

**Policy into Practice and Practice into Policy:  
How disability practice informs policy: Uganda and Ghana.**

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### **How disability practice informs policy: Uganda and Ghana**

Sightsavers International is a non-governmental organization with social inclusion objectives that address the lives of blind and visually impaired people in developing countries. Research in our organization is gaining more prominence.

The aim of this presentation is to show how our grassroots research influences policy on disability issues, and how policy change informs our research. I illustrate this ongoing bidirectional approach with two case studies. These case studies will focus on community based rehabilitation (CBR). Sightsavers has gathered information, qualitative stories and statistical data from across its programmes in two countries to support the development of the forthcoming WHO/ILO/UNESCO<sup>1</sup> Guidelines on Community Based Rehabilitation.

I conclude that disabled people's organizations (DPOs) in developing countries can play a role in shaping public policy. These organizations can use their own experiences to inform and develop domestic policy in country in order to secure the rights of disabled people.

Key words: Disabled people's organizations, policy, research, community based rehabilitation.

Sightsavers vision is that no one is blind from avoidable causes and that visually impaired people can participate equally in society. Our mission is to eliminate avoidable blindness and promote equality of opportunity for disabled people<sup>2</sup>. Sightsavers works in 34 developing countries and engages with Community Based Rehabilitation as a strategy to ensure irreversibly blind and visually impaired people are able to fulfil their potential in their local communities. Sightsavers has been involved in developing the WHO/ILO/UNESCO Guidelines, bringing years of practical experience to inform the Guideline development. Global CBR policy has also informed and influenced Sightsavers International's policies and practices on CBR.

#### **History:**

In both 1958 and 1969 the World Health Organisation's Expert Committee on Medical Rehabilitation emphasised rehabilitation as essential component of all

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<sup>1</sup> WHO is the World Health Organisation, ILO is the International Labour Organisation and UNESCO is the United Nations Educational, Scientific and Cultural Organization.

<sup>2</sup>I use the term 'disabled people' in this paper to reflect the social model of disability and the language adopted by the disability movement in the United Kingdom. The term people with disabilities (PWDs) is used extensively in developing countries, and I do not intend to undermine this concept or people who favour this concept.

health care. During this time both developed and developing countries adopted conventional systems of service delivery through urban based rehabilitation institutions and 'care' homes. In 1978, the Alma Ata Declaration<sup>3</sup> of 'Health for All' placed obligations on governments to take rehabilitation into account in national plans for comprehensive health care. In light of the principles of the Alma Ata Declaration and the lack of specialized medical rehabilitation services in the developing world, the World Health Organisation (WHO) began to articulate the concept of Community Based Rehabilitation.

The aim of CBR is to ensure that rehabilitation services are provided to all disabled people, whether they live in an urban or rural setting and whether they are rich or poor. This approach involves measures taken at community level to use and to build upon the resources of the community as well as drawing on specialized secondary and tertiary services as appropriate. WHO has recognized that most basic rehabilitation activities can be carried out in the disabled person's own community, using the community resources and benefiting from the primary health care system. From the beginning, the focus of CBR was on training a disabled person to carry out daily activities such as being part of family and community activities, making a living, going to school and playing – mainly by using local resources. To facilitate this process WHO published a CBR Manual 'Training in the community for disabled people' in 1989<sup>4</sup>. It took years to complete, including the field testing of three earlier versions in 1979, 1980 and 1983. The manual consists of 34 modules: four guides and 30 training packages. The guides are for local supervisors, community rehabilitation committees, disabled people and schoolteachers. The training packages were aimed at assisting family members who support people with different kinds of impairments. The manual played an important role in the promotion of CBR and in changing the quality of life of disabled people in developing countries. It has been translated into more than 50 languages, and is still being used regularly in many countries. In Uganda and Ghana, Sightsavers' CBR programmes have used these manuals extensively. In many countries, Ministries of Health and Non Governmental Organisations (NGOs) have come to play a vital role in promoting CBR in developing countries. Sightsavers assists with the funding of a diploma course in CBR at the University of Winneba in Ghana, many of the modules have been based on the WHO CBR manual. However, after a review two years ago, the course now reflects a more human rights based approach to CBR in addition to impairment specific aspects.

During the 1980s several key initiatives and declarations served to reinforce the direction of travel of the CBR discourse away from purely medical model approaches and towards social and rights based approaches. Namely the United Nations decade of Disabled Persons, the World Programme of Action Concerning Disabled Persons and the introduction of The United Nations'

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<sup>3</sup> International Conference on Primary Health Care, Alma-Ata, USSR, 6–12 September 1978, [http://www.who.int/hpr/NPH/docs/declaration\\_almaata.pdf](http://www.who.int/hpr/NPH/docs/declaration_almaata.pdf)

<sup>4</sup> WHO training manual on CBR 'Training in the community for disabled people (1989)' <http://www.who.int/disabilities/publications/cbr/training/en/index.htm>

Standard Rules on the Equalization of Opportunities for Persons with Disabilities<sup>5</sup>. These initiatives played a significant role in promoting equality of opportunity and dignity alongside many examples of domestic legislation. Disabled people demanded to become actively involved in the planning of strategies and policies that affected their lives at a global level. Gradually DPOs began playing significant roles in CBR initiatives globally, policy makers began to recognize the important role disabled people, their families and organisations could play in the quest for equality and human rights.

However, the focus on medical model discourse remained a feature in the 1980s, as demonstrated by the International Classification of Impairments, Disabilities and Handicaps (ICIDH). It gradually started shifting, and later the concept of International Classification of Functioning and Participation was introduced in 1990. This shift was part of the recognition that medical approaches alone did not work and that a comprehensive and holistic approach of disabled people's needs was required. However, although shifting, the dominance of the medical model approach often still prevails today.

In 2003, the Government of Finland hosted a global consultation to review the progress of CBR in its 25th year. The Helsinki review brought together stakeholders from across the globe. It was organized and attended by WHO, ILO, UNESCO, international organisations of, and for disabled people and international nongovernmental organisations working in the CBR field. Among many recommendations, the most notable ones are to a) promote CBR as a part of wider poverty reduction strategies b) adopt a multi-sectoral approach and involve DPOs in CBR c) work to make disability part of international, regional and national agendas, namely poverty Reduction Strategy Papers (PRSP); Millennium Development Goals (MDGs) and New Partnership for Africa Development (NEPAD). To highlight the Helsinki recommendations, ILO, UNESCO and WHO updated the CBR Joint position paper<sup>6</sup> and redefined CBR as 'a strategy for rehabilitation, equalization of opportunities, poverty reduction and social inclusion of people with disabilities.' The purpose of the Joint Position Paper was to promote human rights and the call for action against poverty. It defined CBR as a strategy within the scope of general community development, one that focuses on the rehabilitation, equalization of opportunities and social inclusion of all disabled people. It recognized that CBR is an effective strategy to meet the needs of disabled people. The paper noted that CBR needs to be implemented through the combined efforts of disabled people themselves, their families, organisations and communities, and the relevant governmental and non-governmental health, education, vocational, social and other services. It also acknowledged the role of DPOs as a key resource to strengthen CBR programmes.

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<sup>5</sup> The Standard Rules on the Equalization of Opportunities for Persons with Disabilities, Adopted by the United Nations General Assembly, forty-eighth session, resolution 48/96, annex, of 20 December 1993, <http://www.un.org/esa/socdev/enable/dissre00.htm>

<sup>6</sup> ILO, UNESCO and WHO CBR Joint position paper – 2004, <http://www.who.int/disabilities/cbr/en/>

Although CBR is practised in more than 90 countries and is part of many national strategies, most CBR programmes continue to follow a vertical approach, focusing on one or at most two domains of life. For example, many strategies focus on health alone or exclusively on physical rehabilitation. Others focus on education or income generating activities. The single domain approach does not adequately address the multi-dimensional needs and interests disabled people living in communities in developing countries. Sightsavers has, until recently, adopted vertical approaches, with a major focus on issues of health and a limited focus on the primary education sector. Its work had traditionally been focused on eye care service delivery, with smaller programmes for irreversibly blind and visually impaired people to deliver daily living, orientation and mobility skills; or provide assistive devices. The Helsinki Review and the revised Joint Position Paper provided Sightsavers with a new framework, and in 2005 Sightsavers wrote a new internal CBR policy aligning its work within human rights, social inclusion and a comprehensive approach to inclusive development.

In order to ensure that CBR continues to be relevant to the needs and interests of disabled people, their families and the communities in which they live, it must adopt a multi-sectoral comprehensive approach addressing the key domains (or components) of well-being. The CBR Joint Position Paper promoted multi-sectoral and rights-based approach, and at the same time focused on poverty reduction within an inclusive community. Putting the policy into practice however requires Guidelines. The publication of the CBR Joint Position Paper created a demand for developing 'Guidelines' to implement the CBR joint position paper. WHO, ILO and UNESCO agreed to develop Guidelines, with full collaborative stakeholder engagement. Sightsavers became one of the many international NGOs to work with the UN agencies as a major stakeholder, namely, the lead author on the 'social' component, and as a member of the education group team.

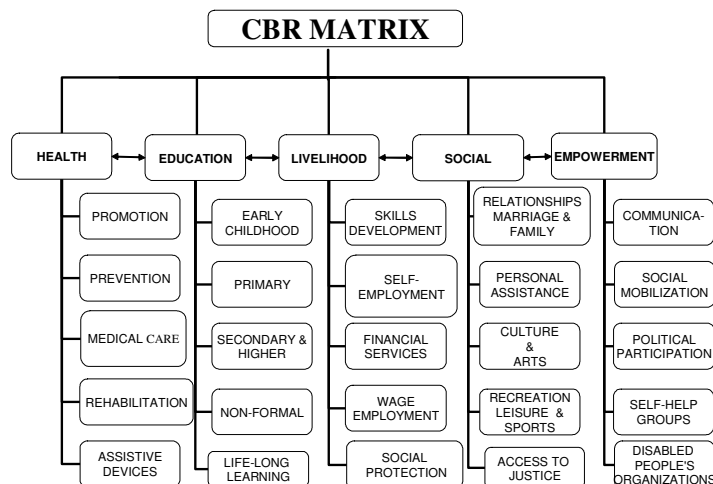
### **Current developments**

The CBR Guidelines are being developed by three UN agencies: WHO, ILO and UNESCO. It is being actively supported by 13 International Non-Governmental Organisations (NGO) including DPOs. Over 150 experts from across the globe have contributed to the draft Guidelines which have now been field tested in 25 countries.

The Guidelines have five major components: health, education, livelihood, social and empowerment. Beside these five components, the Guidelines also focus on management of some special scenarios including CBR and HIV/AIDS, CBR and leprosy, CBR and mental health and CBR in crisis situations. It was acknowledged that all communities are different – in terrain, culture, their political systems, socio-economic conditions and many other factors. Therefore there is no single model of CBR appropriate for the whole world. There are many models for CBR programmes reflecting unique situations and conditions. However CBR programmes have commonalities and there is a need for some

common norms to guide all CBR programmes and a common framework which will truly reflect a comprehensive multi-sectoral approach.

To promote a holistic model of CBR, further work has been done to identify the key elements or sub-domains of the five key components, which resulted in the development of the CBR matrix. This matrix provides a framework for a coherent CBR programme. The matrix illustrates the areas which combine to form a CBR strategy. It consists of five components (domains), each divided into five elements (sub-domains). Each of these elements has a dedicated chapter in the Guidelines. The matrix represents the topic areas which an effective CBR programme may contain, depending on local circumstances.



The goal of the CBR Guidelines is to enable inclusive development and inclusive societies for disabled people. The CBR Guidelines focus on mainstream local means and initiatives to promote well-being and life with dignity, such as healthcare from existing health facilities, education from regular school or college, livelihood through traditional skills, income generation programme, micro credit, inclusion and participation through local

cultural initiatives and community life. Formation of Self-help groups (SHGs) or DPOs needs to be the centre of a CBR strategy to access mainstream opportunities and to sustain it. These all together will promote and reinforce the concept of community-based inclusive development.

The CBR Guidelines are not prescriptive – they contain different ideas, different experiences and examples to promote and illustrate an up-to-date, practical strategy. The Guidelines suggest ways to achieve these aims through community

based initiatives that focus on inclusive development. The key approaches are to:

- Meet basic needs and reduce poverty
- Build capacity
- Create opportunities for livelihood, health, rehabilitation, education and social life
- Involve DPOs or facilitate disabled people to organize
- Collaborate across sectors – partnership
- Involve the whole community
- Involve local government and leaders
- Use the legislation, judicial and political systems

## **Participation**

The Guidelines development process as an exercise in multi-stakeholder cooperation. As a first step towards developing the Guidelines, a concerted effort was made to develop a multi-stakeholder consensus on CBR, its various components (domains) and elements (sectors).<sup>12</sup> Various stakeholders including UN Agencies (ILO, UNESCO and WHO), representatives from Member States, from academia, from NGOs, DPOs, professionals' organisations and CBR experts including pioneers in the field came together to finalize the outline of the CBR Guidelines and agree upon a common agenda called 'Inclusive development to promote inclusive society.' It was agreed that if it is going to live up to this agenda, CBR must use the principles of community action to ensure equality of access to health, education, livelihood opportunities, life in family and community, social mobility and political empowerment. Special efforts have been made to ensure sufficient participation of disabled people and CBR practitioners from developing countries in developing the Guidelines.

Since its inception, the development of the Guidelines has been a participatory process. Participatory processes to validate, or field test the CBR Guidelines have been an extremely important part of the Guideline development. Approximately 30 CBR programmes in 25 countries contributed by reviewing the draft Guidelines. Feedback from this field validation process has been incorporated into the Guidelines. The extensive field testing and participation has provided critical analysis of the framework for CBR from a grassroots perspective, and highlights examples of good practice in the field.

### Field testing/validation

Field testing in Ghana and Uganda took place in focus groups between September and November 2007. Participants across the two countries included: the United Nations, DPOs, INGOs and local NGOs, medical and healthcare professionals, local government officials, itinerant teachers, university lecturers and students from a CBR course, CBR personnel, disabled people religious and

traditional leaders. In Uganda, field testing highlighted that the deafblind community were not taken into consideration adequately, and were not mentioned among the different categories of impairment.

### **Wider community engagement:**

The participants from Ghana thought that views should have also been sought from opinion leaders and the wider community, in order to compare their responses with the outputs from focus groups so that a wider more practical approach could be obtained.

Difficulties have been encountered in implementing CBR programmes because of lack of cooperation from the community members, PWDs and their families. The challenges faced by local CBR personnel are often engaging people to volunteer their expertise, skills and knowledge. Some of the solutions offered included:

- building partnerships with people and organizations
- providing business development facilities because CBR programme is interdisciplinary, multi-sectoral and cross cutting
- including everybody to achieve the set objectives.

The teams thought that when the guidelines when followed they gave CBR workers the insight of where, when and how to work with persons with disabilities - especially building partnerships with mainstream organizations.

Beyond the community, Uganda explained that CBR networking nationally and globally should be elaborated upon. They also mentioned the need to create linkages between CBR, PWDs and all other social networks in communities and development initiatives.

### **Livelihoods and lack of opportunities**

In Ghana people with disabilities are expected to accept *any* job without being critical because there is a perception that they should be grateful. However, in developing countries the scarcity of jobs available in many sectors is an issue for all unemployed people, disabled or not. The team felt that people with disabilities needed greater skill diversity, solidarity building, self confidence and the ability to speak as a united group on employment and skill issues. Uganda explained that disabled people are often emphasized as consumers of goods and services, whereas the suppliers also need to also be made aware of disability issues.

### **Role of religion and culture**

In Ghana, the Guidelines were felt to be culturally sensitive because the use of traditional medicine and herbal treatments were documented. The team also found that they would largely employ non-formal mechanisms of redressing grievances because disability issues in official circles are subject to deeply ingrained societal stereotypes. It was felt that CBR workers needed to be able to analyze his/her environment carefully before suggesting activities. For example,

in most 'Christian' communities animal husbandry involving fowls and pigs would be a successful venture but in a Muslim community, rearing of pigs would be a disaster as no one would patronage and the business will collapse. It is important that a community to decide what is good for them. After much deliberation from the team, it was agreed that religion and culture played a major role in making people accept their impoverished lives as divine and that they could not imagine a life different from what they have. This is because of strong cultural beliefs in most parts of the community that when a couple gives birth to a disabled child, it is said to be a curse. This in turns to hinder the development of that disabled child as the child grows.

In Uganda, the cultural appropriateness of the Guidelines were also highlighted. For example, the practice of youngsters taking care of toddlers siblings. However, it was felt that unique groups such as nomadic peoples and their specific ways of life, need to be more thoroughly addressed. The issue of cultural rights also needed greater clarity to aid understanding.

### **Gender**

The Ugandan team stated that gender issues focused on women instead of the power dynamics between women and men. In Ghana, they highlighted that the notion of marginalization is not peculiar to disabled women alone, but rather a phenomenon associated with women generally. They suggested that this issue could be dealt with as a human rights violation.

### **HIV/AIDS**

In Ghana the teams highlighted the issue of HIV/AIDS education for people with disabilities, and the issue of the lack cooperation from health personnel to receive training in some cases. The Ugandan team felt strongly that sex and sexuality needs to be clearly addressed under the HIV/AIDS section of the Guideline.

### **Involvement of PWD and capacity building inc. self-esteem**

Both the Ghana and Uganda team welcomed the importance of communicating with and involving PWDs, particularly their communities and families. It was noted that this was missing from the original WHO CBR Manual<sup>7</sup>. However, the Ugandan team felt strongly that the role of children and youths with disabilities were not given enough emphasis. Instead adults seem to be the category most targeted for increased participation in community activities and programmes.

In addition, one of the key concepts considered missing in the 'empowerment' component was counseling and guidance. This is considered essential in order to help the person with disability to overcome the emotional/psychological effect

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<sup>7</sup> WHO training manual on CBR 'Training in the community for disabled people (1989)' <http://www.who.int/disabilities/publications/cbr/training/en/index.htm>

of their impairment and to achieve confidence and self esteem and in turn to enhance group solidarity and dignity amongst persons with disabilities.

Both teams wanted to see greater emphasis on the importance of PWDs as role models. When PWDs have been used as role models in their respective communities by the CBR programmes within and outside the community it has really helped change the mind set of other PWDs in the community.

### **Collective responsibility versus leadership**

Within the 'self-help groups' component, the development of leadership skills for all PWD is a key element. However, the Ugandan team thought that this might not be suitable in the community project, where premium is placed on the strength of each individual to influence other members of the group to achieve their objectives. Self-help groups have to be developed on the basis of common need and problems faced by disabled members in order to achieve collective responsibility. The participation of all PWDs in developing the group will ultimately lead to increased visibility of group members within the community and in turn the development of individual members. Individual strengths enhance the group a whole rather than singling out the leadership potential of just one member.

### **Lack of infrastructure and resources**

Lack of infrastructure and accessibility is seen as a challenge to programmes, especially roads and transport. This presents a real barrier to reaching target groups for both service providers and users because PWDs are geographically dispersed.

Some of the activities listed in Guideline require specialized treatment and experts. As a result of the African 'brain drain' of healthcare professional, some specialists are simply not available. For example, working with people with severe developmental impairments has always proved difficult even at the national level in Ghana. Most general healthcare professionals do not receive training on disability issues, partly due to lack of funding, and partly due to lack of political will. As a result, healthcare course curricula are difficult to change.

The lack of adequate budget allocations at a local and national level was unclear from the Guideline; as a result both human and financial resources are lacking in both countries.

### **Beyond medical rehabilitation**

The Guideline clearly locates poverty and development as key factors that influence incidence and prevalence of disability. The Guideline moves away from rehabilitation standing alone to broader and current thinking in international development. There is more emphasis on empowerment of PWDs rather than PWDs as objects of pity and recipients of charity and service delivery, which emphasized the medical model. Both teams welcomed the shift in debate to

PWDs as rights holders, stating the benefits of human rights discourse and sustainability. In Africa, in particular it is important to move away from charity model, especially since many CBR programmes have been started by the church. However, the Ghanaian team highlighted an omission in the Guideline of sensitizing religious leaders about the importance of early childhood education for children with disabilities.

### **Partnerships**

The Ghana team recognized that at a community level, partnerships between DPOs and CBR personnel were very important, especially in relation to rehabilitation aids and appliances. DPOs are able to promote the sustainability of CBR through their ongoing involvement and participation.

DPO partnerships with government are crucial in developing flexible educational curricula which are responsive to children with disabilities requirements. Beyond education, the Ugandan team stressed the role of government as key implementers of CBR programmes.

In Uganda, partnerships between healthcare centres and DPOs were key. The Coordinator of Bawku hospital eye unit commended the collaboration between the CBR programme and the unit. According to him, the CBR programme contributed a great deal in making outreach programmes successful and also getting clients prepared for both consultations and surgery. However, it is also important to sensitize PWDs to register with the National Health Insurance Scheme to access better health care.

### **Strengthening legislation**

Many of the principles and key concepts in the CBR Guidelines reflect the provisions of the UN Convention on the Rights of Persons with Disabilities. Undoubtedly these Guidelines will become an important tool for implementing the CRPD at a local level in developing countries. Current legislation in both countries produce a number of institutional barriers. DPOs could serve as pressure groups to lobby governments who are not immediately willing harmonize domestic legislation in line with the CRPD. In Ghana, it was felt that various district assemblies could strengthen existing domestic legislation to ensure inclusion of PWDs in all sectors of the economy. The Guidelines have clear statements that can help promote respect for the PWDs and linkages between DPOs could build bridges between local-district-national-regional and international policy. The Ugandan team would like further guidelines on how to link the forthcoming CBR Guidelines to the CRPD<sup>8</sup>.

### **Power and corruption**

Both countries agreed that as stated in the Guideline, political structures are the most powerful. Some of the suggested activities in the Guideline were

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<sup>8</sup> Basic information on this issue is available from Diane Mulligan, Disability and Social Inclusion Advisor at Sightsavers International, dmulligan@sightsavers.org

considered controversial, given the political affiliations of some opinion leaders. Since almost every decision made by political leaders affects local people, and that people with money often influence these leaders, subsequent decisions are not likely to favor the situation of PWDs.

The Guidelines have now been peer reviewed by cooperating universities and external experts, and the final CBR Guidelines are expected to be published in December of 2009. A concerted effort has been made to ensure larger ownership and partnership and to develop a practitioners document for CBR managers. The momentum that has been created through the process of developing the Guidelines will continue to grow. Further occasions for cooperation and knowledge sharing and additional opportunities for working in alliance across the spectrum are already being discussed and considered. One of these opportunities is to use the CBR Guidelines as a tool to implement the United Nations Convention on the Rights of Persons with Disabilities (CRPD) at a grass roots level.

### **Conclusions**

I conclude that disabled peoples organizations in developing countries can play a role in shaping public policy. These organizations can use their own experiences to inform and develop domestic policy in country in order to secure the rights of disabled people. Sightsavers has launched a strategic plan 2009-2013 that has three out of four overall goals which can be located within the forthcoming CBR Guidelines and are aligned the CRPD. I have demonstrated that the WHO/ILO/UNESCO Guideline development process has used the experience of Sightsavers programmes to inform its content and ensure relevance in African contexts. Sightsavers' grassroots research has influenced policy on disability issues, in turn, policy dating back to Helsinki has changed and informed Sightsavers research and practice.

The CBR Guidelines are an important step forward in promoting CBR as a community based inclusive development strategy. The Guidelines focus on meeting basic needs, reducing poverty, accessing benefits of mainstream developmental initiatives, inclusive community and empowering people with disabilities and their families. It also focuses on implementing the CRPD using community-based initiatives. CBR must also change. Increasingly, it needs to operate in terms of a rights-based and inclusive development strategy in order to ensure that the benefits of development initiatives reach disabled people and their families. Poverty is often the major barrier in improving quality of life, accessing health care, education, housing and other services. Accordingly, CBR will need to increasingly focus on reducing poverty, facilitating access to basic human rights such as food, healthcare, education, and housing while at the same time working for full inclusion and participation.