

GUEST EDITORIAL

**THE ROLE AND POSITION OF DISABLED PEOPLE'S
ORGANISATIONS IN COMMUNITY BASED REHABILITATION:
BALANCING BETWEEN DIVIDING LINES**

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ABSTRACT

The role of disabled people in CBR is increasingly being seen as of vital importance for the success of CBR. In actual fact participation of disabled people and self advocacy have become two of the principles of CBR as seen by the World Health Organisation and associated organizations behind the new CBR thinking.

This paper deals with the position and role of disabled people themselves in CBR programmes. It critically looks into the role Disabled Peoples' Organisations in terms of promoting equal access to essential and acceptable quality of rehabilitation programmes for all and especially the poor of this world. It is argued that DPOs should join the ranks of those (professionals) who are committed to ensure that rehabilitation becomes accessible to all. The current global situation of an ever widening gap between the 'ones who have and those who don't have' requires a critical reflection on ones' own work in CBR and DPO development. We cannot permit ourselves anymore a division among those who are disabled and those who are non-disabled as there are other divides among groups of people that are by far more profound and serious to the majority of disabled people worldwide.

While the urban elite of disabled people who live in a conflict-free, open and democratic society may be well concerned with issues such as accessible tourism, CBR as essential service provision is often unavailable for the poor rural masses and those living under illegal conditions in slums of the cities of Africa, Asia and South America. CBR as philosophy seeks for solidarity with those who live under appalling conditions; threatened by conflict, eviction

and hunger. This paper calls for collaboration between DPOs and the CBR movement in order to address diversity and ensure that the implementation of basic human rights are truly addressed.

INTRODUCTION

CBR as it developed in the late seventies and early eighties was largely a response to the physical rehabilitation needs of many disabled people who by that time were not reached through so-called institution based rehabilitation. CBR became an approach to make rehabilitation accessible to disabled people at the community level. CBR in those days developed from within a medical model perspective, implemented in the context of the health sector, and was concerned with coverage. CBR in those early years focused mostly on the notion of “Rehabilitation for All”, much in line with the WHO strategy of “Health for All”. There was nothing wrong with it and those who seriously want to address the vast needs of the majority of disabled people living in lesser developed countries should still take note of the early ideas. If the current coverage and access to rehabilitation services is compared with the situation some thirty years ago it may very well be that the situation on the ground has not much improved. CBR remains limited to pockets of - more or less - acceptable standards of rehabilitation services. However, all too often it is limited in terms of coverage, scope and comprehensiveness. In spite of many initiatives worldwide and in spite of renewed interest in CBR the real situation is that the majority of disabled people do not have any access to any form of rehabilitation. Unfortunately this notion seems not to be heard anymore. It appears as though CBR is now well-accepted and applied. However, even in countries claiming to have national programmes such as Vietnam, the coverage is limited and while many provinces may have CBR (74% coverage), it is a few districts in those provinces (24% coverage) and a few villages in those districts (24% coverage) that in actual fact benefit from the national CBR programme (1). Similar examples can be given from other parts of the world. While coverage may be limited, there is also quite some evidence - probably not in the scientific literature but certainly among those who work on the ground - that the notion of quality is a point of concern too.

Although claims have been made by some critics that CBR as presented in the eighties was largely a top down development, the reality is that most CBR developments were and are

more bottom-up grassroots initiatives managed by non-governmental organizations (NGOs), rather than by governments. A survey among 29 African countries compiled by WHO (2) suggests that there is “no national [African] programme where multi-sectoral CBR activities cover the whole country”, and CBR is mostly confined to pilot projects in some areas, with foreign funding.

CBR as it was developed in the early years - with a focus on coverage and on individual rehabilitation - became labelled as a so-called medical or individual paradigm of viewing disability, a distortion of all that was CBR. Yet, in those early years of development many official and non-official CBR initiatives were already working from within a much broader social or human rights paradigm, sometimes unaware of theoretical debates on paradigm shifts in disability, but conscious about the complexity of the disability experience and the need to respond to felt needs of disabled people. These early CBR initiatives comprised of small parent support groups that were initiated by mothers of disabled children in rural kwaZulu Natal in South Africa; or a cooperative of men and women, all disabled, weekly making thousands of baskets in a slum north of Johannesburg in South Africa (3); or in another continent, Projecto Projimo in Mexico, one of the early CBR programmes with basically only disabled people involved in the management and execution of the programme (4). Should we retrospectively criticize such developments while it is questionable if we are doing any better in 2008?

The current forms of CBR, based on social model thinking and human rights tend to be seen as the best, the ideal or even only truly CBR. Such strategies may be seen as the only way to ensure that disabled people become part of the mainstream. Let us however critically scrutinize such programmes and ask ourselves what the scope is of these programmes and their impact on the lives of the millions of disabled people living in absolute poverty.

CBR is - rightfully - nowadays seen as an empowering strategy. However, in view of the above remarks there should be some concern about a too pointed individual human rights focus in our work as they may create false dawns. Disabled people will not automatically have a better quality of life because of legislation only. Therefore, we should ensure that through our efforts in CBR the actual needs of disabled people are being met, and then if we meet those needs we may comply with international human right laws such as the Universal Declaration of Human Rights (1948): i.e.,

- the so-called classical rights such as the right to live; the right to food; integrity rights.
- Socio-economic and cultural rights, such as the right to education; the right to employment; the right to Basic Health Care.

However, this paper is not written to evaluate or judge CBR worldwide. This paper deals with the position and role of disabled people themselves in CBR programmes. Moreover, it critically looks into the role Disabled Peoples' Organisations play in terms of promoting equal access to essential and acceptable quality of rehabilitation programmes for all and especially the poor of this world: those people who live in the rapidly expanding slums in Asia, Africa, South- and Central America; the rural disabled people living in the periphery of their countries, in deserts, in the hills, the hamlets, the homesteads in the swamps and in the mountains.

LEGAL HISTORY OF DISABLED PEOPLES' ORGANISATIONS

The role and position of disabled people in rehabilitation programmes should be seen in the context of the global history of disability and rehabilitation on one hand and the more recent history of the disability movement on the other hand. In this section an overview is given of at-times- coinciding developments.

With the current euphoria about the ratification of the UN Convention on the Rights of Persons with Disabilities (CRPD) it is good to realise that this is the end result of a process that took over 30 years to achieve. It is not in the scope of this paper to elaborate on the history of the rise of disabled people's organisations. Yet there are a number of moments in this history that coincided with CBR developments, that are worth noting.

The year 1975 marked the signing of the UN Declaration of the Rights of Disabled People. Although it is not legally binding, this Declaration provides a framework for the equal treatment of disabled people and their access to services. This milestone meant for many disabled people an understanding and acceptance by the community of what their lived experience of disability meant: disabled people want to be seen and valued as fully human and where needed, to be supported to reach their full potential.

During the mid-seventies a process of de-institutionalisation of services took place in a number of western countries. In the field of psychiatric conditions and intellectual disability in particular,

programmes and services were developed at the interface or within communities. The growing assertiveness of consumer movements in western countries formed a facilitating factor in this development. Almost parallel with these developments in western societies, WHO and later other UN organisations started to promote CBR. However, it should be noted that less formally all kind of grassroots initiatives were already taking place, with characteristics of CBR.

The year 1981 marks the International Year of Disabled People and during the same year Disabled People International (DPI) held its 1st World Congress in Singapore. It was however, in 1980 in Winnipeg, that the concept of an international organisation of disabled people emerged and DPI was formed as a reaction to professional paternalism within Rehabilitation International, the then global organisation on disability and rehabilitation issues.

A major outcome of the International Year of Disabled Persons was the formulation of the World Programme of Action concerning Disabled Persons, adopted by the General Assembly in December 1982 (5). The World Programme of Action (WPA) is a global strategy to enhance disability prevention, rehabilitation and equalisation of opportunities, which pertains to full participation of persons with disabilities in social life and national development. The WPA also emphasises the need to approach disability from a human rights perspective. "Equalisation of opportunities" is a central theme of the WPA and its guiding philosophy for the achievement of full participation of persons with disabilities in all aspects of social and economic life. An important principle underlying this theme is that issues concerning persons with disabilities should not be treated in isolation, but within the context of normal community services.

The proclamation in December 1982 of the United Nations Decade of Disabled Persons (1983-1992) prompted a flurry of activity designed to improve the situation and status of people with disabilities. Emphasis was placed on raising new financial resources, improving education and employment opportunities for the people with disabilities, and increasing their participation in the life of their communities and country.

The 1993 Standard Rules on the Equalisation of Opportunities for Persons with Disabilities were intended to complement the World Programme for Action Concerning Disabled People. The Standard Rules cover a wide range of areas of everyday life such as access to employment and education as well as rehabilitation and international cooperation. Although they are non-binding, the Standard Rules require States to remove obstacles to equal participation and to

actively involve non-governmental agencies (NGOs) dealing with disabilities as partners in this process. The Rules emphasise equal rights and equal obligations – not special rights, but the achievement of equality on the same terms as all persons. The social model of disability thus became common thinking within CBR development, with a shift from service delivery (only) to more human rights models of CBR which include attention for equal opportunities, empowerment, building linkages and networks, ownership and an increased emphasis on advocacy as a tool to ensure that rights are being fulfilled.

At regional levels, there were various initiatives such as the declarations of regional ‘decades of disabled persons’.

The focus on disability has come into a new era with the development with the recent coming into force of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). The ratification of the CRPD means - in the opinion of some disability activists - the end of centuries of a predominantly moral- and medical approach to viewing disability. The Convention once ratified is a binding instrument on governments to ensure the protection of rights of their disabled citizens.

The CRPD, based on the social model of viewing disability, does however also describe medical issues encompassing the lives of disabled people; however, this is done within a human rights perspective. In such a perspective, the disabled person - and family - have a central role in determining the course of action. It is not only the professional who determines the proposed rehabilitation goal and plans.

THE IMPORTANCE OF DISABLED PEOPLES’ ORGANISATIONS

The growth of Disabled Peoples’ Organisations (DPOs) can be viewed basically as the consequence of exclusion and discriminatory practices toward disabled people. Very much in line with the emergence of consumer movements in the seventies, a search for emancipation took place from the early eighties in western societies as well as in lesser-developed countries. In some ‘third-world’ countries DPOs became powerful and politically driven organisations demanding a strong stake in for instance a new political dispensation.

DPOs are usually seen as social (human rights) movements, though a genuine review of lots of community-based DPOs will indicate that many of them are in fact self-help groups

(SHG), trying to promote usually some income generating activities for their members. The more developed of such self-help groups become engaged in advocacy type of work and become a mouthpiece for those who are denied their rights. Sometimes, SHGs may form federations, which can be observed in a number of States in India. Such federations have a stronger voice; they foster active citizenship and together or under a national umbrella organisation they may be very successful in combating injustices in society. It was in South India for instance that the joint effort of SHGs helped to successfully fight corruption at the pension pay-out points.

THE TRUE DIVIDE IN THE DISABILITY BUSINESS

Disabled Peoples' Organisations are a mirror of society and reflect both the beauty as well as the cruelty that we see in society. As much as society excludes people, DPOs also include some and exclude others. DPOs exclude for instance rehabilitation personnel, largely because of suspected professional paternalism among these people; but they also exclude other disabled people: depending on the type of organisation they may exclude people who have epilepsy or people who have communication disorders. Another group of usually excluded people is formed by intellectually disabled people. Parents of disabled children are usually not welcome to be part of the disability movement as well. Parents of disabled children may even be seen by some as one the worst enemies of disabled children (6). A special group of discriminated disabled people is formed by people with leprosy, who in many instances face, on top of the stigma and isolation from society, also exclusion from mainstream disability organisations. It should not then be a surprise to see some new liberation movement being formed. The last civil rights movement was certainly not the disability movement. It also will not be the movement of parents of disabled children in some countries (e.g. DICAG in South Africa); nor it would be disabled blind women who are not chosen as board members of a national organisation of the blind in an African national state. It also will not be the International Association for Integration, Dignity and Economic Advancement (IDEA), an advocacy organisation of people with leprosy.

Burdick explains that current publications on social movements tend to assume that they are trying to mobilise whole constituencies such as "women," "middle peasants," "cannery workers," and so on (7). The use of such language masks the fact that, in almost all cases,

the majority of people who belong to a movement's potential constituency remain non-mobilised (7). While it is difficult not to equate DPOs with the disability rights movement, there is a fundamental difference. DPOs are organisations and they play or played a role in the movement of achieving equal rights (8). The disabled people's movement has in many respects failed to address diversity. However, there is some comfort as this applies most likely to all social movements. It is evident that in (some) western societies a debate takes place about this issue. However, it appears that this debate is not being held in lesser-developed countries, though it is not a luxury debate, since it appears all too often that national DPOs have alienated themselves from their constituency. Is not one of the problems of especially national DPOs that they have become institutionalised, with their - initial charismatic and sincere - leadership turning into the greatest beneficiaries and at the same time criticising what happens (usually in a CBR-like approach) in the disability field with and among the disabled masses? The true divide seems not anymore between disabled people and professionals or between disabled children and their parents and teachers. The true divide seems to be more a matter of the wealthy versus the poor; the urban versus the rural; men versus women; jet-setters versus refugees; academics versus illiterates; and 5-star hotel conference goers versus unemployed shack-dwellers. That is a harsh analysis, but in view of continued criticism on the - by far too few - community based services and programmes for those who live on the fringes of society, it becomes time for DPOs to reflect upon the outcome of their work. The CRPD as stated earlier is a great achievement by the disability movement. It would be even greater if in a sense of mutual responsibility, rights will be effectuated and translated into - at least - essential services and programmes for the disabled masses of this world. That is a responsibility of governments in the first place; however powerful stakeholders such as DPOs as well as professionals have a moral or professional obligation to influence policy making processes as well, in such a way that it is not a minority elite that is benefiting from the new human rights law.

Voices of renowned disability activists (such as Shakespeare) in the UK argue already for a pluralistic approach to disability politics that better acknowledges disabled people's diverse views. Others emphasise the importance of disabled people becoming part of a far wider struggle to create a better society for all. Few are likely to reject either of these proposals, but how are they to be taken forward? (9)

First of all it appears that it is important to accept that we are all living in an unjust and unequal world. There is exclusion anywhere in this world and there is widespread exclusion among disabled people and within DPOs. Secondly it is important to ask the question if it is always necessary and desirable to be truly inclusive of all? The concept of an egalitarian world is great and commendable but it is certainly against most philosophies. It is also not in line with the current tide of individualism, which in essence leaves abundant room for diversity. It is also against an appreciation of cultural diversity.

Keeping in mind these considerations the notion of interdependency seems to be useful. If this is not understood disabled people will continually polarise the discussion and create a divide between themselves and those who do not see themselves as disabled. It is questionable if that will help in the development of the much needed implementation of the CRPD. For the CRPD to become income into operation, joint efforts between DPOs and (CBR) professionals are needed. It does not mean that DPOs should disappear. Certainly not and the fact that discrimination will continually and persistently be there in our societies will require also continually new emancipation- and liberation - movements. As such it may very well be that an organisation like IDEA should not be part of mainstream DPOs but rather should emerge as the emancipation movement of people with leprosy.

CBR WITHIN THE CONTEXT OF THE UN CRPD

The UN Convention of the Rights of People with Disabilities (CRPD) ratified in April 2008 by 20 countries provides a new instrument in ensuring equal opportunities for disabled people. It also may form a powerful tool to ensure further CBR development. In spite of some opposition towards CBR from Disabled Peoples' Movements - who see CBR personnel as much as an enemy as rehabilitation professionals at times – the CRPD makes room for Community Based Rehabilitation (article 26) where is stated “Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.” Interestingly this article implicitly refers to CBR, even taking into consideration the fact that coverage and access to rehabilitation services is often marginal; something which certainly applies to the African and Asian continent.

CBR is not an end in itself, but it is an approach or means to ensure integration and equal rights. The question arises if CBR is successful if equal rights for all have been achieved. While most people would immediately agree with this proposition, others would be a bit more hesitant and prefer to critically follow the process towards implementation of those rights. A disability activist from South Africa expressed some concerns on an e-mail list and asked herself “*What does the treaty mean to Lawrence Nkumba from N’wamitwa village in the deep rural area of Tzaneen in Limpopo Province? I am mindful of the Advocacy Road Show by the Department of Public Service and Administration which I’m not sure if DPO’s have been consulted and/or are involved. We need a stronger civil society to avoid a situation where government is talking to itself. I think we need to start an implementation process so that ordinary people with disabilities can start benefiting from the conducive environment brought by progressive legislation in our country...*” (Magic Nkhwashu, 02-04-2007).

Rights without implementation and enforcement are meaningless and therefore it becomes time that the CBR movement starts to implement meaningful programmes for those who are in biggest need. The great majority of disabled people in Africa, Asia and South- and Central America are not organised into DPOs and even large numbers of the membership of DPOs are not benefiting from legislation and programmes set up by DPOs. It is those people, in the periphery of the country; those living in slums who probably never heard of national legislation, let alone the CRPD, but who long for a better quality of life. It is those people who are denied their rights to even the most basic amenities; and it is those people who could be reached with well planned; good quality CBR programmes. It is also those people who do best understand that mutual interdependence is key to progress in a community.

Rights are great if you can take someone to court. That may be possible for the urban elite, living in a conflict-free, open and democratic society, but is hardly imaginable for the poor rural masses and those living under illegal conditions in slums of the cities of Africa. In such contexts the rights of disabled people are best served with a CBR programmes that seriously takes into consideration the basic principles of CBR as described in the new CBR Guidelines. In order to make that work, DPOs should join the CBR movement and together influence policies and strategies for change. That means that on one hand mainstream developments should be fostered but where necessary special affirmative action programmes need to be designed for those who are not able to join the mainstream.

CONCLUSION

After nearly 30 years of experience worldwide, CBR is still struggling to gain recognition as a legitimate model of service-provision to disabled people. Its claims that it is an effective, cost-efficient, sustainable model need to be borne out by evidence. In this regard we have sought to present some considerations, and identify that there are different levels at which to explore different kinds of evidence. First, it was noted that there are promising possibilities for obtaining and incorporating evidence at the direct service-provision and CBR technique level. Second, it was identified that there are encouraging studies emerging for obtaining evidence at the CBR service-level by synthesising evaluation reports and other related documents. Third, the suggestion was raised that the incorporation of values as well as research findings in establishing evidence at the model level may also be a clarifying distinction. Fourth, we suggested that in keeping with underlying values in CBR, creative new methodologies for determining evidence should include participation at the community level, including the service-users themselves, their advocates in DPOs, and local community members. Appropriate research methods, drawn from the experience of the wider community development field, should be included alongside the earlier mentioned evidence strategies to enable the voice of village disabled people to be heard and incorporated into a unique, multifaceted evidence base for the discipline of CBR.

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CHILDREN AND VIOLENCE - THE WORLD OF THE DEFENCELESS

Author: Einar A. Helander

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This book addresses the severe health and social consequences for victims of childhood violence, which include increased alcoholism, drug abuse, criminal violence and damage to the central nervous system. Drawing on data from 152 countries, the author estimates that every other living person has been a victim of childhood violence: sexual, physical and/or emotional abuse. The book provides a critical review of interventions by governments and international agencies; and proposes a universal, community-based prevention programme.

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