Information Sharing and Community-based Rehabilitation

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SUMMARY

Information technologies offer opportunities for improving community-based projects and programmes. Through the use of computers and access to the internet, information and experience can be located and exchanged more easily. However, the amount of information available on the internet grows every day and it becomes more and more difficult to identify what is relevant. Resource centres can help organisations or individuals in this process. This chapter explores how these new information technologies have developed and how they can help CBR workers become more informed. A list of useful web sites is presented at the end of the chapter.

INTRODUCTION

Since the 1980s, community-based rehabilitation has been implemented in many countries in Africa, Asia and Latin-America. Despite the common name it developed in various forms appropriate for the local and regional conditions, probably due in part, to difficulties in communication between the communities concerned. Until some years ago the exchange of information and experiences between organisations in different continents was mainly limited to meetings, articles in journals and slow letters. Publications took a long time to reach people who were interested in them.
During the last two decades new ways of publicising, presenting and communicating, have developed through Information and Communication Technologies (ICT) such as the Internet, affordable computers and CD-ROMs.

ICT have changed the ways of exchanging and obtaining information over the last decade. Personal computers have become more powerful and affordable to individuals and organisations. Floppy disks and CD-ROMs have enabled larger amounts of information to be circulated and shared with people all over the world, making it possible to print documents or watch films.

In particular, the increasing popularity of the Internet in the mid-1990s, improved accessibility of information and ease of communication - including the flow and exchange of experiences, knowledge and publications - between organisations and individuals in different countries. Even in countries with limited and very slow internet connections, it is now possible to go online in an internet cafe, library or resource centre.

These possibilities have enabled organisations to exchange information resources and experiences more easily. Publications in electronic form are easier to distribute and share. Forms and formats of communication have also changed over the last few years. It is now possible to join a mailing list, an online forum or just to browse through recent websites to get access to important and up-to-date information. Online discussion forums such as the DGroups (www.dgroups.org) and online encyclopaedias such as Wikipedia (www.wikipedia.org) now attract users worldwide.

The national and international disability movements have made use of these new opportunities. Many DPOs and disability NGOs have started to publish materials and to spread news about their activities on the Internet (e.g. www.disabilityworld.org). The Internet has become a platform for lively discussion and information exchange.

However, despite the many possibilities that the Internet offers, many people are still excluded or have limited access. This may be for logistical reasons, economic or social factors, discrimination or just the unfamiliarity with the use of computers. Even with full access to the Internet, it can be difficult to find particular information. Lack of accessibility is largely a problem for organisations in developing countries. As the UNDP Sustainable Development Programme states on its website:

"[...] recent statistics indicate that, contrary to many expectations, the information gap between industrialised countries and developing countries is growing. Moreover, within many developing countries, the gap between 'haves' and 'have nots' is increasing at an even faster pace. Recent estimates indicate that the global number of Internet users is about 180 million, of which only 14% are in developing countries. In the African continent alone, there are around 1.3 million users; of these almost a million are in South Africa. In other words, the average number of users is 6,000 people per country - once we exclude South Africa. Some analysts have described this process of uneven development of the Internet as the emergence of the Fourth World in the global economy."

(Source: www.sdnp.undp.org/about/)

The sharing of information, knowledge and experience is necessary for sustainable empowerment and support of people and organisations in middle and low income countries, so their community work in the areas of civil society, rehabilitation and disability can further be improved. A good example has been the mailing list of the Disability Knowledge and Research round tables which were accompanied by a lively mailing list and online resource platform (http://www.dgroups.org/groups/disability_KaR/index.cfm?op=dsp_info).

Information resource centres can play an important role in identifying and adapting information to the local context in which it is required. Resource centres often function as information access points, providing internet access and training facilities, as well as important resources, in different languages. International cooperation between different centres would enable an improved sharing of knowledge and experience in the field of community-based rehabilitation.
One online resource centre is Source (www.asksource.info) that identifies information resources in the field of disability. Beside a key topic area about disability in development, Source offers a number of commented bibliographies, so called Key Lists. Especially for developing countries with little access to ICT, access to the internet is a problem that only partly can be addressed through the continuation of paper based information or collections of information resources on CD-ROM.

One example of a resource centre in a developing country is the Disability Information Resource Centre in Uzbekistan (www.dirn.uz). It is part of a network of information points in libraries and rehabilitation centres, which provide disability information resources. The network covers the eastern region of Uzbekistan. Besides the physical collection, the resource centre maintains a website that provides important documents in Russian and Uzbek.

Bearing in mind some of the difficulties of accessing information on the internet, one of the problems to a new user is knowing the address of useful sites. The following list is an attempt to address this problem and aims to provide the reader with a selection of addresses that have useful information about disability and community based initiatives, that provide useful and stimulating information and ideas to readers.

**CBR**

Community Based Rehabilitation (CBR) Resources

Many resources related to CBR are presented on this site. The site is structured in sections: CBR websites, CBR related websites, CBR books, CBR academic programs, CBR NGOs (non-governmental organisations). The site is maintained by a PWD, who has graduate and post-graduate qualifications in rehabilitation and has worked in the disabilities field in the USA. [http://www.cbrresources.org](http://www.cbrresources.org)

Community Based Rehabilitation (CBR)

STUBBS, Sue

This document contains personal reflections from the IDDC co-ordinator, Sue Stubbs on CBR. They are drawn from 10 years of experience working in the field of international disability and development. [http://www.iddc.org.uk/dis_dev/strategies/cbr.pdf](http://www.iddc.org.uk/dis_dev/strategies/cbr.pdf)

**Empowered to Differ: Stakeholders' Influences in Community-based Rehabilitation**

FINKENFLUGEL, Harry

'Empowered to differ' equally addresses researchers and CBR professionals. The book gives an overview about the developments in the field of community-based rehabilitation since 1978, using the examples of CBR projects in Southern Africa. Finkenflugel asks for the knowledge and the evidence for CBR and to what extent the roles, interests and powers of stakeholders can contribute to this knowledge and evidence. ISBN:9077595112


In 1994, the ILO, WHO and UNESCO published the first version of this joint position paper. Since then progress has been made in several fields. Nevertheless many disabled people are still not reached or included in the fields of rehabilitation, employment or education. Especially disabled women, people with mental health problems or HIV/AIDS and poor disabled people are not reached. This paper underlines that community-based rehabilitation is a strategy promoting multi-sectoral collaboration to reach different community groups. CBR has to be based on the
principles of equal opportunities, participation and human rights.
ISBN: 92 4 159238 9
http://unesdoc.unesco.org/images/0013/001377/137716e.pdf
World Health Organization (WHO) Marketing and Dissemination, CH-1211
Geneva 27, Switzerland

Disability Coming on the Front-line in Development
KONKKOLA, Kalle
This article summarises the changes in development work over the last ten years. It describes the work of UN agencies, the different banks and Nordic NGOs as well as overall aspects of disability in development.
Netzwerk Menschen mit Behinderung in der Einen Welt
http://www.bezev.de/literatur/docs/DISABILITY%20COMING%20ON%20THE%20FRONT-LINE%20IN%20DEVELOPMENT.PDF

A Manual for CBR Planners
THOMAS, Maya; THOMAS, M J Eds
This manual has 13 sections. A very useful overview of the history of CBR is given, with valuable introductory reading for newcomers to the field. The following 5 sections cover needs assessment and suggestions of how to understand local communities and encourage community participation in CBR programmes. The final 6 sections are concerned with programme management issues, for example organising self-help groups, training personnel for CBR, and the sustainability of projects including evaluation and management of change

Poverty and Disability
DURHAM, Michael
This is a summary of the report "Perspectives on Disability, Poverty and Technology" written by Albert, B; Mcbride, R and Seddon, D. This summary defines disability and impairment, and emphasises the social model of disability. It demonstrates the links between poverty, disability and impairment, and advocates for the mainstreaming of disability into all development projects.
http://www.disabilitykar.net/pdfs/odg-summary.pdf

Chronic Poverty Report 2004-05
CHRONIC POVERTY RESEARCH CENTRE (CPRC)
This major report presents an overview of the chronic poverty facing some 400 million people, and the policy implications. The report examines what chronic poverty is and why it matters, who the chronically poor are, where they live, what causes poverty to be persistent and what should be done about it. A section of regional perspectives looks at the experience of chronic poverty in sub-Saharan Africa, South Asia, Latin America and the Caribbean, transitional countries and China. A statistical appendix brings together data on global trends on chronic poverty

Disability, Poverty and Development
DEPARTMENT FOR INTERNATIONAL DEVELOPMENT (DFID)
This is a major policy document of DFID, the British Government's overseas aid department. It assesses the significance of disability as a key development issue, and its importance in relation to poverty, human rights and the achievement of internationally agreed development targets. It also sets out ways in which development cooperation, including DFID's own work, can help incorporate the rights and needs of disabled people into the mainstream of poverty reduction work and the achievement of...
human rights. It is useful for disability policy-makers, NGOs and disabled people working in advocacy and development

Measuring Welfare for Small but Vulnerable Groups: Poverty and Disability in Uganda
HOOGVEEEN, Johannes G
When vulnerable groups such as disabled people are surveyed, representative welfare estimates from non-purposive sample surveys becomes an issue. This paper takes the example of Uganda and describes the connections between disability, poverty, well-being and social welfare. This is possibly the first time that, for a developing country, statistically representative information on income poverty amongst disabled people has been generated.

Poverty and Disability: a Survey of the Literature
ELWAN, Ann
This review summarises the literature on disability and its relationship to poverty, including education, employment, income, and access to basic social services. Despite the dearth of formal analysis, it is clear that in developing countries, as in more developed areas, disabled people (and their families) are more likely than the rest of the population, to live in poverty. It is a two-way relationship — disability adds to the risk of poverty, and conditions of poverty increase the risk of disability. Disability in developing countries stems largely from preventable impairments associated with communicable, maternal and perinatal disease and injuries, and prevention has to remain a primary focus. An increasing emphasis on community-based participatory rehabilitation, reflects growing recognition of the inadequacy of past official programmes, particularly involving specialised and exclusionary institutions.

RESEARCH

Label us Able: Proactive Evaluation of Finnish Development Co-operation in Disability Issues
NATIONAL RESEARCH AND DEVELOPMENT CENTRE FOR WELFARE AND HEALTH (STAKES)
The Finnish Ministry for Foreign Affairs evaluates with this report its development policies for disabled people. This report looks at the last ten years of Finnish development co-operation and how a maximum impact on human rights and social development can be achieved. The four parts of the report investigate the main Finnish policies, the major findings and how disability can be mainstreamed into development issues. This evaluation report is valuable for international NGOs, disabled people's organisations and policy advisors who are looking for ways to mainstream disability. http://global.finland.fi/evaluations/labelable/

Data and Statistics on Disability in Developing Countries
Current disability statistics is far from robust or comparable globally and is particularly weak in low-income countries. There is a strong need for design development and standardisation of measures to be applied in both censuses and representative surveys. Important work in this regard is underway through the work by the Washington City Group and the DPO initiated research in Southern Africa. It is argued that it is important
to go beyond the issue of prevalence, and to produce statistics that can compare and analyse differences in standards of living between disabled and non-disabled persons. The disability - living conditions - poverty link should be the number one priority for broadening disability statistics (in low-income countries) from the current focus largely on prevalence. This publication explores the needs for data that can give a thorough picture of the situation for disabled people, possibilities for comparing between groups (including disabled and non-disabled people), documenting and analysing mechanisms explaining the close link between disability and poverty.

http://www.disabilitykar.net/docs/thematic_stats.doc

**INFORMATION SHARING**

**ICT and Development: Enabling the Information Society**

GUISLAIN, Pierre Ed
Prepared for WSIS, this compilation addresses how ICT contributes to economic and social development and how public policy plays a critical role in reducing the digital divide. It emphasises policies related to information and communication infrastructure, including telecommunications and the Internet. It suggests, that bridging the digital divide requires first and foremost, the adoption and implementation by national governments and regulators of pro-competitive policies and regulations that remove existing bottlenecks to sector growth and access.


**Disabled People and the Internet: Experiences, Barriers and Opportunities**

This report explores how provision of goods and services over the Internet affects people's lives. While the Internet might have some capability to provide goods, services and communication at a distance, improving access in doing so, some research findings in the early days of e-commerce suggested diminished access for some groups. This research focuses on the impact of the Internet on people with disabilities. There is the possibility that provision of information and services through the Internet might actually narrow rather than widen choices, because it might lead to the phasing out of traditional ways of providing services preferred by some disabled people.


**EDUCATION**

**Enabling Education Network (EENET)**

Excellent site focusing on inclusive education. This site is regularly updated with publications from the South. Includes a a bibliography of resources, a newsletter and information on child-to-child, parents, policy, teacher education, early childhood and communication disability. It also has some publications in documents in Arabic and other languages.

http://www.eenet.org.uk

**A Blind Child in my Classroom : a Handbook for Primary Teachers Summary**

GALE, Gillian; Cronin, Peter
This book gives ideas what can be done in a simple and effective way to include a child with vision disabilities in a class

**HEALTH**

**Double Burden : a Situation Analysis of HIV/AIDS and Young People with Disabilities in Rwanda and Uganda**

YOUSAIFI, Aisha and EDWARDS, Karen


Abstract: This situation analysis gives an in-depth picture of how young people with disabilities in Rwanda and Uganda are affected by HIV/AIDS. Results from focus group and individual interviews conducted in each country, reveal that young people with disabilities are highly vulnerable to being infected by HIV/AIDS. The study also shows how they are less likely to be able to learn how to protect themselves because of communication difficulties, discrimination by health service workers and educators, and difficulties accessing health centres. The situations of Uganda and Rwanda are analysed separately and compared - giving a thorough insight into the extent of the problem. Recommendations on policy, programming and research are given.


**Rethinking Care from the Perspective of Disabled People : Conference Report and Recommendations**


Abstract: This conference report includes recommendations for government action, using a rights-based approach. It covers a range of care issues including a holistic approach to access; legislation and funding; medical rehabilitation; support service; and awareness raising. http://www.who.int/ncd/disability/report.pdf

**Revising the United Nations Census : Recommendations on Disability**

MBOGONI, Margaret, ME, Angela (First Meeting of the Washington Group on Disability Statistics, Washington, 18-20 February 2002)


This paper describes the issues concerned with the revision of the disability section of the United Nations Principles and Recommendations for Population and Housing Censuses. The discussion includes how the newly published International Classification of Functioning, Disability and Health (ICF) can be incorporated in the recommendations. Issues for consideration are: (i) new approaches in defining disability; (ii) a new list of types of disabilities based on the ICF; (iii) improvement of the wording and structure of questions to identify persons with disabilities; (iv) improvement of the dialogue between users and producers; and (v) the need to perform cognitive and quantitative testing of questions on disability. The paper also gives an overview of how countries have used the census to collect data on disability and it underlines advantages and disadvantages of its use highlighting its importance in the collection of information on persons with disabilities, particularly in developing countries.

http://www.cdc.gov/nchs/about/otheract/citygroup/products/me_mbogoni1.htm

**Towards a Common Language for Functioning, Disability and Health : ICF The International Classification of Functioning, Disability and Health**


This is the introduction to WHO's International Classification of Functioning, Disability and Health, also known as the Beginner's Guide. It provides an introduction to the ICF and its use. It sets out what the ICF offers to health workers, planners and policy-makers. It also includes a list of organisations, agencies and NGOs who are part of the ICF collaborating network. http://www3.who.int/icf7beginners/bg.pdf