFIS. To achieve this, different activities are organised by the association:

- Participation in the National Day parade: On September 7th, Brazil's national day, parades are organised in the city centres. ADEFIS has participated in the national parade held in Santarem since 2004. This gives the association significant public visibility and stimulates a number of its subsidiary activities.

For the annual parade, a group of persons with disabilities works to make colourful dresses with the logo of ADEFIS. A common dress is considered important in overcoming the sense of shame among members and is a way of affirming the right to dignity for everyone. Dressmaking is also an income-generating activity, and showcasing the dressmaking abilities of the group is instrumental in getting these persons work for other cultural events.

In different parts of the city, ADEFIS members who are unable to participate in the parade come together to watch its live transmission on the television and organise local activities on the occasion.

- Organising workshops in city schools: Every month, ADEFIS members and volunteers are involved in 10-15 workshops in city schools, to talk about disability, inclusion of children with disabilities in schools, and barriers faced by persons with disabilities.

At the same time, children with disabilities identified in the schools are encouraged to visit the ADEFIS office with their parents so that they can receive information about their rights and entitlements. Showing them positive role models among self-sufficient and independent members of ADEFIS is important to create a sense of hope and future possibilities.



- Activities for World Disability Day: Every year on 3rd December, which is World Disability Day, ADEFIS organises public meetings, and theatre and cultural activities in the city. These include dance, music and singing programmes by the members.
- Publication of an information bulletin: This is an occasional publication which depends on the availability of funds.

**(b) Different activities for promoting social relationships among members of ADEFIS:** Most persons with disabilities feel lonely and isolated by physical and attitudinal barriers. Hence, promoting leisure activities for the members is an important role for ADEFIS. These activities include organising picnics and cultural visits, sports (including a football team of persons with amputations and a Taekwondo martial arts team of wheelchair users), and celebration of festivals.

**(c) Home visits:** Members and volunteers of ADEFIS visit homes of any newly identified persons with disabilities in the communities. Persons with disabilities are often isolated, do not study or work and have no information about national laws and the opportunities available for them. During home visits, ADEFIS members and volunteers also speak to family members to ensure that rights of persons with disabilities are respected and there is no exploitation or abuse. The home visits are also important to expand the membership base of ADEFIS.

**(d) Facilitating access to services and equipment:** ADEFIS collaborates with different government departments, hospitals, rehabilitation services, NGOs and other organisations to facilitate access to different services and equipment. For example, in collaboration with a local faith-based organisation, 40 high-quality wheelchairs made of lightweight and resistant materials were distributed to ADEFIS members in 2012.

ADEFIS has a special collaboration with an organisation called APAE that works for children with intellectual disabilities and runs an orthopaedic workshop. All persons with disabilities, who require an appliance, can get it from the APAE workshop if they have a government prescription, and then get the cost reimbursed by the government. ADEFIS facilitates this process. ADEFIS members also receive support for disability certificates and government pensions.

**(e) Promoting income generation and economic independence:** ADEFIS organises different professional training courses for its members. For example, it runs a cutting and sewing workshop, two computer-learning workshops, and a serigraphy workshop (printing designs on clothes such as T-shirts).

ADEFIS has the contract from the city government to manage 5 public bathrooms and toilets, where there are pay-and-use services. Persons with disabilities manage the services and ensure that the bathrooms and toilets are clean. Each bathroom and toilet is managed by different groups of ADEFIS members by rotation, to ensure that persons with little or no income can get some support.

**(f) Support and networking with other DPOs and federations:** ADEFIS organises regular meetings with other DPOs active in Santarem. An important part of these activities is supporting specific groups of persons with disabilities to start their own DPOs. Thus, during 2011-12, deaf persons and persons needing dialysis (they are included among persons with disabilities according to the Brazilian laws) were provided support and now both these groups have their own independent DPOs.

Meetings were also held to encourage persons affected with leprosy to form their own organisation, but this did not work out. Instead, some persons with disabilities caused by leprosy have joined ADEFIS.

**(g) Advocacy and lobbying activities:** ADEFIS is involved in different advocacy and lobbying activities, especially in relation to finding solutions to barriers. For example, ADEFIS campaigned for accessible public telephone booths and ATM machines and, as a result, the city government has provided symbolic solutions by setting up a few accessible public telephones and 1 accessible ATM machine.

Another example of advocacy activities was in connection with the new raised walking platform built along the Amazonas River in the city centre, which was not accessible to wheelchairs. After the campaign by ADEFIS, the city authorities agreed to build 2 ramps.

## **CASE STUDY 2: CBR SUPPORTS SETTING UP OF A DPO IN INDIA**

Bidar district is located in the north-eastern part of Karnataka state in south India. It has a population of 1.7 million persons in an area of 5,448 square km. The district is composed of 5 sub-districts (*Taluks*). There are 675 villages and 175 *panchayats* (elected village councils, one for every 2-4 villages).

A CBR project was started in Humnabad sub-district of Bidar, in 2004. Over the past decade, this programme has been extended to cover the whole district. The district CBR programme is managed by a local non-governmental organisation

called ORBIT (Organisation of Bidar Integral Transformation). In 2012, the CBR project in Bidar district involved around 23,000 persons with disabilities. The programme includes 6 DPOs, one a district level DPO, with 675 members.

### **DPO in Bhalki sub-district**

Bhalki is one of Bidar's sub-districts. There are 130 villages in an area of 1117 square km and, according to the 2001 census, a population of about 257,000 persons.

In 2008, the persons with disabilities united to create a sub-district level DPO called "Ravi Kiran Viklang Chetna Sangh, Bhalki" (RKVCSB). This DPO was registered at state level in 2010. The CBR programme had helped to set up a self-help group (SHG) of persons with disabilities in each village of the sub-district. Members of these village SHGs can become members of the sub-district DPO by making a one-time contribution of 50 Rupees (less than 1 US Dollar). In 2012, RKVCSB had around 160 members (60% male and 40% female).

With support from the CBR programme, the DPO was given a room at the local church in Bhalki, to hold meetings. However, RKVCSB is now negotiating with the city council to be given a more accessible room which will be easier to reach using public transport.

### **DPO membership and management**

The membership of the DPO is open to all persons with disabilities above 18 years of age. For persons with severe disabilities and communication difficulties, a family member can also become the DPO member. However, the majority of persons on the Board of the DPO must be persons with disabilities.

The DPO Board is composed of 11 members. The general assembly meets once a year and elections are held every 2 years. The president, secretary and treasurer cannot be re-elected to the Board for a second consecutive term. At least 2 Board members must be women. Persons with different disabilities are encouraged to join the Board, so that all the different interest groups are represented.

### **Origin of the DPO**

During their meetings with the SHGs, CBR workers discussed the importance of setting up a DPO. After about 3 years, the decision was made in 2008. The CBR programme facilitated contacts with DPOs in other parts of Karnataka and access to their statutes.

The CBR project facilitated persons with disabilities to travel to the initial meetings, and helped in the registration of the DPO. It also supported capacity building of DPO members to manage the organisation.

There are 38 *panchayats* in Bhalki sub-district and persons with disabilities from all these *panchayat* villages are represented in the DPO. Meetings of the RKVCSB are held in Bhalki city, the headquarters of Bhalki sub-district. The furthestmost village from where members need to come to the DPO meetings is 40 km away.

## DPO Activities

RKVCSB is involved in the following activities:

**(a) Federating the SHGs:** An important role of the DPO is to share information and promote joint action of the SHGs in different villages of the sub-district. The DPO members have the responsibility of informing other SHG members in their villages. At the same time, if there are problems in some villages, they can organise collective action and raise their issues at the sub-district and district levels.

**(b) Fighting against discrimination:** The DPO promotes awareness among the authorities and community leaders, and organises protests against discriminatory practices. Special programmes are organised on occasions like the World Disability Day.

**(c) Providing information and facilitating access to government schemes:** There are different government schemes for persons with disabilities, such as scholarships for school education, poverty reduction programme, free transport for persons with disabilities, etc. The DPO works together with CBR workers to ensure that such information can reach the SHGs, and assists people to access these schemes.

**(d) Participating in district-level DPO meetings:** Two representatives of the sub-district DPO are members of the Bidar district-level DPO and therefore participate in all the district-level meetings. In this way, a network is created between the district-level DPO and the self-help groups in the villages. In future, this network will expand to include the state-level DPO.

**(e) Facilitating access to orthopaedic appliances:** The DPO collaborates with the CBR programme to collect information from the villages about the needs of SHG

members, and then liaises with the government agency to receive and distribute the appliances.

## DISCUSSION

The 2 case studies illustrate the links and synergies between the CBR programmes and the DPOs.

The experience of ADEFIS in implementing CBR raises questions about the possible specific characteristics of DPO-managed CBR. For example, ADEFIS operates exclusively through volunteers at community level without any specific CBR workers, and strengthening the DPO function of the organisation is a fundamental part of its CBR work.

CBR programmes usually make a distinction between those who implement CBR activities (CBR workers or CBR volunteers) and those who benefit from those activities, though sometimes CBR workers/volunteers are also persons with disabilities. In the ADEFIS CBR programme, there are no clear boundaries between implementers and beneficiaries - new persons with disabilities enter the programme as beneficiaries and in course of time become implementers of some activities. The impact of this model of CBR implementation on its ownership and sustainability needs to be studied.

The example from India illustrates the potential of CBR to strengthen and expand the reach of DPOs. Often the DPOs are based in big cities, and persons with disabilities who live in rural areas have little contact with them. The case study from Bhalki sub-district in Bidar district, India, shows that CBR programmes can play a vital role in promoting the setting-up of DPOs in peripheral and rural areas, and in creating links between the local DPOs and state and national-level DPOs.

According to this case study, the sub-district level DPO called RKVCSB was formed quite recently and with support from the CBR programme. Hence there are at present no apparent conflicts between the DPO and the CBR programme. However, as the local DPO becomes stronger in the future, it can play a monitoring role in the CBR programme. Another possible area of development could be in terms of transfer of some CBR activities from the CBR programme to the DPO.

DPOs play a fundamental role in advocacy, lobbying and fighting for the human rights of persons with disabilities. In this regard, DPOs may sometimes protest against service providers if they feel that there are problems with the service

provision. As the present case study did not look at the ways in which sub-district and district DPOs are influencing the CBR activities, this could be an area for future research.

## **CONCLUSION**

Involvement and active participation of persons with disabilities and their families in all the different activities are fundamental prerequisites of all CBR programmes. CBR programmes are asked to support and strengthen DPOs at community level and to work together with DPOs for the implementation of CRPD.

Often the main role of DPOs is seen in terms of advocacy, influencing disability-related policies and fighting against barriers, while CBR programmes are seen as implementers of development activities for and with persons with disabilities at community level. However the boundaries between roles and activities of CBR programmes and DPOs are not very clear cut, especially when DPOs are involved in implementation of activities at community level.

If CBR programmes wish DPOs to play an active role in their activities, they may need to think of capacity building and empowerment of DPOs. These activities must be discussed with DPOs and decided together, as shown by the case study from India. There is also a need to document and critically appraise the links and relationships between CBR programmes and DPOs.

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### **Conflict of Interest**

Sunil Deepak works for AIFO, the Italian NGO that has been contributing to the funding of the two CBR programmes managed by ADEFIS and ORBIT. Ládía Rufino dos Santos is a Board member of ADEFIS. Deolinda Bitencourt de Santana is Director of BRASA and has been the representative of AIFO in Brazil. Jayanth Kumar is the CBR coordinator at Amici India Trust. Santosh Bapu is director of ORBIT. None of the authors received any funding for this research and for the creation of the article.

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