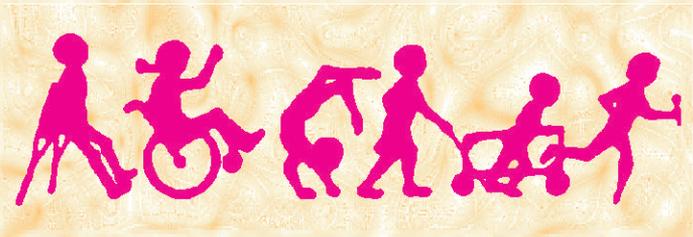


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ASIA PACIFIC DISABILITY REHABILITATION JOURNAL

Volume 20 ■ No. 1 ■ 2009

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Produced by: Shree Ramana Maharishi Academy for the Blind, 3rd Cross, 3rd Phase, J.P. Nagar,
Bangalore - 560 078, India. Tel : 91-80-26581076, Fax : 91-80-26588045 Email: srmab@vsnl.com
website: www.welcome.to/srmab

Printed at: National Printing Press, 580, K.R. Garden, Koramangala, Bangalore - 560 095, India.
Tel : 91-80-25710658 Email: nppbangalore@touchtelindia.net

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Website: <http://www.aifo.it/english/resources/online/apdrj/journal.htm>
Sponsored by AIFO, Bologna, Italy

APDRJ is indexed in:
CINAHL Information Systems
1509, Wilson Terrace, Glendale
CA 91206, USA

Elsevier B.V.
Bibliographic Databases
P.O. Box 2227
1000 CE Amsterdam
The Netherlands

EDITOR'S COMMENT

The Convention on the Rights of Persons with Disabilities and its Optional Protocol were adopted by the United Nations General Assembly in December 2006, and opened for signature in March 2007. The Convention received its 20th ratification on 3 April 2008, ensuring the entry into force of the Convention and its Optional Protocol 30 days later. As on date, there are 137 signatories to the Convention, 81 signatories to the Optional Protocol, 44 ratifications of the Convention and 26 ratifications of the Protocol (source: www.un.org/disabilities). The Convention and its Optional Protocol are serviced by a joint Secretariat, consisting of staff of both the United Nations Department of Economic and Social Affairs (DESA), based in New York, and the Office of the High Commissioner for Human Rights (OHCHR) in Geneva. The Committee on the Rights of Persons with Disabilities has been set up to monitor the implementation of the Convention and its members include people with disabilities. OHCHR has conducted a study on civil society and recently held a stakeholder consultation with Member States, inter-governmental organisations, national human rights institutions, representatives from NGOs and DPOs as well as other interested individuals, on key legal measures for ratification and implementation of the Convention.

Although it is more than 8 months since the Convention came into force, it appears that the whole process of signing, ratification and implementation of the Convention is still at an initial stage in most countries. The responses from member states and civil society to the OHCHR studies and consultations on the Convention over the last one year clearly indicate this. In fact, the response rates were low (137 for the study and 74 for consultation). The OHCHR study highlighted that awareness is low among many stakeholders (especially civil society and DPOs) on the UN Human Rights system and instruments, including the Convention. The study also stressed the role of civil society in lobbying and advocacy with their governments for signing, ratification and implementation of the Convention. OHCHR has subsequently made attempts to inform and educate the key stakeholders in governments, civil society and DPOs, through their website, newsletters, meetings and publications.

Another study conducted by the Commonwealth Foundation on the challenges in ratification and implementation of the Convention in its member states showed that in the countries that have signed and ratified the Convention or are committed to ratification, the major

contributing factors were the commitment of the governments; presence of existing policies and legislation on equal opportunities and rights protection, that acted as a forerunner for the CRPD in these countries; and the presence of a vibrant civil society that has espoused the rights based approach to disability issues. DPOs in these countries have been particularly influential in working with governments in the drafting of the Convention, and in advocacy with the governments for signing and ratification. The study also highlighted the fact that implementation of the Convention in these countries is another matter. Implementation is proceeding slowly, in a tentative manner, comprising mainly of examination and analysis of existing laws to make them in line with the Convention, setting up of committees, inter-sectoral meetings and discussions at different levels. Resource allocation for implementation is a major challenge, as developing countries with existing legislation have experienced.

The role of civil society in the ratification and implementation of the Convention is now being repeatedly emphasised as one of advocacy and lobbying with their governments. Capacity building of NGOs and DPOs is a key issue, to move towards a rights based approach and to work in a coordinated manner; to be aware, informed and updated about the Convention, and the UN Human Rights systems and instruments; and to advocate with their governments for national legislation and implementation of the Convention. Many useful tools for information and advocacy are available on the UN website (www.un.org/disabilities), and it is important for DPOs and civil society to keep themselves informed of developments and to work with their governments and the UN system, for ensuring effective implementation of the Convention.

The APDRJ team wishes its readers a very happy new year!

Dr. Maya Thomas

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GUEST EDITORIAL

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

Huib Cornielje*

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

ISBN 978-0-230-57394-9, published 2008.

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.

Main publisher: Palgrave Macmillan, Basingstoke, UK, and New York, USA

DEVELOPMENTAL ARTICLES

**TRANSITIONS TO ADULTHOOD FOR YOUNG PEOPLE
WITH DISABILITIES IN INDIA: CURRENT STATUS
AND EMERGING PROSPECTS**

Nidhi Singal*, Roger Jeffery**

ABSTRACT

In 2001, it is estimated that 270 million Indians belonged in the 12-24 years age group. While attention is being focused on these young people's potential for social transformation, some of them - such as those with disabilities - remain alienated from mainstream debates on development. It may be estimated that there are somewhere between 5 and 5.5 million persons with disabilities in the 12-24 years age group, hence, a significant minority. However, little is known about how they and those around them make sense of their lives and perceive their transitions to adulthood, as their surrounding milieu is transformed. This paper adapts the framework of transitions proposed by the World Bank's 'World Development Report 2007', to examine opportunities for young people with disabilities in the areas of learning, work and citizenship. The authors draw on existing literature and secondary data to analyse the lived experiences of young people with disabilities. What are their prospects in a time of optimism for Indian youth?

INTRODUCTION

Optimism of the 'youth bulge'

Collective identity and action necessitate points of inclusion, but conditions of poverty, disability, delinquency, disease and conflict, with their accompanying features of lack of access to food, health care, education, employment, media, markets and political institutions, serve as points of exclusion of young people (1).

The World Development Report 2007 (2), (Development and the Next Generation is only the latest of several reports [for example, those listed in (1)] that appear to bring a typically

neo-liberal approach to their attempts to bring 'youth' into mainstream development concerns. There has never, says WDR 2007, been a better time to invest in young people living in developing countries. Of the 1.5 billion people in the 12-24 years age group worldwide, 1.3 billion are living in developing countries, the most ever in history. WDR 2007 points out with great enthusiasm to this 'window of falling dependency rates': an expanding work force that has fewer children and elderly to support, thus providing the opportunity to spend on developing human capital. The arguments here are not merely economic (though that remains an important imperative), rather the need to invest in the young is essential as they are the next generation of parents and heads of households, with significant ability to impact and shape the lives of their children.

Youth also have a political potential, however, one that is addressed ambivalently: Herrera notes that there is 'mounting awareness of the potential roles of young people in forging more stable, democratic and economically prosperous societies', while also acknowledging them as potential 'forces of instability, radicalism, and impoverishment' (1). Herrera points out the issues highlighted by the emerging new global discourse on youth, and more significantly, to those it leaves hidden. In this paper the authors wish to draw attention to one of these in particular – the lives of young people with disabilities – through considering the case of India in some detail.

India is one of the countries with a low dependency window of opportunity, where only 7.1 percent of the population is 60 years and above (3). Approximately 51 percent of its population of 1.1 billion is under 25 years and two-thirds is under 35 years. In India, the euphoria around generation X is evident in reports suggesting that it is the driver behind the retail boom, providing a large proportion of the new consumers of the technology revolution (4).

In general, it is argued that while attention is focused on young people's potential contribution to social transformation (both positively and negatively), some young people – such as those with disabilities – remain alienated from mainstream debates. Consistently across the globe, especially in developing countries, mainstream policies and programmes working with young people overlook the needs of those with disabilities, while efforts aimed at people with disabilities tend to focus either on children or adults. Thus the unique social, psychological and physiological concerns of young people with disabilities tend to go unaddressed. Young people with disabilities 'are among the neediest and most overlooked

of all the world's children' (5) and are subject to a double marginalisation, being overlooked in the literature and policies focused on youth, as well as in literature and policies addressing issues related to people with disabilities.

The Biwako Millennium Framework for Action highlights the gravity of the situation by noting that, 'persons with disabilities, and especially women, youth and those in rural areas, remain disproportionately undereducated, untrained, unemployed, underemployed and poor' (6). The vulnerability of those living in poverty is especially marked, as 'disability is both a cause and consequence of poverty' (7). The poor are more likely to be disabled by impairments that are preventable or treatable (8). Additionally, a higher proportion of people with disabilities are likely to experience severe and chronic poverty than the proportion of non-disabled people (9), in both developed and developing countries.

The global total for adolescents and young adults with disabilities is between 90 million and 180 million, 85 per cent in the developing countries (10). Significant increases in their numbers are predicted over the next few decades, not just reflecting the increasingly youthful age structures in developing countries, but also because medical advances allow those who might not have been able to do so earlier, to survive, and all people with disabilities to live longer lives. Young people are also at a greater risk of acquiring a disability due to work related injuries, risk taking behaviour such as extreme sports, motor vehicle accidents, experimentations with drugs, unprotected sex, and indeed through violence and warfare. Global and regional estimates of the injury-specific causes of disability are lacking, but some estimates suggest that up to one quarter of disabilities may result from injuries and violence, though studies on violence-related injuries that result in disability are poorly documented (11). Evidence from developed countries suggest that the incident rates of spinal cord injury are high (12), especially amongst those aged between 15 and 24 years (13).

On one hand, the lifestyles of rising numbers of affluent young people in developed and developing countries may contribute to additional accidents and injuries, leading to impairments. On the other hand, in developing countries poor immunisation regimes, growing numbers of under nourished children and the spread of avoidable infectious diseases contribute to increasing numbers of young persons with disabilities.

A UNICEF (1999) report uses vignettes of experiences of youth with disabilities across the globe, to highlight their lack of participation in education, employment, their increased risk of substance abuse, sexual exploitation, social isolation, prejudice and inappropriate care (5). It raises significant concerns regarding the opportunities available for participation and development of capabilities and the resultant transitions that young people with disabilities make into adulthood.

Focusing on transitions is important, because it is more than just an administrative point or a biological marker, rather, the 'transition process implies changes in status, both in how we see ourselves as well as how others see us' (14). Cultures have different rituals and rights to mark the passage of time - and grant rights and place responsibilities- to give a sense of direction and purpose to life. These markers vary, for instance different cultures emphasise different degrees of autonomy and relatedness. While in some countries, young adults moving out of the family house is essential, in others young adults taking on greater care and responsibilities is desirable.

Dee regards transition as a process and uses three complimentary perspectives to examine it: (1) phase-related model, which regards transition to adulthood as one of a number of stages through which individuals pass through a lifetime, such as paid employment, granting of legal and civil rights, friendships and family roles and responsibilities; (2) agency-related model, which reflects the degree of agency or control that a person has in determining the course of their lives; finally, (3) time-related model, which states that development is more than getting older (14). Rather, it is 'intertwined with the historical context in which one lives, as well as the social expectations of a particular culture at a particular point in time' (15). These three perspectives allow one to acknowledge the structural and the individual factors which shape the lives of young people.

This paper focusses specifically on the lives of young people with disabilities in the Indian context. As far as possible, the discussion of 'young people' in this paper is limited to the 12-24 years age group that is the focus of WDR 2007. This category overlaps with 'adolescents', as referred to by UNICEF (10-18 years) and 'youth', as referred to by the United Nations (19-24 years). Indeed, many of the needs of a 24 year old individual are different from those of a 12 year old, disabled or otherwise. However, they are brought together in this paper to focus on a time in an individual's life which is marked by

physiological and psychological maturation, acquisition of essential skills, greater control over making own choices and decisions and the transformation of social relationships, to equip them in taking their place in the adult world.

Youth with disabilities in the Indian context

One problem with dealing with young people aged 12-24 is that the Indian Census uses different age categories in its presentation of data, both on disability and more generally. The figures used in this paper, except where an alternative source is cited, are derived from Table C 20 (3). The authors estimates for the 12-24 population (total and for young people with disabilities) are calculated by adding 80 percent of the figures for the age category 10-19 to 50 percent of the figures for the age category 20-29, unless figures are available for 15-19 and 20-24 separately. The authors also draw on data from the 2002 National Sample Survey, where similar problems of age grouping can be found.

Table 1. Distribution of young people by reported impairment

	Seeing	Speech	Hearing	Movement	Mental	Multiple	Total PWD
Census							
12-24	2158063	530215	206581	1673873	647018		5215749
Percent	41.4%	10.2%	4.0%	32.1%	12.4%		100
NSS							
12-24	180480	255120	181920	2461860	465960	463080	4008520
Percent	4.5%	6.4%	4.5%	61.4%	11.6%	11.6%	100

Notes: In the table for NSSO, Blindness and Low Visibility have been combined into a total for visual impairment; mental retardation and mental illness have been combined for mental impairment.

There is no separate reporting of multiple impairments in the Census data.

Census figures for age group 12-24 are created by taking 80% of the age group 10-19 and 50% of the age group 20-29.

NSS figures for age group 12-24 are created by taking 60% of the age group 10-14 and the whole of age groups 15-19 and 20-24

Table 2. Number of persons by usual activity status per 1000 disabled persons of age 20-24 years for any disability

ANY Disability	Employed							Not in the Labour Force						Estimated number in the total population
	self-employed in agriculture	self-employed in non-agriculture	regular employee	casual labourer	total	unemployed	attended educational institution	attended domestic duties	beggar	others	- total			
<i>Males</i>														
Urban Male	9.8%	8.9%	11.1%	9.7%	39.5%	6.7%	19.8%	1.7%	0.1%	32.2%	100%	215,700		
Rural Male	12.2%	17.5%	4.3%	15.2%	49.2%	4.4%	8.3%	1.8%	0.1%	36.2%	100%	656,000		
All Male	11.6%	15.4%	6.0%	13.8%	46.8%	4.9%	11.2%	1.8%	0.1%	35.2%	100%	871,700		
<i>Females</i>														
Urban Female	2.5%	1.6%	3.5%	1.8%	9.3%	2.1%	9.9%	46.3%	0.0%	32.4%	100%	115,000		
Rural Female	2.3%	4.5%	1.4%	6.1%	14.2%	0.6%	4.5%	50.7%	0.1%	29.9%	100%	344,700		
All Female	2.3%	3.7%	1.9%	5.0%	13.0%	1.0%	5.9%	49.6%	0.1%	30.5%	100%	459,700		
All	8.4%	11.4%	4.6%	10.8%	35.1%	3.6%	9.3%	18.3%	0.1%	33.6%	100%	1,331,400		

Source: [25: Table 13]

Table 3. Approximate Percentages of males and females with disabilities aged 20-24 unemployed or not in the labour force, by type of impairment

Type of Impairment	Percent unemployed or not in the labour force	
	Female	Male
Locomotor	87	49
Hearing	78	36
Visual – Severe	94	83
Visual – Lesser	87	52
Speech	83	51
Mental retardation	98	89
Mental illness	95	85

Source: [25: Table 13]

Table 4. Marital status: general population and those with disabilities

	Percent never married		Percent currently married		Percent widowed/divorced	
	General	Disabled	General	Disabled	General	Disabled
Age 25+	5.30	16.28	84.98	62.19	9.72	21.50
Age 15+	22.74	28.51	70.16	53.35	7.09	18.12
Age 15-24	66.34	91.93	33.13	7.49	0.53	0.57

Source: General population, Census 2001

Disabled population: NSS 58th Round

In India, while infant mortality rates have dropped, some child immunisation rates have worsened in the past 10 years. National data sets, such as those from the National Family Health Survey, indicate that ‘the pace of annual progress after 1998 in many reproductive and child health indicators is slower than before and a few indicators (e.g., child-immunisation) have worsened, despite the expenditure on the programme being doubled’ (16). While the national pulse polio campaign has decreased the number of children and adults suffering from polio, eradication is elusive and critics of the campaign point to evidence that cases of lower-limb paralysis have fallen far less than the claims of the programme managers would suggest, and the focus on polio has contributed to deteriorating rates for protection against other childhood diseases (17, 18). Thomas, quoting a study undertaken in Gujarat, notes that ‘70 percent of the disabled people identified were disabled before school age’ and points to high rates of malnutrition among the under fives, maternal mortality and poor early childhood care as the main causes (19). Evidence about changes in poverty levels in India is highly contested, but nutritional and food availability data suggest that hunger remains a substantial problem today (20). The authors are therefore sceptical that India’s ‘disability transition’ (from communicable, maternal, perinatal, and nutritional disorders to non-communicable diseases and injuries) will be as rapid as Murray and Lopez suggest (21). There is no reason to believe that the causes of disability that flow from poverty will be rooted out soon. In parallel, India’s affluent middle classes with changing lifestyles are at greater risk of acquired impairments. As in many other spheres, in India, the ability of the state to deliver a wide range of social services (including those designed for people with disabilities) has been severely compromised in much of the country, by processes of liberalisation (22). In these circumstances, relatively small groups of well-placed citizens are often able to ensure that they benefit both from public and private resources, whereas those less well-placed (because of poverty, rural residence, ethnic group membership or other household features), find it hard to access even those small public resources to which they are nominally entitled (23).

It is very difficult to find reliable data about the prevalence of disability in India. In general, the search for a single prevalence rate is a chimera: different estimates should be used according to the specific purpose at hand (24). Even so, the range of estimates in India, and their varied origins, makes it difficult to say very much with assurance about people with

disabilities in general, or young people with disabilities in particular. The two main large data-sets are the 2001 Census (3) and the 2002 National Sample Survey 58th Round (25). Unfortunately, as Mitra and Sambamoorthi point out, the definitions of disability used by these two enquiries differ in some fundamental ways (26). In addition, the distributions of impairments by age show some worrying inconsistencies. The 2001 Census, covering five types of disabilities, recorded a prevalence rate of 2.13 percent, or 21.91 million people with disabilities out of a total population of 1028 million. The National Sample Survey Organisation (NSSO) 58th round (July-December 2002) survey reported that 1.8 percent of the population (18.5 million) had a disability (25). While 18-22 million people with disabilities is a large number, this may arguably be a gross underestimation. A leading Indian disability NGO, the National Centre for Promotion of Employment for Disabled People (NCPEDP), argues that 5 to 6 percent of the population has a disability. The World Bank (27) says that, 'the real prevalence of disability in India could easily be around 40 million people, and perhaps as high as 80-90 million if more inclusive definitions of both mental illness and mental retardation in particular were used'.

The Registrar General of India (2001) agrees that the Indian data on disability are unreliable, due to few well-trained field investigators, and issues of social stigma. Underreporting due to stigma is also noted by the World Bank report on India, which suggests that people with mental illness and mental retardation are most likely to be missed in surveys, and argues that this is closely related to explanations of the 'cause' of such disorders being attributed to *karma* [fate, or the effects of actions in a previous life (27)]. Additionally, a study of 1600 rural households in South India noted that 'the factors that influenced the identification were: local perceptions and definitions of disability; social dynamics, particularly those of gender and age; ... type of disability and the associated social implications and stigma of that disability' (28). Similar factors were highlighted by Erb and Harriss-White, who noted a significant bias in the prevalence of disability towards upper caste Hindus, in rural Tamil Nadu (29). It is not clear why such trends exist, but, it is likely that a greater willingness to define oneself as disabled exists when there are certain benefits in doing so. Changes in India since the research of Harriss-White and Erb, in particular the effects of the Persons with Disabilities Act 1995 (30), may mean that their conclusions no longer hold, or not with the same force, as when they wrote (31).

Current survey methods are unable to minimise and/or account for these factors. They are not only unsuccessful in providing a reliable picture of prevalence rates of disability, but there is also a greater likelihood of the identification and reporting of some easily identifiable impairments, while others remain hidden. Thus, it is difficult to state if differences in estimates provided by various data are 'real' differences in impairments, or due to other factors. Survey approaches also tend towards an individualistic approach, which may underestimate the extent to which disability has collective, rather than just individual effects. Where extended kin groups retain significant rights and obligations (as in much of Indian society), the impact of disability will be broader than where kinship groups are smaller and more individuated. The lack of reliable estimates and underestimations impact on the kind of policies and provisions framed, for people with disabilities and indeed those for their families.

The emerging trends of youth disability

There is no alternative but to work with the available data on disability, despite all the earlier mentioned caveats. About 35 percent of the people with disabilities are identified in the 10-29 years age group in both the Census and the NSS. These data-sets also suggest that prevalence rates reported amongst females are lower than those reported amongst males: Census figures are 1.87 percent for females and 2.13 percent for males, while NSSO rates for males (2.12 and 1.67 per cent in rural and urban India, respectively) are higher than those for females [1.56 and 1.31 per cent (25)]. No obvious explanation is offered for these differences in either source.

By comparison with 1991, incidence rates amongst the 0-9 years age group have shown a decline, but there has been an increase in the incidence rates among the age groups of 10-29 years. The decreasing trends could be attributed to immunisation coverage for polio eradication, especially since the figures for movement disabilities among the 0-4 age group in 2001 are well below those for the 5-9 and 10-19 age groups. The increasing rates among young adults could be due to factors such as accidents, on the road or at work. The prevalence rates for this age group were higher in the urban areas than in the rural areas, unlike the pattern noted for the total disabled population. The prevalence rate was lower in urban (1.93 percent) than in rural areas (2.21 percent).

Despite the many uncertainties that remain about the lack of reliable data and inadequate research on young people with disabilities, one needs to consider what is known about their lives and the opportunities available to them. *WDR 2007* suggests that the five areas of youth transitions; continuing to learn, starting to work, developing a healthy lifestyle, beginning a family, and exercising citizenship, 'have the biggest long-term impacts on how human capital is kept safe, developed and deployed' (2). A focus on these five areas is important and essential for all young people, but for some young people these remain ambivalent and ambiguous through their continued exclusion and participation in mainstream society. Here, the authors consider the lives of youth with disabilities in three areas, namely: learning, work, and social participation. By doing so, it is not argued that these are the most important areas, nor do we wish to desegregate the lives that people lead, however, by doing so the authors wish to argue that such a focus will allow a critical examination and also hold true to the belief, that transition goals for young people with disabilities should be the same as those of their age groups (32). Thus, examining the status of young people with disabilities in such a manner will enable all to reflect on their lived realities.

Participation in the education system

The unreliability of data on the educational participation of young people with disabilities is marked, both in terms of estimates of children with disabilities in the school going age group and indeed the numbers actually attending school. Mukhopadhyay and Mani quote an NCERT survey, suggesting that about 84,000 children with disabilities were enrolled in schools in 1998; and unpublished data gathered for the Ministry of Human Resource and Development (MHRD) suggested that approximately 55,000 children with disabilities were enrolled in schools in 1999. Hence, these authors state that 'the picture (of school enrolment for children with disabilities) is dismal', since (by these counts, and using the highest estimate of the total population of children with disabilities) less than 1 percent of children with disabilities attend school (33). Even using the Census estimates for the total population of children with disabilities, rather than the 5 percent figure preferred by Mukhopadhyay and Mani, would only increase the figure of those attending school to about 2 percent of the disabled age cohort.

A position paper drafted by the NCERT notes that, ‘the Office of the Chief Commissioner of Persons with Disabilities stated that not more than 4 percent of children with disabilities have access to education’ (34). Yet, the MHRD claimed in 2004, that 1.08 million children with disabilities were being educated, and by using a very low estimate of the total number of children with disabilities, thus arriving at an estimate of 67.5 percent of children with disabilities receiving education (35). Again, a different figure would be found by using the Census estimates for the total number of children with disabilities, and the MHRD data would then suggest that around 28 percent of children with disabilities were enrolled in school.

These discrepancies are so huge - from less than 1 percent to over 67 percent - and so little information is provided in these sources about how the figures were calculated, that the obvious explanations (different definitions of disabilities, varying notions of education, whether enrolment or attendance data are used, and so on) are inadequate to make sense of what is going on.

Similar issues surround estimates of one of the main supposed outcomes of schooling - the extent of literacy among the adult population of people with disabilities. Data gathered from the NSSO 58th round survey (Jul- Dec 2002), suggest that about 45 percent of people with disabilities are literate (25). In contrast, the 2001 Census literacy rate of the total population is 64.8 percent. According to the NSSO data, 25 percent of the literate population of people with disabilities had received education up to the primary level (five years of schooling), 11 percent up to the middle level (eight years), while a mere 9 percent had nine or more years. Interestingly, enrolment ratios for those with disabilities aged 5 to 18 years in a mainstream school were higher in rural areas than in the urban areas. This is not surprising because there is some empirical research to the effect that children with disabilities in rural areas are more likely to attend mainstream schools. Miles refers to this as ‘casual integration’ (36). Moreover, it is also possible that with the advent of increased bureaucratic reporting, children may get listed on the enrolment register but never attend school. The classroom may remain an alien space in which they are not seen as equal participants.

In urban areas, around 11 percent of those with disabilities in the 5 to 18 years age group were enrolled in special schools, while this was less than 1 percent in rural areas. This reflects the significant recent growth in the number of special schools, especially in urban

areas. In the early 1990s, there were about 1,035 special schools (37). Nearly a decade later, it was estimated that there were about 2,500 special schools in the country (38). Most of these schools are in urban areas, with Mumbai having the highest number of schools (33). This rise of special schools has gone unchallenged even though there is evidence from other countries, that building such a parallel system will only perpetuate the continued exclusion of this group from mainstream society and support the continued fostering of stigma and prejudice.

Since 1990, there have been some important developments in the provision of educational opportunities for children and young people with disabilities. In 1987, the Integrated Education for Disabled Children (IEDC) scheme was launched at a national level, but it did not meet with much success. Few people knew about the scheme and only a few children received any equipment and services, while teachers remained untrained and unable to respond to their needs. In 1995, the education of children with disabilities came under renewed focus in the District Primary Education Programme (DPEP) and this has continued in the more recent *Sarva Shiksha Abhiyan* (SSA or Education for All).

The First Joint Review Mission of SSA in 2005 (39), referring to the education of children with disabilities, noted that ‘whilst invariably improving, coverage remains incomplete and an examination of the physical and financial progress reported by States thus far for the current year shows implementation to be poor, suggesting that this area is not receiving sufficient priority. Interventions reported tend to follow a medical model with attention to providing aids and appliances to physically challenged children’. Similar views were expressed in the Third Joint Review Mission for Bihar undertaken in Jan. 2006, where it was noted that while enrolment was being considered ‘attention will now need to be given to the provision of quality education to children with disabilities’ (40). Thomas, reporting a conversation with a government official, states that:

“the significant financial resources allocated to the SSA programme were actually a problem,... there is great pressure on education staff to spend, and be seen to be spending, their budgets. The result is that money is thrown at very visible and easy areas. Shiny new ramps and rails are a suitable quick fix.” (19).

Indeed there is growing evidence that the focus in the field continues to be on identifying and assessing children with disabilities, and responding to their needs through the provision of assistive aids and appliances. This focus on changing structural issues, rather than reviewing the teaching and learning processes in the classroom, is very limiting. The perception of disability as a problem located in the child and needing to be corrected at an individual level still dominates. Little focus is placed on examining the environmental factors that might be negatively impacting on the child's ability to participate. Overall, the emphasis is primarily on giving access to children with disabilities, with little regard being given to their participation in the classroom, its culture or the curriculum (41,42).

While enrolments have seemingly increased for children with disabilities, data still suggest that only very few of them complete the primary cycle of education and even fewer make it to the secondary, let alone higher levels of education. This has a notable impact on their employment opportunities later in adult life, especially in the context of a rapidly changing market economy. Tilak notes that 'while primary education gives the basic three R's, rarely does it provide skills necessary for employment-self employment or otherwise-that can ensure a reasonable level of wages and economic living' (43).

This comparative exclusion of children and youth with disabilities from education unarguably results in their inability to access some very significant opportunities for further development, particularly reducing their access to vocational training, employment and involvement in other income generation activities.

Work participation rates

The ability and the opportunity to earn a livelihood - whether in a formal job or through some kind of self-employment - is an important determinant for an individual's well-being. In addition, and indeed apart from education, vocational training is an important way in which people with disabilities can become economically independent.

While the Ministry of Labour has set up various Vocational Rehabilitation Centres (VRCs), only a small percentage of people with disabilities receive vocational training. In 2002, the figures were an appalling 1.5 percent and 3.6 percent of the people with disabilities in rural and urban areas respectively, who received any training. These figures have not changed much since 1991. Other government initiatives encourage people with disabilities to explore

avenues for self-employment through schemes such as the *Sampoorn Gramin Swarozgar Yojana* (SGSY). This scheme promotes self employment opportunities through self help groups and, according to official estimates, it has assisted 24,235 people with disabilities from 1999-2003 (44). Additionally, the National Handicapped Finance and Development Corporation (NHFDC) under the Ministry of Social Justice and Empowerment (MSJE) is involved in forwarding loans at low rates of interest for encouraging persons with disabilities, to establish their own micro-enterprises either on an individual basis, or by establishing self-help groups. However, there is no appreciable information to indicate how successful these attempts have been.

Since 1995, under the Persons with Disability Act (30), there has been a 3 percent reservation in all categories of jobs in the government sector and a strategy of giving incentives to private sector employers for promoting employment of people with disabilities. Such a strategy would take some time to have an impact on the employment status of young people with disabilities, especially since formal sector employment is a very small part of the Indian labour force, and within that, public sector recruitment has slowed down considerably since 1991. NSSO (2002) data shows that for urban males aged 15-24 years, 8.7 percent were 'salaried-wage employees', but the picture for rural males, and for urban and rural females is well under 3 percent. Rural and urban, males and females, were all about 30-35 percent out of the labour force and not in education, or involved in domestic duties, and how they spend their days is unclear. In general, for all age groups, the chances of a person with disability being in employment of any kind were roughly 60 percent as compared to those of the general population. In a multivariate analysis of the factors that increase or reduce employment prospects, for example, 'being married strongly increases a man's probability of being employed while it reduces that of a woman's' and that 'surprisingly, education has a limited effect on the probability of being employed for persons with disabilities. Although vocational training was associated with a higher probability of employment, this finding is not consistent across samples' (45). Work participation varies quite dramatically by the type of impairment, and young men with locomotor, hearing, lesser visual and speech impairments were more likely to be in employment, compared with those with severe visual or mental impairment, while women in all categories were much less likely to be in employment (25).

Across the board, irrespective of the type of impairments, most people with disabilities tend to be casual labourers, or attending domestic services, but (at least as far as the NSS is concerned) not likely to be beggars. The 2001 Census reports that 52 percent of those not working are 'dependents', with another 15 percent engaged in 'household duties' and 25 percent 'students' (3). Unemployment and underemployment for young people with disabilities continues to be higher in comparison to that of non-disabled people in similar age groups (3). Zutshi, using NSSO data, notes that the majority of the vocationally trained people with disabilities received low profile non-engineering training (46). He argues that while only 1.8 percent and 7.3 percent in rural and urban areas respectively were in regular paid employment, even the nature of their employment was in low profile low-income jobs.

Reporting the results, a survey conducted of the top 100 companies by the NCPEDP during 1999, Zutshi further noted that the average percentage of employees with disabilities in the public sector (23 companies) was 0.54 percent, in the private sector (63 companies) was 0.28 percent, and in multinationals (14 companies), 0.05 percent (46).

A disturbing feature is the high likelihood that people lose or have to change their job after the onset of disability. Quoting NSSO (2002) data, Zutshi suggests that about 56 percent and 53 percent of those who had been working before the onset of their disability lost their job after the disability, in urban and rural areas respectively, and another 13 percent had to change their job (45).

Even though enabling legislation exists, its implementation is likely to be slow, and faced with weaknesses such as poor political will, low financial support and excessive bureaucracy. Additionally, not only is there little awareness of the Act amongst the general population, but this ignorance is prevalent even in government departments. There are also no strong monitoring mechanisms for its implementation, and the absence of strong advocacy groups makes it even more difficult to influence decisions and policy makers on this front.

Social participation

In addition to education and employment, other important dimensions in the lives of young people are those related to 'developing a healthy life style, beginning a family, and exercising citizenship' (2). While concerns related to the education and employment of young people

with disabilities get acknowledged in legislation and sometimes in practice, they remain excluded from other important areas of social participation. Their right to be an individual, a parent and to companionship often get overlooked.

Health care services have a very poor record in responding to the need of young people with disabilities. Mainstream sexual and reproductive health programmes, for example, do not consider them in the information provided and/or in the training of health workers. Groce notes that often health professionals refuse to provide reproductive health information to young people with disabilities because it is felt that they do not need it (10). The health system seems to operate with a notion that people with disabilities are non-sexual. This perception of people with disabilities as being asexual is widespread and their sexual and reproductive rights continue to be overlooked.

NSSO data for 2002 and Census data for 2001, suggests that 16.3 percent of people with disabilities aged 25 or more have never married, compared to only 5.3 percent of the population as a whole. Amongst young people aged 15-24, only 7.5 percent of people with disabilities were currently married in 2002, compared to 33.1 percent of the total population of the same age in 2001. Young people with disabilities get married at a later age than the rest of the population, and are about three times as likely to remain unmarried. They are also twice as likely to be widowed or divorced.

Data from the NSSO on the residential patterns of young people with disabilities suggest that men and women 15-24 years (82.9 percent and 75.2 percent respectively) are most likely still to be living with their parents. Young women were more than twice as likely to be living with a spouse (16 percent) than were young men (7.5 percent), reflecting their earlier age at marriage. By the age group 25-29 years, however, as many as 43.9 of men and 49.3 percent of women were living with a spouse, while 45.5 percent of men and 40.4 percent of women were living with their parents, without a spouse. These young people may be very vulnerable to exploitation after the death of their parents, the risk factors for women being more marked than for men. There is overwhelming anecdotal evidence to suggest that if a woman becomes disabled after her marriage, in most cases the husband will leave her for another wife, or if she has children she will be judged as incapable of looking after them and they will be placed in the care of grandparents (47).

Young women with disabilities are most at risk of sexual assault and exploitation. Quoting a strategy paper written by Rao for the National Commission for Women, Mohapatra and Mohanty note that ‘women and girls with disabilities are particularly vulnerable to violence within their home situation. Sexual abuse is quite common, especially among women with mental and/or hearing disabilities. Abuse by physicians and caregivers, e.g., forced sterilization, is common’ (47). In their study which covered 595 women with physical disabilities, and 134 with mental challenges covering 12 districts of Orissa and focusing on ‘domestic violence against disabled women’ Mohapatra and Mohanty concluded that:

“there is no question that abuse of women with disabilities is a problem of epidemic proportions that is only beginning to attract the attention of researchers, service providers, and funding agencies. The gaps in the literature are enormous. For each disability type, different dynamics of abuse come into play....certain commonalities exist across disability groups, such as economic dependence, social isolation, and the whittling away of self esteem on the basis of disability as a precursor to abuse”(47).

While the existing literature does not highlight the abuse faced by young men with disabilities, Addlakha draws on four case studies to portray vividly the ‘deep sense of personal devaluation and foreboding’ faced by the two young men with visual and physical impairments (48). In contrast to the young women with disabilities, these men expressed a preference for a non-disabled partner, so that they were able to compensate for their impairment by aligning themselves with ‘a non-disabled spouse in a society which equates absence of vision with individual invalidation and social disfranchisement’. Addlakha asserts that ‘both preferences show the importance of the “us-them” (disabled, non-disabled) distinction in the experiences of some persons with disabilities, be they in the area of education, employment or sexuality’ (p.121).

It is interesting to note the seemingly complete absence of literature that addresses issues around civic participation of people with disabilities. At a time when there is renewed focus on the involvement of young people in building a strong democracy there is little to suggest how these issues are being made sense of, by and for young people with disabilities.

People with disabilities, particularly young adults, continue to live at the margins of mainstream society, even though at the international and the national levels commitments have been made to significantly reduce poverty and accelerate the pace of economic, social and human development. While poverty results in various forms of social exclusion, these intersect further with disability to form multiple layers of disadvantages. This scenario is further complicated when differing combinations of structural factors (such as caste, gender, religion etc), life cycle factors (being young or elderly, household composition) and other idiosyncratic factors (ill health, the nature and severity of the impairments) create and maintain the poverty of some, while giving others the chance to avoid or escape it (49). While structural factors and the various intersectionalities are indeed very important, there are broad commonalities in the lives of people with disabilities which transcend divisions based on gender and class. This commonality is illustrated in the significant deprivation that these people face as a result of their status of being a person with disabilities (50). DfID rightly notes that ‘given the high proportion of people with disabilities among the poor, it is unlikely that these targets (international targets of poverty eradication etc.) can be properly achieved without specific efforts to tackle disability’ (7). Addressing issues around disability needs to become an important focus and must generate political commitment and indeed academic and research focus.

MOVING FORWARD

The need for reconceptualising understanding of disability

An important concern in the Indian context is the current understanding of disability. Within the Indian legislative framework the identity of disability is contingent on the certification process carried out by the state constituted boards which work on the basis of a medicalised ‘degree of impairment’. People with disabilities are defined as those suffering from less than 40 percent of any ability as certified by a medical authority (30). Based on this labelling process, the individual is then granted some privileges. Not only is it rather difficult to get these certificates, but also different states or different hospitals within the same state operate in widely discrepant ways in issuing certificates (51). Furthermore, the assumptions underlying this process are fraught with complexities.

By giving a certificate, the person is labelled for life, as there is no reassessment of her/his disability after the age of 18 and the person is never really re-examined. As Ghai points out, that the fact that ‘there might be appreciable change in given conditions such as muscular dystrophy or polio is therefore not reflected in the definitional closures inherent in a one time certification process’ (51). The assumption here is that disability is a fixed category, a static state located within the individual. Even at the most basic level, it fails to acknowledge biological development.

Consequently, it not surprising that the primary focus in India is on providing people with disabilities with various aids and appliances, immunisation, etc, that can help them function like others, rather than addressing social barriers that result in their exclusion or non-participation from the mainstream. However, even though most government programmes primarily focus on provision of aids and appliances, quoting a study undertaken in Gujarat, Thomas notes that only 25 percent of the people with disabilities were using aids and appliances (19). People found it difficult to access these provisions, as rehabilitative services tend to be concentrated in urban areas, and the devices given were inappropriate, difficult to repair and maintain in rural areas. Appliances from the Artificial Limbs Manufacturing Corporation of India, the government provider, were generally recognised as being poor in quality, and accessing them was time consuming and bureaucratic. This becomes especially problematic for young people, who would require replacements at regular intervals, especially of some prosthetic devices, such as artificial limbs and wheel chairs.

An understanding of disability as a medical, preventable condition holds some merit, because, as noted earlier, many of the factors resulting in various impairments are preventable or treatable. However, the dominance of this perspective has led to a scenario where the naturalness of these labels remains unquestioned and there is a continued neglect of social factors. Such an understanding does not acknowledge that disability is a fluid category and changes character not only as a consequence of the development that a person undergoes, but also as a consequence of the shifting conditions around her/him. Coker notes that, ‘disability, like most dimensions of experience is polysemic – that is, ambiguous and unstable in meaning – as well as mixture of truth and fiction that depends on *who says what, to whom, when and where*’ [(52) emphasis added].

In addition to the prevalent medical discourse, the dominant cultural beliefs suggest that disability is a personal affliction. It is seen as resulting from the wrath of fate—retribution for past *karmas* (*past life deeds*) and punishment for sins committed in a previous life (53). Such perceptions serve many purposes. Firstly, regarding someone as the victim of their (or their family's) sins leads to the manifestation of pity towards these sinners. This pity gives rise to benevolent acts of charity, which are further reinforced by the strong religious orientations. For example, it is observed that during '*shrads*' (acts of charity undertaken to mark the death of family members), alms are given to individuals with disabilities. Secondly, such a perception reinforces a distancing of one's own responsibility in the acts of exclusion.

The dominance of the medical and charitable perceptions had led to a failure where there is little acknowledgement of the fact that since an individual's functioning and disability occurs in a context, it is useful to regard disability in terms of impairments of body structures and functions, but also limitations of activities and restrictions of participation placed by social and cultural structures (54). An understanding of disability thus needs to be located within a specific context, the context which is the lived reality of the individual with disability.

Such a reconceptualisation of disability, though challenging, will have a significant impact on not just how data are collected but also how to respond to the needs of people with disabilities. It is no longer about focusing only on the impairments, which can indeed be challenging, but it is also about re-examining the provision of various services. Simply put, it is not only about providing someone with a wheel chair but it is also about ensuring that there are accessible roads on which these can be used safely, and more importantly, it is about a change in societal attitudes which acknowledges the individual rather than just the wheelchair.

Equal is not enough: notions of equity and development

Focusing on 'opportunities' is an important step forward in ways of thinking how far policies and institutions allow for young people to develop their future skills- not just work related, but also social skills (2). Indeed, 'the distribution of opportunities matters more than the distribution of outcomes' (55). It has been argued in this paper that young people with disabilities face very different opportunities than their able-bodied peers. Furthermore, whereas young able-bodied people living in chronic poverty have two important exit routes

— high dependency on their own labour (in the absence of financial and material assets) and formal education, which improves the quality of their labour — neither of these is likely to be available to young people with disabilities (49). For example, people with disabilities are less likely to be economically active, more because of the discrimination and societal perceptions that they are likely to encounter, than because of the inherent quality of their impairment. Similarly, limited opportunities (lack of trained teachers, restrictive curriculum, physically inaccessible buildings etc) and negative perceptions (stigma, low expectations etc) about their ability to participate in the formal education system, makes access to educational institutions also very difficult. Thus, societal beliefs and norms may limit the possibilities of escape from poverty for these young people, who are also at a greater risk of being systematically excluded from basic health care services, political and legal processes, pushing them into the margins of mainstream society.

While the government is drafting disability legislations and policies, it is failing to engage with underlying issues of exclusion and marginalisation. Providing reservations is just one step and much more needs to be done to convert these into actual usable opportunities. In the terms of a capabilities approach, one can argue that reservations or financial compensation can be conceptualised as specific types of asset – ones that are not meaningful – i.e., constitutive of capability – until people can both access reservations and use compensation to improve the quality of their lives. Sen further elaborates on this issue with specific reference to people with disabilities. He proposes the notion of a ‘conversion handicap’: not only do people with disabilities have difficulty earning an income (which he terms as the ‘earning handicap’), but the disability also ‘makes it harder to convert income into the freedom to live well’ (56). Sen adds that ‘the conversion handicap applies, thus, not only to converting personal incomes into good living, but also to converting social facilities into actually *usable opportunities*’ (p. 5, emphasis added). Therefore, identifying factors that enable or hinder young people with disabilities to make use of the facilities that are available to their non-disabled peers is an important concern. To make this feasible, it is essential that mechanisms are established that enable a greater involvement and participation of people with disabilities in the policy making process, both at the levels of national and local policy. Greater focus must be placed on listening to the voices of people with disabilities, to enable the development, implementation and evaluation of truly disabled friendly policies and programmes.

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ACKNOWLEDGMENT

This paper forms part of the Research Consortium on Educational Outcomes and Poverty (RECOUP), funded by DFID, 2005-10. Views expressed here are those of the authors and are not necessarily shared by DFID or any of the partner institutions. For details of the objectives, composition and work of the consortium see: www.educ.cam.ac.uk/RECOUP.

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DISABILITY EQUALITY TRAINING (DET): POTENTIALS AND CHALLENGES IN PRACTICE IN DEVELOPING COUNTRIES

Kenji Kuno*

ABSTRACT

This paper reviews the analysis of the potentials and challenges of the implementation of the Disability Equality Training (DET) in the Asia and the Pacific Region.

As a potential of DET, seven elements were identified in two categories; as a disability education for non-disabled people and as an empowerment process for disabled people. These potentials are developed by two key features of DET, i.e. a firm and logical framework on disability which is based on the Social Model of Disability, and the methods used in DET, i.e. a facilitated participatory learning approach.

In contrast, eight elements were identified as challenges in the aspects of implementation of DET and training of DET trainers. These challenges are mainly due to the persistent influence of the Medical Model of Disability which is rooted to meritocracy and capitalism, and due to lack of awareness and legislative and administrative support of rights in general.

INTRODUCTION

The true nature of “disability” is neither an individual’s mere functional limitations nor the difficulties of performance which arise directly from such limitations. “Disability” is oppression, discrimination, social exclusion and the restriction of participation. This view of disability as a social construct is called the Social Model of Disability, and removes the focus from the individual disabled person as being “the problem” and shifts the onus on to society to remove the barriers which prevent full inclusion and participation of disabled people.

This Social Model of Disability made a significant impact on the development of new disability agendas, such as the United Nations Convention on Rights of Persons with

Disabilities, the International Classification of Functionings, Disability and Health (ICF) of the World Health Organisation, and the rights-based approach of the Biwako Millennium Framework of Action.

Disability Equality Training (DET) was originally developed by disabled people in the United Kingdom and has been implemented since the late 1970s as a means to promote an understanding of disability from this Social Model perspective (1).

This DET has been gradually taken as a practical tool of disability education to promote equal rights of disabled people in developing countries by several development agencies (2). The Japan International Cooperation Agency (JICA) and the Department of Welfare Malaysia have together developed a wide range of human and material resources. These have been used in the practical implementation of DET, to develop a comprehensive programme. This paper critically examines its development and implementation experience to discover the potentials and challenges of DET implementation in developing countries, as a development intervention on disability issues.

DISABILITY EQUALITY TRAINING (DET)

The ultimate goal of DET is to change societal attitudes to become just, equal and inclusive, where full participation and equality for disabled people are assured.

To realise this aim, DET has two core objectives and components. The first one is to facilitate participants to have an alternative view of disability, so as to examine it as a social issue, i.e. the Social Model of Disability. Although this is the main part of DET, it is not enough to complete DET. An equally important component is to facilitate participants to develop their own concrete action plans to break down barriers which hinder participation of disabled people in relation to their own work and daily lives. Often so-called disability awareness seminars end up only containing the first one, and do not facilitate the development of participants' actions. DET is neither a simple lecture to add knowledge of disability nor a critique of discriminative attitudes. DET aims to challenge one's sense of values of disability, and to facilitate the development of each participant's proactive action to break social barriers, i.e. assisting participants to be agents for social change.

DET values equally, both its contents and process of learning. People do not change their actions and sense of values under force. These can be changed only if and when participants themselves become aware of their mistakes and the importance of alternative views and actions. Therefore, both contents; the provision of a logical explanation of disability, and the discovering process as methods in the learning experience, are equally important.

Therefore, DET should not be taken as a tool for propaganda or agitation to impose the Social Model view to participants. DET is rather, an educational process to assist internal reflection within the participants, to critically (re)consider their perception on disability.

Disability equality training (DET)

- Takes disability as social issue of rights, discrimination and equality rather than individuals' functional issues.
- Is based on the Social Model of disability, not the Medical Model.
- Aims to support participants to discover causes and mechanisms which create disability (social oppressions); and to act to change society to be more just and inclusive, rather than simply change superficial behaviours.
- Avoids using simulation exercise which merely leads to the understanding and emphasis of 'inability' and functional limitations of disabled individuals.

Difference between DET and DAT

DET is different from the traditionally practised disability awareness approach, so-called Disability Awareness Training (DAT), which usually utilises impairments simulation exercises as its main tool. A fundamental difference between these two types of training is that DAT focuses on the functional aspect of disabled people, i.e. what disabled people cannot do, whereas DET deals with disability as social discrimination and inequality. DAT was developed based on the concept of the Medical Model of Disability which regards impairments as the causes of various issues faced by disabled people. On the other hand, DET is based on the Social Model of Disability which regards disabling social institutions as the main cause of the issues faced by disabled people.

DAT aims merely to teach participants how to help disabled people when they are in trouble. It does not pay much attention to the reasons why they are facing such problems and troubles.

On the other hand, DET aims to facilitate participants to learn why such barriers are made, and how to break or prevent the creation of such disabling social institutions and infrastructures.

Another key difference is the position of participants in each training course. In DAT, participants are considered as having a neutral position, with no direct relationship to the disability issues; “bona fide third person.” This individual would wish to learn how to help disabled people because disability is perceived as an issue of functional limitation or inabilities, in the framework of the Medical Model, which is the theoretical basis of DAT. On the other hand, participants of DET are expected to identify themselves as the oppressor or discriminator, contributing to create a disabling society. DET recognises that this is often a result of ignorance and indifference of the issues and needs of disabled people, rather than the intentional wish to act as such an ‘oppressor’ or ‘discriminator.’

However, DET also emphasises the transformation from such a ‘victimiser’ position to one of a ‘change agent.’ This ‘change agent’ can reform society to become more inclusive, by supporting the development of their own action plans through their own will and power.

DET pays more attention to the questions of why such disabling barriers are made, rather than simply identify and make a list of such barriers; i.e., “why” you need to do, rather than “what” you need to do. A slogan ‘Let’s help disabled people’, does not contribute to the breakdown of disabling barriers. It may rather contribute to the maintenance of such institutional barriers by encouraging paternalistic attitudes and by diverting attention from the real cause of disability.

Limitations of Simulation Exercises

Simulation exercises e.g. placing non-disabled people in wheelchairs or blindfolding them to experience moving around, only illustrate the experience of functional difficulties, and not the experience of inequality or discrimination resulting from an exclusive society. Emphasis on such experiences may limit understanding of disability in functional aspects and make it difficult to be aware of disability as an issue of rights and equality (3,4).

Furthermore, simulation exercises provide only an experience of instant, sudden impairment which usually leads to inability and disorientation. These emphasise what people cannot do

if they suddenly have these impairments. This may create negative connotations around disabled people as being incapable or less-able, although this is certainly not the case for the many who lead independent lives.

It is true that simulation exercises can be used to experience physical barriers in society, such as steps and stairs. However, simulation exercises are often used only to identify what a 'barrier' is; and end up by simply teaching participants how to help others climb up the steps, or how to guide a blind person. DET emphasises the importance of examining the causes why such barriers are made, and facilitates action to break them and prevent their creation.

Implementation of DET: Project by JICA and the DSW

JICA and the Department of Social Welfare Malaysia (DSW) commenced a project for Capacity Building on Social Welfare Services for disabled people in 2005. This project has been designed based on the Social Model of Disability, and DET is taken as one of the key components of the project in addition to the promotion of the Independent Living movement, Supported Employment (Job Coach system), and Self-Advocacy of persons with learning difficulties. In this project, a five-day training course for DET trainers was held three times over three years, and 41 people, all of them disabled people, from ten countries, (namely, Malaysia, Thailand, Singapore, Indonesia, Nepal, Bangladesh, Pakistan, Kyrgyzstan, Maldives, and Afghanistan), were trained as DET Trainers. Manuals on DET were also published in this project as "DET Manual Series" (DET Manual Series: all are published by Utsusan Publications (Kuala Lumpur) No. 1. Liz Carr, Paul Darke and Kenji Kuno (2008) *Training Them and Us: A Guide to Social Equality for Society*. No.2. Kevin McLaughlin and Kenji Kuno (2008) *Promoting Disability Equality: From Theory into Practice*. No. 3. Sue Rickell, Yuko Yokotobi and Kenji Kuno (2008) *Disability Equality and Inclusion: Making a Difference – DET Resource Book*).

Trained DET trainers have implemented DET in their own countries, and conduct further local trainers' training courses too. As a result, for instance in Malaysia, a low fare airline company takes DET as a compulsory module for the training for cabin crews and ground staff. DET is used as part of a leadership training course in Thailand and Pakistan. Asia Pacific Development Centre on Disability (APCD) in Thailand, implements further trainer's

training together with those who were trained in this project. As a regional effort, the Asia Pacific DET Forum was also formed in 2006 (www.detforum.com). Experiences of the implementation of DET in these countries have been accumulated; and potentials, challenges and steps for further development of DET are discussed in the network of the forum. The following sections are the analytical summary of these discussions.

Potential of DET

Two key categories and seven elements were identified as potentials and advantages of DET implementation in developing countries. One category is the methodological advantage of disability education for equality to non-disabled people. Another is the potential as an empowerment practice for disabled people.

DET as Disability Education for Non-disabled People

Four potentials and advantages of disability education were identified. The first potential is the methodological advantage of DET. Often, people show hesitation and repulsion to disability awareness and disability education programmes by feeling that they are being imposed upon to do something which they think “is not my business” especially in private sectors. However, such negative attitudes occur less in DET because of its methodological advantage, i.e. the facilitated participatory learning approach which facilitates a self-discovering process in contrast to the other approaches which often fall into the trap of propaganda or self-righteousness.

Second, is the advantage of DET to create a logical understanding on the Social Model of Disability. Often, the Social Model is misunderstood as it ignores issues of impairments and the importance of medical interventions. In fact, the Social Model does not deny these, but contrasts issues on impairments and issues on disability, with a clarification of the limitations of a recovery oriented rehabilitative approach, and so shows the importance of a social change oriented approach to the issues on disability. Logical explanations on disability and self-discovering methods reduce such misunderstanding in the process of DET.

The third potential is to make participants aware of disability as one of their issues. Proactive action plan making, facilitate participants to become aware of their own potential and power to change their organisations or community better through feasible efforts.

A fourth and important advantage of DET is that, it helps each participant to deal with their own negative attitude on disability and disabled people constructively: It supports each to create a practical and concrete path to rebuild an alternative sense of value by a facilitated participatory learning process. Action plan making plays an important role in this aim, by giving each participant the opportunity to create their own solution to break their own barriers in their work and everyday lives.

DET as Empowerment Process of Disabled People

DET gives three elements for empowerment of disabled people. The first is that DET gives disabled people a logical explanation on disability as discrimination and social exclusion, which they always faced as problems, but which many of them could not explain logically before. It also gives a logical explanation of the Medical Model of Disability's failure and limitation to understand and fight against the entity of issues on disability.

The second is that DET gives them a method through which to logically and simply explain the Social Model perspective to non-disabled people. This empowerment was apparent among participants of the DET trainers' training. Contents (theory of the Social Model) and methods (facilitated participatory learning approach) are inseparable elements of DET.

The third is that DET builds a new positive and affirmative identity of disabled people, by redefining their identity from the Social Model perspective. This contrasts with the inferior status which is usually accorded under the Medical Model perspective.

Examples of empowerment were often seen among the participants of DET trainers' training courses, since they gained a more comprehensive understanding on disability from the Social Model perspective, and trained as trainers to become able to "explain" the Social Model by using facilitated participatory learning approaches. Some young disabled people who did not have much experience taking leadership roles before the DET trainers' training course, have started to play an active leading role not only in their organisation, but also as regional leaders. One such example is the young male participant with learning difficulties. He gained the confidence in trainers' training to start work as one of 5 trainers of a regular disability training course for a private company, and become a resource person for a UN ESCAP meeting on self-advocacy in 2007.

The Social Model itself has the power to empower disabled people. DET adds more by providing methods to use the theory of the Social Model practically. It becomes a tool to explain disability as a social issue which can empower disabled people as educators and agents for change on disability issues.

Challenges of DET

Eight issues in two categories of concern, were identified as key challenges to the implementation of DET in developing countries. The first category is the challenge for the implementation of DET; and the second one is the development of DET trainers. These challenges were thrown up by two fundamental reasons. Firstly is that the lack of awareness of human rights in general, even the most basic human rights and security such as freedom from poverty are not secured in many of these developing countries. Hence political, legislative, and administrative supports for activities and programmes such as DET (which are based on rights-based approaches) are not given a priority in practice. The second reason is that the Charity Model and Medical Model of disability still dominate people's sense of values, which are bound up with meritocracy and capitalism.

Challenges in the Implementation of DET

The promotion of the Social Model of Disability faces challenges even in western societies despite there being a general awareness of rights, and well prepared legislative and administrative measures. Many more difficulties and challenges are surely to be expected in implementing DET in developing countries, where awareness of human and civil rights, and the necessity of legislative and administrative measures for these are limited. Also, poverty and other social issues are accumulated; involvement in a capital market economy is forced, with competition faced in a disadvantaged status; and there are many differences in terms of culture, religion and society in western societies, eg. civil and human rights and the concept of entitlements. These issues have caused further difficulties and challenges in the implementation of DET.

The first challenge is to shift the paradigm of welfare interventions from the first generation (Charity Model: Care-oriented approach) and the second generation (Medical Model: Recovery-oriented approach) to the third Generation (Social Model: Inclusion and

Participation-oriented approach). This is the hardest challenge in most developing countries, where care and rehabilitation are still the central interventions on disability. Promoting rights or a rights-based approach, i.e. denying charity-based approaches was controversial in practice in the societies where legislative and administrative measures to protect the life and rights of the vulnerable, including disabled people, are not regulated, and charity and donation are the main sources of inflow (It is quite difficult to distinguish charity itself and the Charity Model perspective on welfare and disability).

Secondly, influences of religious dogma which often promote a charitable outlook also cannot be ignored in developing countries. Religious leaders often exert a strong influence in communities and expressing contrary thought to parts of religious doctrine is regarded as a challenge to the religion itself; and triggers various problems in the community.

Thirdly, in contrast to the care and rehabilitation oriented programmes, funding is quite limited to the educational programme on disability for the public. Often, such educational programmes are taken as a “free of charge” programme and DET trainers are not paid as professional trainers as compared to other professionals.

How to deal with “charity”, religious thoughts and funding issues, are ongoing topics of discussion among DET trainers in the project.

Challenges in Human Resource Development

The first challenge is that there are not many disabled people who are fully aware of, and have strong sense of, human rights. Even some disabled leaders and activists promote charity interventions, although they themselves choose the language of “rights”. Many Disabled Peoples’ Organisations (DPOs) still play a role as mere self-help groups and have not yet transformed into agents for social change for inclusive society.

The second challenge is that many disabled people cannot work as fulltime trainers, because DET trainers are not paid well as professionals. Disabled people who have their own jobs can spare their time for DET only on weekends, and even those who are working as staff of DPOs also have duties in their own organisations. It is important for the implementation of DET that it be funded or paid sufficiently to guarantee disabled people security and the ability to work as professional DET trainers.

The third challenge is that the 5-day training is the minimum to train a DET trainer, and there is a need for further training on both the Social Model and methodologies of facilitated participatory learning (FPL) approaches. A three-day follow up training as an additional course was conducted on FPL for Malaysian participants; and it covered several aspects on methodologies. Although the earlier mentioned internet discussion group of AP DET Forum is an alternative method of follow up by exchange of experiences and information, actual follow up training courses or extension of the length of the training course are required to ensure the quality of trainers.

The fourth challenge relates to the third one. Most disabled activists and leaders are likely to be good propagators and agitators to fight for their rights. Although a better understanding on their rights is an advantage to be a DET trainer, being familiar with a rather “impeaching” style can be a challenge to overcome, to be a good DET trainer in a methodological sense. DET is a facilitated educational process and the trainers’ role is neither as an accuser nor crammer, but a facilitator for the participants’ discovering and learning process. An accusing, oppressive situation by impeachments of the one in charge may be essential in disability movements, and DET is also born from such disability movements and shares the same philosophical foundation through the Social Model. However, DET takes different approaches for the same aim. Both are important but should be implemented appropriately. One such example is the case of a low-fare airline company in Malaysia. Public demonstrations to accuse inaccessibility of its services at the airport broke the barrier of the company. DET was then used as an educational tool for them to rebuild new and better foundations through which they could make their services accessible. Therefore, sufficient training and lots of practice to acquire methodologies and skills of FPL approach are vital to be a good DET trainer.

Lastly, inaccessibility of transportation and training venues also restrict disabled trainers in conducting DET courses, although this can be a good opportunity to raise awareness of organisers on the importance of accessibility.

CONCLUSION

Most peoples’ perception on disabled people is influenced by the Medical Model. This model is strongly rooted to capitalism and meritocracy, which are the dominant sense of

values in current world society. Such perception seems much stronger in developing countries which are now swamped by the wave of globalisation and competition. Therefore, the Medical Model is not merely a 'model' of disability, but an intrinsic part of peoples' fundamental standard values, impossible to change by a mere half or one-day DET course. What DET can do is to provide an opportunity for participants to start thinking critically of disability and to view their own sense of values from an alternative perspective. DET can facilitate them to continue thinking, by posing problems and providing tools and a theory to examine disability.

DET is not panacea. However, it is a concrete strategy and activity to promote the Social Model of Disability and rights-based interventions on disability. Experiences of implementation of DET in the earlier mentioned countries show explicitly its potential to empower disabled people and raise awareness on disability from the perspective of human rights. There are lots of challenges to overcome in implementation, and therefore it is worthwhile to continue developing DET to be more appropriate to developing countries. It also has the potential to examine the larger dominant values such as meritocracy, capitalism and ablism (discrimination in favour of the able-bodied) from the values developed by disabled people themselves.

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ORIGINAL ARTICLES

**THE INFLUENCE OF HIV/AIDS ON COMMUNITY-BASED
REHABILITATION IN DAR ES SALAAM, TANZANIA**

William Boyce*, Laurence Cote

ABSTRACT

Community-Based Rehabilitation (CBR) is the method of choice for delivering services for people living with disabilities in many countries. HIV/AIDS is changing the daily lives of many women by adding to their responsibilities. How realistically can such women participate actively in community development activities like CBR? This paper examines the impact of HIV/AIDS on CBR in Dar es Salaam, Tanzania. Observational sessions and individual interviews were conducted with caregivers of children with disabilities, CBR workers and managers over a three month period. Among the findings was a significant decrease in CBR activities in families affected by HIV/AIDS. This change in family priorities was due to better knowledge of acute diseases and increased stigma of HIV/AIDS in comparison to disability. Older CBR workers were more likely to incorporate elements of HIV/AIDS care with CBR, while younger CBR workers were more likely to avoid HIV/AIDS support. The ability of CBR workers to adapt their working habits to an environment with high HIV/AIDS prevalence is linked to their sense of skill competence and their knowledge/beliefs about risk of infection. Further integration of CBR work with general health development initiatives may improve this situation.

INTRODUCTION

Community-Based Rehabilitation (CBR) is the method of choice for delivering services for people living with disabilities in many African countries. However, these countries are currently facing the major crisis of HIV/AIDS. While the international scientific community has started to look at the impact that HIV/AIDS represents for many areas of development (e.g. education, health care, economy), little has yet been done to explore its impact on the

field of rehabilitation. This paper examines the impact of HIV/AIDS on CBR in Dar es Salaam, Tanzania.

LITERATURE REVIEW

Disability in Tanzania

The necessary programs for people living with disabilities in Tanzania include prevention, treatment of impairments, rehabilitation approaches and referral components. It is estimated, however, that less than 5% of disabled people in Tanzania receive rehabilitation services (1). These services have been organized and maintained mainly through internationally funded initiatives and Non Governmental Organizations (NGO). The country has adopted CBR as a national strategy to target disability issues, but few concrete actions have been taken because of a lack of specific programs and trained staff (1).

The initial concept of CBR has evolved over the years from a focus on restoring function to a holistic approach, considering the environmental factors that influence disability (2). Through a community development approach, people create partnerships and contribute to the creation of a more inclusive environment for those with disabilities (3).

Many internationally initiated CBR projects in developing countries have failed to be self-sustaining (4). The main challenges in CBR implementation and long-term survival are: a rapid turnover of volunteers (or workers); difficulties in the mobilization of local resources; lack of technical and professional support; lack of ownership of the projects by the communities where they are implemented (often secondary to a “top-down” implementation (5)); and poor participation of the local authorities (6).

Poverty, particularly in Africa, also constitutes a considerable barrier to community participation in CBR. Resources are scarce everywhere and it is understandable that people are concerned about their own needs and may not be disposed “to meet the needs of the minority group such as disabled persons” (7).

HIV/AIDS

The HIV/AIDS epidemic is taking dramatic proportions in sub-Saharan Africa. The situation there is particularly disturbing, with more than 10% of the adult population infected by the

virus in 12 countries (8). The number of people living with HIV/AIDS in Tanzania was estimated at 1,500,000 at the end of 2001; of these, most were adults, constituting 7.8% of the adult (15-49 years old) population (9).

While most of the research effort on HIV/AIDS is directed towards medically related aspects, such as prevention and treatment, there are some reports on the economic effect of the disease and on the social consequences of the epidemic (10, 11). The impact of HIV/AIDS on the education system, reflected by the loss of teachers and students, is already the subject of some investigation (12). However, the consequences of the HIV/AIDS epidemic on community based rehabilitation programs are not well documented, although in that context, these two issues represent many commonalities due to psychological, gender, and poverty factors.

In a study about HIV/AIDS related stigma in Uganda, the association of the disease with sinful behaviors, or the transgressions of cultural taboos, were common (13). In particular, beliefs about witchcraft and curses were important contributors to the stigmatization of people affected by AIDS and their family members.

The HIV/AIDS epidemic has a particularly important impact on women due to the added workload of sick family members (14). Women in Africa are traditionally the main family caregivers and are responsible for most of the household chores and related activities (fetching firewood and water, cooking, gardening). They have to take care of more children (due to the high number of orphans), care for sick people in advanced stages of AIDS, take more responsibilities for earning income, while often being themselves infected by the virus. This pattern is also true in Community Based Rehabilitation programs where more women volunteer than men (15, 16). HIV/AIDS is changing the daily lives of many women by adding to their responsibilities. How realistically can such women participate actively in community development activities like CBR?

METHODOLOGY

Setting

The study was conducted within the “Comprehensive Community-Based Rehabilitation, Tanzania (CCBRT)” organisation. CCBRT started its activities in 1994 as a small CBR

project, but then began operating a disability hospital, offering both hospital and mobile clinic services.

The CBR program was managed by a coordinator, reporting to the director and was assisted in his work by two supervising physiotherapists. Together, the coordinator and physiotherapists oversaw the work of 14 Community Rehabilitation Workers (CRW) workers, dealt with issues surrounding daily management of CBR work, such as working schedules and leaves, and oriented the development of the program.

CCBRT subsequently started an HIV/AIDS initiative, recognising the urgency of taking action to contend with the epidemic's impact. The initiative offered a wide range of services to people living with HIV/AIDS including: voluntary counselling and testing; medical counselling and treatment; home based care; legal aid; community based orphans program; and a school education program. These services were provided only to people living in Dar es Salaam.

Study sample

The study participants were both men and women currently active in providing or receiving CBR services. Particular attention was given to involving as many men as women in the study. However, very few men took part in the study because the CRWs and family caregivers of persons with disabilities were mostly women (4 men, 19 women).

The people interviewed in the families were all women and the main caregivers of a disabled child. These were the mothers or grandmothers of disabled children and were in direct contact with the CBR project. The CRWs were all currently working in the CBR program and had been involved for between 1 and 8 years. The managers in the study were the persons in charge of supervising the work of the CRWs, providing training, and developing the program. Two managers were in direct contact with the families, through field supervision of the CRWs.

Data Collection

Ten organised observational sessions took place in the first month of the study. The daily activities of CBR workers, their use of time, and the perceived direct and indirect impact of

HIV/AIDS on the CBR program, were the focus of the observations.

Individual interviews were then conducted with all study participants to get a deeper understanding and descriptions of their experiences. Individual interviews consisted of open-ended, non-leading questions and lasted between 30 and 45 minutes.

Data Analysis

The data consisted of interview transcripts, observation notes and fieldnotes. A content analysis process was used to identify the main ideas, recurring themes and relationships between concepts which were then used to create an explanation of the HIV/AIDS - CBR phenomenon (17).

RESULTS

The environment of HIV/AIDS in Dar es Salaam

As in most African urban cities, people come to Dar es Salaam in search of employment, as a way of getting out of the poverty and difficult living conditions in the villages. However, poverty and poor living conditions are important problems in Dar es Salaam, and, in many situations, social support is non-existent. A typical story includes the following:

Bibi¹ Samuel is sitting on the floor of her little house. It is very small and has 2 beds and a cooking area. She is the main provider of the family: her husband is not around: he is not assisting the family in any way. Bibi Samuel has had 4 children. One of them died some years ago. The husband of her daughter also died and left her daughter and grandson alone with no resources; they had to come back and live with her. Her grandson Samuel, 8 years old, is disabled. He can't stand, sit or walk. She has to feed, dress and clean him every day. His mother had to leave the house and go away to work and try to earn some money, so Bibi Samuel is the one responsible for the care of Samuel.

A few months ago, the sister of Bibi Samuel came to live with her. She was sick with AIDS and had nowhere else to go. Bibi Samuel felt she had the

¹ Grandmother (a pseudonym is used)

responsibility to take care of her sister. It was difficult for her to find the time to do all the required activities in the day. The CBR worker, Maria, came to visit Bibi Samuel every week to advise her on what to do with Samuel. At the same time, Maria noticed her sister who was sick and talked about the HIV/AIDS home-based care program. She arranged for the HIV/AIDS workers to come and give her advice and support. But still, it was not possible to do the exercises with Samuel the way it was before. Bibi Samuel had to care for people at home, work for money, and after her sister died, she had to organize and pay for the funeral...

Coping in families with disabilities and HIV/AIDS

The daily roles and responsibilities of women are changing. In addition to caring for people with disabilities, the caregivers have to pursue their regular home activities and earn money to meet added living costs. When the caregiver is affected by HIV/AIDS, these other responsibilities can be difficult to meet. The support the families receive from the CBR program takes many forms including: receiving information; getting access to services (for disability and AIDS); and getting direct support in the form of money or food.

Care-giving Roles

Tasks related to rehabilitation of a disabled child are seen as distinct responsibilities of the women in the household. These responsibilities include being available for meeting with the CRWs when they visited and providing regular skill training for the child. The latter aspect of care seemed to be often neglected by the caregivers due to caring for a sick person in the home. One mother explained why she was not able to do exercises consistently with her disabled child:

After having his meals I do his exercises. You can see that his body is now not stretching because it's been a long time since I did exercises with him. I had no time to do exercises for him, because I was the only one to take care of my dying son.

Another important parental role for women is to take care of orphans. This is frequently the case when the caregiver is a grandmother. HIV/AIDS, in addition to disability, has led some families to make difficult decisions about whom they should prioritize in the family. It has also brought an added financial burden, lack of space, and lack of food. Overall, because there are more responsibilities and more tasks to do in a day, caregivers have less time for the care and rehabilitation of the child with a disability. When the caregiver of the child is also sick with AIDS, the situation is even more difficult:

Mama Lydia is sitting on the floor of her small room. It is about 9 feet square and there is 1 bed, 2 kerosene stoves, a few chairs, a bed and some dishes. She lives there alone with her child. The child is about 2 years old and has cerebral palsy. (...) While we are talking, the mother is preparing a meal for her disabled daughter. She only has water and flour. She pours a little bit of flour in boiling water, and then adds a pinch of salt because she doesn't have enough money to buy sugar. That is the only food she has to feed her daughter. Lydia is crying and coughing a lot (...). The mother explains that she is completely abandoned, not only by her husband, but also by her own family. When I ask why it is like that, she says it is maybe because she has a "bad life" is not married and has a child on her own. When she started to be very sick last July, she went back to her mother's home to get some assistance. When she realized she was not getting any help, she came back alone with her child to her little room in Dar es Salaam (...). She went for HIV testing² last week, and she is very scared of the result. She says she is thinking of taking poison to kill herself if the result is positive (...). When I ask her if she has a question or something to add, she says: "If I continue to be sick like that, and because I am so alone, without support or help, what will happen with my child?"

Excerpt from fieldnotes, November 8th 2002.

² The result of the test was found to be positive

Urgency and Knowledge of HIV/AIDS

Most caregivers who have to choose between providing care to a person living with AIDS or a child with a disability, consider AIDS as a more serious problem and give more care and attention to that person. Caregivers have the perception that the child with a disability has a condition that is not “changing” and that the disability will still be much the same, even if they neglect the exercises. However, the person with AIDS requires more care, because of the sudden onset of opportunistic diseases that are considered serious and life threatening:

And in most cases, I was taking more care of that patient³ than the disabled child because I was thinking that the sick one was more serious than the disabled.

Caregivers’ level of knowledge also contributed to setting priorities. They generally seemed to have a better understanding of what should be done with someone who is sick, as compared to someone with a disability. They will bring the person with AIDS to see a doctor or a traditional healer, and buy the required medicine if they can afford it. In contrast, they have less knowledge about the need for making the disabled child more independent, investing in special equipment, or arranging corrective surgery.

Stigma of HIV/AIDS

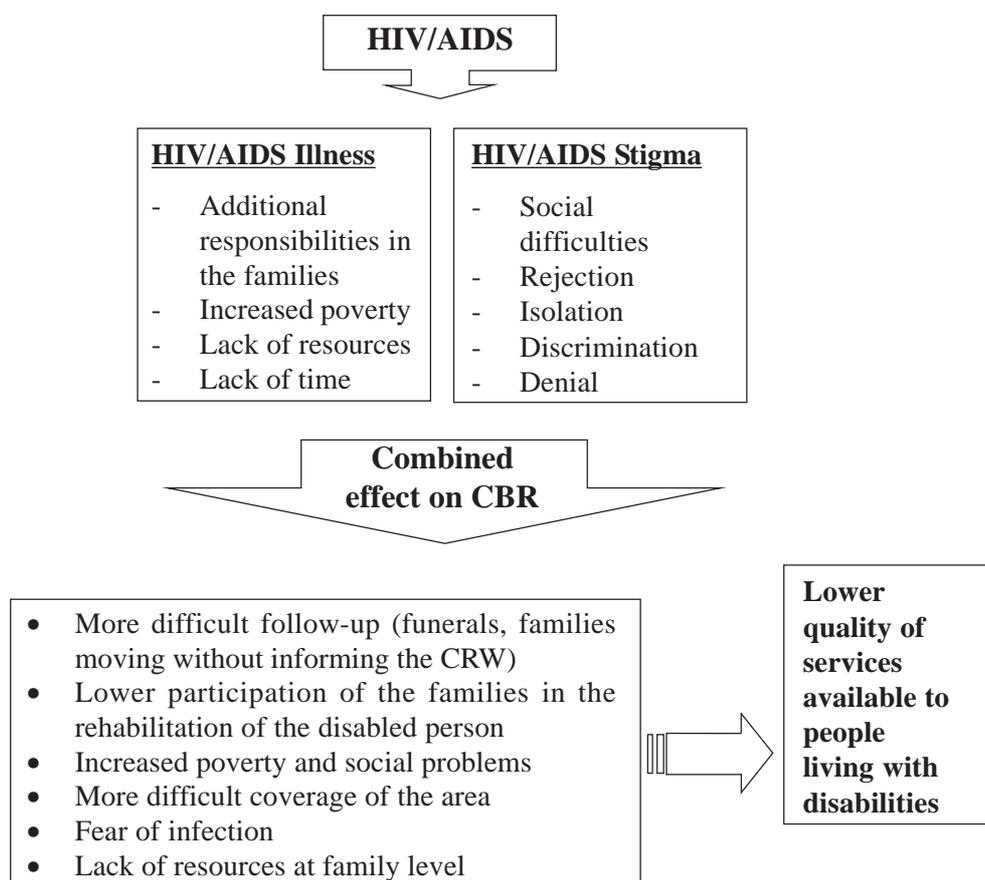
To be able to respond effectively to the issues that AIDS brings into CBR work, the problematic of AIDS in the community needs to be recognised. However, there is still resistance to talk about HIV/AIDS and to acknowledging its presence in Tanzania. People fear discrimination if they are known to be affected in any way by HIV/AIDS.

Sickness from AIDS-related illnesses is usually not confirmed by HIV testing, so it is easy for people to attribute their sickness to causes other than AIDS and to avoid talking about it. When HIV status is known, family members are scared to reveal it because of the stigma associated with the disease, and the negative social consequences and discrimination it may bring to them or their families. Thus, AIDS is known to be in communities, but most people prefer to believe it is not affecting them directly. Families do not tell the CRWs that they

³ Referring to the person living with AIDS

have fewer resources and more difficulties in caring for their disabled child because of being sick with AIDS, or of having an added burden of caring for more people (orphans or a sick relative). The CRWs do not report their field difficulties or having come across a person living with AIDS to the CBR coordinator because they are not sure if it is their responsibility or they simply choose to ignore it. Consequently, the CBR management is not fully aware of the HIV/AIDS realities in the community and is not able to take appropriate measures to assist and support their workers. A model for understanding the effects of HIV/AIDS illness and stigma is illustrated in Figure 1.

Figure 1. The effect of HIV/AIDS and stigma on CBR



Process of health-decision making

To better understand the implications for CBR, it is essential to understand the distinction people make between disability and HIV/AIDS. This understanding can be applied to the decision-making process when it comes to the allocation of limited family resources.

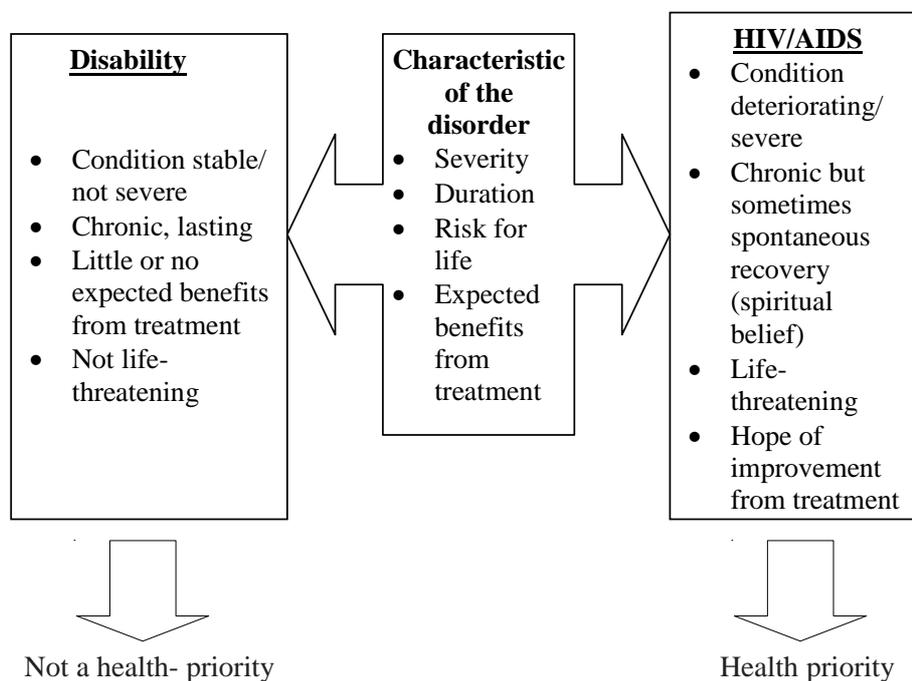
Caregivers of disabled children and CRWs often refer to disability as something that does not change much over time and is not life threatening. Unlike other health-related conditions, disability does not mean rapid deterioration, even without specialized care and intervention. Disability is perceived as a chronic condition, but not an emergency, and a disabled person can remain unattended for some time without consequences. Families who receive attention from the CBR program have the impression that the changes in the life of their disabled child were minor and even imperceptible to the layperson, despite the fact that families had provided the child with special care and attention for a prolonged period of time. Their overall impression is that disability does not change much with or without treatment. Families do not know what to expect from on-going rehabilitation services and have little expectation of seeing improvements. In comparison to other acute health conditions (that might involve recovery), the slow progress of the rehabilitation process discourages the caregiver and eventually diminishes the efforts she makes in trying to make the disabled child more independent. Collaboration of the caregivers with the CRWs on rehabilitation goals becomes increasingly difficult, but in the context of AIDS, the caregiver is already drained because of other responsibilities. Some families continue to request CBR services because of the expectation of other tangible benefits, other than rehabilitation and advice for their disabled child.

The perception of health problems due to HIV/AIDS is quite different than the perception of disability. Usually people do not refer to the health problems as AIDS itself, because of the strong stigma associated with the disease, or because they just do not suspect AIDS. Instead, they notice an ongoing, recurring illness in a family member. The condition is very often acute, judged severe and life threatening by the family, and requires help and support from traditional healers or modern medicine, or both, according to the beliefs associated with the specific symptoms. Families hope that the situation will improve, that things will come back to normal, and that the illness can be cured. Even though people know that AIDS and the severe opportunistic conditions that come with it can all lead to death, they still

believe that there is a possibility to improve and recover. This belief is strongly linked to their knowledge of health and the tendency to attribute a supernatural origin to diseases. Thus, there is always a possibility for improvement from a life-threatening condition, which justifies the provision of special care.

Other studies have shown that health-seeking behaviours in developing countries are influenced by several factors including: the characteristics of the people; their perception and the characteristics of the disorder; and the characteristics of the health services available (18). When comparing Dar es Salaam families' reactions to disability and to HIV/AIDS, the main difference appears to lie in the nature of the condition and the expectation for improvement or deterioration. If there are some expected benefits from treatment, action is more likely to be taken. Thus, in most families, more time and resources are devoted to medical treatment of AIDS, leaving the disabled child with comparatively less attention. These decision-making processes are illustrated in Figure 2.

Figure 2. Decision-making at family level: Disability vs. HIV/AIDS



Community Rehabilitation Workers and CBR work

Maria starts her day at 8h00 every morning. She has planned to visit about 6 families in her day. The first visit is to Mama Lydia⁴. It is a very difficult situation and she knows that she will probably not be able to do anything with the disabled child because there will be other more important problems. Last week, Maria found Mama Lydia very sick in her bed. The child was on the floor crying alone and nobody was there to help. The neighbours are not assisting her. Only once, they went to tell the mother of Mama Lydia that her daughter was sick, but the mother never came. So last week, Maria had to use her own money to buy some medicines for Mama Lydia. She then reported the situation to the CBR office, because she felt that more help was needed.*

So this morning when she reaches the house of Mama Lydia, she finds her a little bit better, trying to cook some porridge for her daughter. But still, she is very weak and the child is crying and has not yet eaten. The child is also coughing and Maria thinks he is also sick. She knows the mother has been tested for HIV and even if the result is not yet known, she suspects it will be positive. Maria is worried that maybe she will get herself infected if she touches the child or the mother, but she has no choice, she can't just avoid the child because it would make the mother feel bad. She will try to come another time this week to check on her, as asked by the CBR office. More help will maybe be offered.

*Excerpt from fieldnotes and interview with *Maria (name changed)*

Community rehabilitation workers in Dar es Salaam are learning to work in a changing environment. It is becoming increasingly difficult for the CRWs to concentrate their efforts exclusively on disability issues. More and more people are sick, or die, because of AIDS and this affects them and the families with whom they work. A CRW explains:

⁴ Mama Lydia's name has been changed

CBR deals with rehabilitating disabled children, but you find that the issue of HIV has come into CBR work. The changes we experience are that we find ourselves doing one, two or three jobs at one time. We visit families where there is a disabled child and at the same time, someone suffering from AIDS.

Commonly, the CRWs find children who are not receiving basic care, such as being dressed, fed, and cleaned. Before the CRWs can start doing rehabilitation interventions, they may have to provide such basic care-giving. This takes the attention of the CRWs away from the original purpose of their visit, and reduces the time spent on giving advice to the families on rehabilitation for the child. When the family financial situation is critical, a supervisor (physiotherapist) is sent to evaluate the condition of the family and decide if financial assistance should be offered.

CRWs are asked about the availability of antiretroviral drugs and the treatment of opportunistic diseases. Some CRWs educate people about the means of transmission of HIV and how to prevent infection. However, the level of knowledge about the services available outside the CBR program vary widely among the CRWs. Most CRWs think that people living with AIDS need assistance from other organizations such as the home-based care HIV/AIDS program of CCBRT. However, some CRWs are fully involved in providing care for people living with AIDS. They consider it as a responsibility and part of their regular work:

And also, it has changed because if I hear somebody is HIV positive, even if there is no disabled person there, I will have to go there and see the problem, and help the family and let them know what to do. The changes are there because I see both of them as disabled, so where there is an HIV patient, I have also to give services. I don't see it as a problem because I feel that I am helping people who are disabled. The HIV person is also disabled because he can never recover from his condition.

Overall, most CRWs believe they can make some intervention because of their training and because of the disabling effect of AIDS. One CRW provides an interesting example of how she could use her rehabilitation skills and knowledge for assisting a person living with AIDS who was having some problems swallowing:

Sometimes when he was drinking water he was vomiting, so I directed him to drink little by little and he doesn't vomit anymore.

Differences between CRWs in addressing HIV/AIDS issues is related to their different levels of knowledge about both HIV/AIDS and disability, and their perception about their own vulnerability to the virus. The CRWs in the younger age group which is most affected by HIV/AIDS seem more resistant to get involved, in comparison to older staff.

Due to the increasing prevalence of HIV/AIDS in Dar es Salaam, it is common that CBR work is disturbed by AIDS-related funerals. When this happens, CRWs have to attend the funeral for a short time before they can go to the next family:

You have to participate in the funeral activities. You are not supposed to go away and take the child to do exercises. Even if you don't stay for so long, you have to present yourself to the family and tell them that you are supporting them with the problem, and then you can tell them that you are going.

CRW Concerns about HIV/AIDS

A main limitation in CBR work is worry and concern about the possibility of contracting HIV. All of the CRWs have strong concerns about these risks and they perceive their work as a potential way of becoming infected. Fear of infection affects CBR work by bringing excessive worries and stress to the CRWs and by making them adopt strategies to avoid infection risks, which ultimately results in neglect of children who they judge to be at high risk.

Working in an environment with a high prevalence of HIV/AIDS makes many CRWs "very unhappy" with their work. They are constantly looking for signs of infection, such as skin rashes. They are also conscious of open sores on children's skin and feel very worried about continuing their work without protection:

Our health is threatened by this AIDS problem. You go to a family without any protective instruments and you do not know whether the child you are giving services to has been infected or not. But from the way you see her you would say the child is infected.

I had to do the exercises to the child but when the rashes were giving out fluid I stopped doing the exercises because there are no gloves.

Some CRWs express concerns about the possibility of transmitting the infection to their own family through their clothes:

So when I touch the child with those rashes and my dirty clothes I can transmit the rashes from that child to others at my home.

Other CRWs were also unsure of their own HIV status and were worried about the possibility of transmitting the infection to disabled children:

When I'm doing my work, I'm not sure whether I, myself, I'm HIV positive or the one I am doing exercises with is HIV positive. I don't know if this family I am dealing with has HIV problems. I don't know.

Most CRWs deplore the fact that they could not wear surgical gloves, and sometimes could not easily wash their hands after touching the children:

A major problem is that for example they say that you should put on gloves when you want to give service to an HIV patient. You can treat a swelling with your bare hands and sometimes you may have cut yourself on the process of cooking or you can touch a child with rashes.

However, CRWs report that it would make the families feel uncomfortable if they were to start wearing gloves or washing their hands. At the same time, they are not provided with gloves by the CBR program. Therefore, some CRWs have adopted strategies to avoid being in close contact with some of the children when they suspect HIV/AIDS in the family. They sometimes avoid doing any type of handling of these children or avoid seeing them altogether:

We try to avoid such things like hugging the children in one way or another by giving the children some presents for example you go there with balloons, so you give the children the balloon before they hug you.

The fear of contracting HIV through CBR work is a common worry. Similarly, a study among physiotherapists in South Africa showed that their relative lack of knowledge had made the physiotherapists overly conscious of the risks of infecting themselves through their work (19).

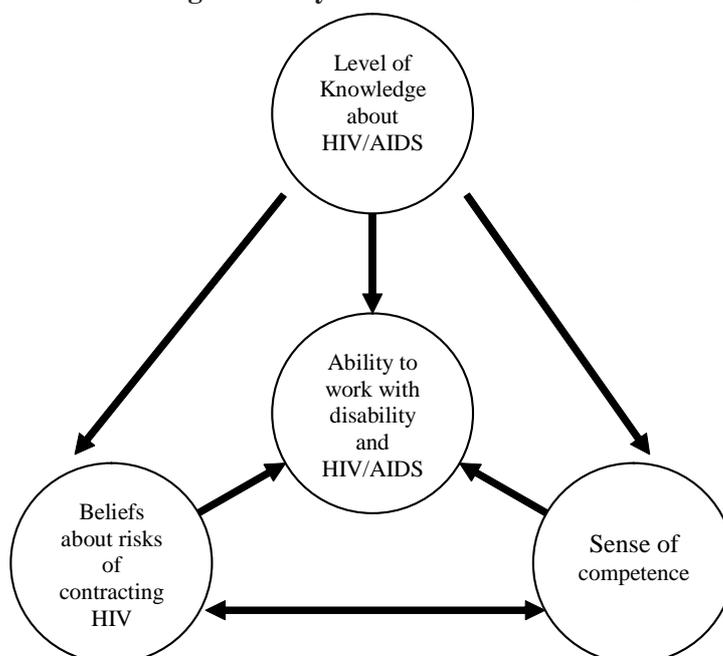
Roles of CRWs' sense of capacity, knowledge and perceived risk

A model for CRW ability to work in AIDS-affected communities is illustrated in Figure 3. CRW attitudes towards HIV/AIDS are quite variable although denial is a major reason. Some CRWs are well informed about the condition but others know very little. This finding is consistent with a study among hospital-based workers in Uganda which found that important gaps in workers' knowledge about HIV/AIDS had a direct effect on their services, and resulted in reduced quality of care offered to patients who were potentially HIV positive. Fear of contagion, and concern about treating AIDS patients were reported by both nurses and doctors. Misperceptions of the risks of infection were common (20).

This finding is also consistent with observations made by Rugalema (21) indicating that the level of awareness about HIV/AIDS was high in various countries of sub-Saharan Africa but the level of infection was not going down, suggesting that acknowledging the existence of HIV/AIDS does not mean knowing what to do about it.

The older, more experienced CRWs are more likely to talk about HIV/AIDS during their CBR work, and to be more involved in providing some type of AIDS intervention, than the younger, less experienced CRWs. Older CRWs seem to be more confident in their skills and to be better able to adapt these to serve people living with AIDS. In some studies the level of knowledge about HIV/AIDS among health-care workers has been related to age, although other studies have found that attitudes towards people living with AIDS was not linked to age (22, 20).

Figure 3. Factors influencing the ability of CRWs to work in AIDS-affected communities



The ability of CRWs to adapt their working habits to an environment with high HIV/AIDS prevalence is linked to a sense of competence in their skills and beliefs about their risk of infection. The latter belief is directly influenced by their HIV/AIDS knowledge base. The experienced CRWs have more years of practice and feel more confident about knowing what to do when confronted with HIV/AIDS during their work. They may also feel less at risk of HIV infection in general, as they are older.

This model reinforces the need for better training and the importance of informing CRWs about HIV/AIDS to increase their sense of confidence in working with people that are susceptible of being infected with HIV/AIDS.

DISCUSSION

The roles of CBR in the context of HIV/AIDS

It is evident that even though no clear policy has been made by CBR programs to take concrete action in the field of HIV/AIDS, there is already something being done. The question

is not if CBR programs should get involved in HIV/AIDS action, but rather how CBR programs can be better used and how that action should be targeted. At the local level, lack of clear direction causes confusion for both family members and CRWs. Lack of direction also leads to a wide variety of responses, that are not necessarily appropriate, because of variability in CRW skills, HIV/AIDS knowledge base and understanding of useful CBR roles. It is unrealistic to think that community-based work can ignore the difficulties that people are facing in AIDS, and simply concentrate on working on disability goals. Without facilitating the involvement of the family to the degree possible, by meeting immediate needs, little will be accomplished with the disabled child.

The WHO international classification of functioning (23) suggests that the environment can act as a facilitator, or as a barrier, to participation of persons with disabilities. Rehabilitation is intended to create an environment favourable for the person living with a disability. In the context of HIV/AIDS, however, the environment is not favourable to the rehabilitation and the inclusion of people with disabilities. Therefore, it becomes important to concentrate some efforts towards allowing caregivers to meet other needs so they have the time and resources to give to the disabled person. But how exactly this can be done within the existing structures of CBR is debatable.

One obvious way of addressing the issue of HIV/AIDS is through a referral process to appropriate resources for HIV/AIDS. Referral systems are already an integral part of CBR and CRWs are already referring people for issues that relate to their disabilities. However, referral is a complex process and does not always provide the needed support to people who require it. Referral rates in most community based health projects are known to be relatively low (24). These low referral rates are due to social, demographic and economic barriers and can also be related to the knowledge and attitudes of staff, as well as to the level of knowledge and past experiences of the referred individual (24). Referral rates can be improved by providing referral training and ensuring that referral sites are appropriate.

Another way to address more immediate HIV concerns is to offer services at the lowest possible level and avoid referral to specialized personnel. CRWs could be involved in providing some basic care to people with AIDS during their home visits. HIV/AIDS home-based care workers could train CRWs in basic care techniques. Training CRWs to be more skilled at identifying HIV/AIDS concerns and referring families to the appropriate resources

would be a great improvement. Because of the stigma in acknowledging HIV/AIDS, people usually resist going to services outside the home unnecessarily and it may be easier to provide these services in the home setting.

There is undeniably a growing role for rehabilitation workers in HIV/AIDS (25). However, CRWs need their concerns to be addressed through general training on HIV/AIDS (means of transmission, ways to protect themselves), and on how it may affect them in their work. This includes identifying the rehabilitation needs of people living with AIDS and the potential roles of the CRWs in assistance (26). People living with AIDS have activity limitations in relation to their conditions and can benefit from rehabilitation advice. Information about available HIV/AIDS services could also be made accessible to the families as part of CRW intervention. Training CRWs in working with other community projects that address HIV/AIDS is essential.

Finally, there is a need to offer support to CRWs in the form of psychological and health care services. These services could offer HIV testing and counselling. This would be a good way to start alleviating the stress that CRWs are going through in their work and lives.

Future research aiming at better describing the complex reality of CBR evolving in an environment with a high HIV/AIDS prevalence could target the following issues:

- The attitudes about disability and the reasons motivating the families to get involved in CBR
- The beliefs associated with HIV/AIDS as compared to those associated with disabilities; and the influence these beliefs have on health-decision making
- The expected outcome of rehabilitation and the perceptions about the importance of rehabilitation for families of people living with disabilities
- The similarities and differences in stigma due to disability and HIV/AIDS

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**PHYSICAL THERAPY ROLES IN COMMUNITY-BASED
REHABILITATION: A CASE STUDY IN RURAL AREAS
OF NORTH EASTERN THAILAND**

Nomjit Nualnetr*

ABSTRACT

This action research aimed to explore how physical therapists could enhance the quality of life for persons with disabilities via a community-based rehabilitation (CBR) strategy. The study was conducted in two rural sub-districts in northeastern Thailand. In each sub-district, several group meetings were arranged for persons with disabilities and their families, and various community members. Participants were encouraged to discuss their perception of problems of the current rehabilitation services for persons with disabilities. Strategies to manage all problems were collaboratively identified and were implemented in order of priority according to the importance of the problem. The outputs of CBR were evaluated by interviews and observation. The findings revealed that physical therapists had numerous roles in CBR, depending on the community's circumstances. They need a high degree of flexibility and a wide range of skills to contribute to CBR. The preparation of such physical therapists requires development of a more client-centered community-oriented education programme.

INTRODUCTION

The incidence of persons with disabilities in Thailand, has been estimated at 8.9% of the total population (1). Most of them are living in rural areas, facing problems such as poverty and discrimination, and are left behind in the development process. The conventional approach for the rehabilitation of persons with disabilities includes the provision of financial support and essential elements for them directly. Such an approach focuses on the recovery of body functions and frequently relies on professionals and institutions. It has been suggested that institution-based rehabilitation is helping no more than 2% of those in need (2). In the 1970s and the early 1980s, community-based rehabilitation (CBR) emerged as an alternative

strategy to deal with disability issues (3). It was promoted by the world bodies as an approach that was suitable for developing countries with limited resources, to provide wider coverage of services (4,5,6). CBR is a strategy within community development for the rehabilitation, equalisation of opportunities and social integration of all people with disabilities. It is implemented through the combined efforts of disabled persons themselves, their families and communities, networking with the appropriate health, education, vocational and social services (7). These circumstances challenge health personnel including physical therapists to apply CBR strategy for upgrading quality of life for persons with disabilities.

Thailand is one of the countries to adopt CBR as a means of delivering effective rehabilitation to persons with disabilities. CBR has been operating in Thailand since 1983, under the responsibility of physicians, nurses, and non-government organisations (8,9). However, the CBR programme managed by physical therapists has been limited. As lecturers in a physical therapy school, the researchers conducted this study to explore how physical therapists could enhance the quality of life for persons with disabilities through the CBR strategy.

METHOD

An action research was conducted between May 2002 and February 2004 in two rural sub-districts, namely sub-districts A and B, in northeastern Thailand. They were selected as study areas due to the large numbers of persons with disabilities and the convenience of the researchers reaching the areas within an hour. There was a community hospital in each study area but a physical therapist was available only in the sub-district B's hospital. The study was divided into three phases: education, empowerment, and implementation.

Phase 1 Education phase: In each sub-district, the researchers established rapport and initiated observations to assess the community context. Several group meetings were organised for persons with disabilities and their families, members of sub-district administrative organizations, community leaders (e.g. sub-district headman, monks), representatives of various community groups (e.g. the elderly, women, and adolescents groups), and local civil servants. The purposes of the meetings were to introduce the CBR strategy as well as the study's details and objectives, and to mobilise communities in sharing their experiences on issues regarding persons with disabilities. Finally, a core organisation that would be the leader of the CBR programme in each sub-district was identified.

Phase 2 Empowerment phase: The core organisation of the CBR programme in each study area was facilitated to arrange group meetings among persons with disabilities and their families, sub-district administrative organisation's members, community leaders, representatives of various community groups, local civil servants, and other relevant sectors. The researchers created an atmosphere for open dialogues and reflection during the meetings. An analysis of the persons with disabilities' current situation was collaboratively discussed among the participants. They were encouraged to discuss problems as well as barriers and limitations of the current rehabilitation services for persons with disabilities. The problems were prioritised, then strategies and action plans to manage such problems were established by the participants.

Phase 3 Implementation phase: The participants implemented their action plans in order of priority, according to the problems' perceived importance. The researchers regularly visited each study area to observe and record its activities, to encourage the core organisation and the participants to keep processing the programme, and to offer any necessary advice and help. The core organisation regularly arranged group meetings among the participants to evaluate the programme, and to review and modify the action plans.

The outputs of CBR programme in each study area were obtained by observation, field-note record and informal interview, and were evaluated in a qualitative manner. The researchers gradually withdrew from the study areas when it was considered that the communities could manage the programmes independently.

RESULTS

The results of the study in each sub-district are shown in Table 1. Besides the sub-district administrative organisation's members, community leaders, representatives of various community groups and local civil servants, 34 and 23 persons with disabilities participated in the study in sub-districts A and B, respectively. Most of them were persons with physical impairment. It was discovered that poverty was the main problem of persons with disabilities.

The core organisations of CBR programmes in sub-districts A and B were the sub-district administrative organisation and the community hospital, respectively. A number of CBR

outputs for persons with disabilities, especially in the form of psycho-social services, were observed (Table 1).

Table 1. Results in each study area

Items	Sub-district A	Sub-district B
Core organization being responsible for the CBR programme	Sub-district Administrative Organisation	Community hospital
Numbers of persons with disabilities participating in the study	34 (17 physical impairments, 7 visual impairments, 10 cerebral palsy and others)	23 (12 physical impairments, 11 cerebral palsy)
Main problems of persons with disabilities	1) Poverty and unemployment 2) Lack of social acceptance 3) Aggressive behavior	1) Poverty 2) Lack of persons with disabilities' identification card 3) Lack of physical rehabilitation
Strategies to manage PWDs' problems*	1) Providing income-generation opportunity 2) Promoting positive attitudes among community members towards persons with disabilities to improve social acceptance	1) Providing income-generation opportunity 2) Formulating a guide-line for registering persons with disabilities 3) Providing home-based physical rehabilitation services

* Strategies to manage persons with disabilities' problems were prioritised according to the problems' importance.

Table 1. Results in each study area (Cont.)

Items	Sub-district A	Sub-district B
Outputs	<p>1) Two career training projects for persons with disabilities and their families were conducted including Thai massage and native chicken farming.</p> <p>2) A CBR committee at sub-district level was established. Representatives in the committee included persons with disabilities, relatives, sub-district administrative organisation's members, community leaders, and local civil servants.</p> <p>3) A programme of quality of life upgrading for persons with disabilities was included in the sub-district administrative organisation's action plans.</p> <p>4) An annual event of sport activity among persons with disabilities and community members was set up.</p> <p>5) About one-third of persons with disabilities had their own incomes from massage and farming jobs.</p>	<p>1) A persons with disabilities was provided a loan by the sub-district administrative organisation to earn a living.</p> <p>2) Six persons with disabilities were registered for identification cards.</p> <p>3) Fifteen persons with disabilities were provided home-based physical rehabilitation by village volunteers.</p>

DISCUSSION

The impact of CBR on the quality of life of persons with disabilities could be promoting positive attitudes of society towards persons with disabilities, understanding and providing effective services, establishing a rehabilitation network in the community, ensuring accessibility of information particularly human rights, laws and policies regarding persons with disabilities, and providing emotional support for persons with disabilities and their families (10). This challenges physical therapists who have an important role in health promotion, disease prevention, and functional rehabilitation for population of all ages (11) to apply CBR for enhancing the quality of life for persons with disabilities. Recognising the need to support CBR and the development of the profession, the World Confederation for Physical Therapy (WCPT) has approved a Position Statement on CBR at the 15th General Meeting of WCPT in 2003 (12).

It is important for physical therapists to understand that rehabilitation in the context of CBR, focusses on the needs of individuals and the wider population and extends beyond a purely medical interpretation. Through empowering persons with disabilities to be active participants and decision-makers in CBR, physical therapists and other allied health professionals have acknowledged that persons with disabilities are not passive recipients of perceived professional wisdom, knowledge and skills. According to the CBR concept (7), it seems that the community participation is an important driving force to ensure the success of a CBR programme. Therefore, to improve the quality of life for persons with disabilities through the CBR strategy, the researchers suggest that physical therapists should initially play a role as programme facilitators rather than programme leaders. The community should decide on a CBR programme leader on their own. Action plans to solve the persons with disabilities' problems should be collaboratively established by the community. Whilst the programme progresses, physical therapists may however, undertake other roles such as expert resources or skill trainers, depending on the community's demand.

From this study, it was found that the role of the researchers as physical therapists was different between the CBR programmes of the two study areas. In sub-district A, the researchers mainly acted as the programme facilitators, meanwhile, acting as programme facilitators as well as skill trainers in sub-district B. This difference in finding may be due to a difference in the context of a CBR programme in each sub-district.

In sub-district A, persons with disabilities and community members were facilitated to process the CBR programme by the sub-district administrative organisation. It is well acknowledged that the main policy of a sub-district administrative organisation is to enhance the community members' quality of life and focus on community participation (13). As CBR is a strategy within community development for the rehabilitation, equalisation of opportunities and social integration of all persons with disabilities (7), it is in harmony with the sub-district administrative organisation's policy. This may persuade the sub-district administrative organisation to pay attention to CBR. Because of these reasons, the strategic plans and activities manifested in sub-district A's programme were likely to empower the persons with disabilities and improve their quality of life through social collaboration. The sub-district administrative organisation and community members could conduct the CBR programme on their own with some facilitation of the researchers. From a socio-cultural aspect, it was observed that persons with disabilities in sub-district A increased their distinct decision-making roles during social events.

In contrast, such findings were not obviously observed from sub-district B's CBR programme which was organised by the community hospital's nurses. As health personnel, the nurses were likely to focus on the health aspect. They might not pay much attention to integrate educational, vocational and social rehabilitation for persons with disabilities. Then, the outputs obtained from the sub-district B's programme seemed to deal with persons with disabilities individually, rather than empower them as a whole. A demand for the researchers to take part in the CBR programme as skill trainers was obvious in sub-district B.

Fifteen persons with disabilities in sub-district B, were provided home-based physical rehabilitation by village volunteers under the supervision of the researchers. In spite of being facilitated to play the supervising role, the community hospital's nurses strongly resisted the responsibility because of their lack of skills and knowledge on rehabilitation. Furthermore, although a physical therapist was available in the sub-district B's community hospital, she hardly participated in the programme due to lack of time from her routine work in the hospital. Then, as physical therapists, it was inevitable that the researchers provide skill training for the volunteers. At the end of the study, however, the supervising role for village volunteers was transferred from the researchers to the community hospital's physical therapist.

Based on these findings, it could be claimed that the role of a physical therapist in CBR would be influenced by the status of the programme leader and strategic plans designed by community members. As stated by Bury (2), physical therapists have the potential to play a number of roles in CBR, dependent on local cultural and socio-economic circumstances. Examples of physical therapy roles in CBR may include instigators of CBR services, team leaders and managers, providers of direct care, and advisers to governments and local communities, on establishing CBR programmes (2). There is no one model of CBR that will suit all circumstances. What is required is a needs-based activity developed in response to local circumstances. Therefore, physical therapists need a high degree of flexibility and innovative thinking, and a wide range of management, practice, teaching and research skills, if they are to contribute effectively to CBR (12).

At present, most physical therapists in Thailand are insufficiently aware of social, political, economic, cultural and religious differences influencing the communities and how this impacts on the health of persons with disabilities and their families (14). Preparing physical therapists to work in community settings with local communities, persons with disabilities and their families may require changes to the curriculum or developments of a more client-centered community-oriented education programme. Qualifying education should equip physical therapists to value community work and respect the knowledge and skills of persons with disabilities and communities. It has sought to challenge the profession-centric model of practice to one that creates a more balanced relationship between professionals and clients, through promotion shared decision-making.

Other findings were presented in this study. It was found that the main problem of persons with disabilities was quite similar between the two sub-districts. Poverty, unemployment and lack of social acceptance were common problems for Thai persons with disabilities (15). This was in accord with the findings in other southeast asian countries (4,16). At the end of the study, the majority of persons with disabilities remained jobless, but it seemed that they received more help from neighbourhoods.

During the study, the researchers observed that the community members of each study area participated in the CBR programme at the level of planning and implementation. Participation of persons with disabilities was in terms of contributors, decision-makers and beneficiaries.

However, persons with disabilities who participated as contributors were mainly persons with mild or moderate physical impairment, and others were beneficiaries.

Regarding the success of CBR, sustainability is considered as an indicator. However, this issue was not examined in the current study. A further study should be conducted for follow-up. It has been recommended that the concept of self-help group should be integrated into CBR (9). It is suggested that ownership of the programme be transferred to persons with disabilities, in order to manage their needs and lives. Then, the societal power would be more balanced among all societal members.

In conclusion, physical therapists have a number of roles in CBR, depending on the status of the programme leader and socio-economic circumstances. Then, physical therapists need a high degree of flexibility and a wide range of skills to contribute to the CBR programme. Preparing such physical therapists may require development of a more client-centered community-oriented education programme. This study's finding would be of benefit for the curriculum reform to prepare physical therapists for working with local communities, persons with disabilities and their families. It might be applied to persons with disabilities in other areas or countries that have similar situations and contexts.

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ACKNOWLEDGEMENT

This study was supported by the Khon Kaen University Research Fund. The author wishes to thank Assistant Professor Anuchar Ninprapan, Mr. Mana Nakham, Mr. Yuthasilp Panpoom and Ms. Lugkana Mator for their help in field work. Special thanks to the areas and communities in which this study was conducted. Sincere appreciation is extended to Ms. Karen Lindqvist and Ms. Joanna MacDougall for help with language.

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A COMMUNITY ASSESSMENT OF POVERTY AND DISABILITY AMONG SPECIFIC RURAL POPULATION GROUPS IN NEPAL

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ABSTRACT

A participatory survey on poverty and disability was carried out among the households of members of women's self help groups in a community development project, in three rural areas of Nepal. This survey covered a total of 19,210 persons belonging to poor and marginalised population groups.

The survey provided information about prevalence and demographic and literacy related information about persons with disabilities in the surveyed population.

It also showed that persons with disabilities form a disproportionately large part of those defined as poorest, by their own poor communities. The survey also showed that a majority of persons with disabilities from the surveyed population do not have access to any services including rehabilitation services.

The survey was used as a first step to promote awareness about disability issues in the women's self-help groups and to support setting up of community groups of persons with disabilities.

INTRODUCTION

Disability and poverty are inextricably linked and lead to a vicious cycle with one being both a cause and a consequence of the other (1). Persons with disabilities are estimated to make up to 15% to 20% of the poor persons in developing countries (2). Worldwide, as many as 50% of disabilities are directly linked to poverty (3).

The links between poverty and disability can be multiple and complex, including through local geographical factors (for example, wars, specific infections like trachoma and schistosomiasis, stress, etc.), insufficient or unhealthy food, insufficient or inaccessible health services (including physical inaccessibility as well as because of related costs), social exclusion and stigma (for example for persons affected with leprosy, for persons with epilepsy, etc.), barriers to employment, etc. (1).

POVERTY

Poverty, whether rural or urban, needs to be looked at from a range of perspectives. Poor women, men and children experience poverty in different ways, in their daily lives. It affects where they live, what they eat, how they spend their days, and above all, their general well-being. It is a multi-faceted issue (4). Absolute poverty has been defined as, “a condition of life so limited by malnutrition, illiteracy, disease, squalid surroundings, high infant mortality and low life expectancy as to be beneath any reasonable definition of human decency” (5).

Often, poverty is seen only in terms of income poverty and is measured in terms of arbitrary dividing lines such as, “persons living with less than 1 US dollar per day” (4). However, poverty is not related only to the economic aspect but is multi-dimensional. It is also related to powerlessness, to not being counted, to not being considered, to be excluded, to be unheard. Poverty is related to exploitation, oppression, victimisation and violence. It is also related to migration, forced displacement, rising urbanisation and loss of livelihoods. Among the poor, the more vulnerable are those who are dependent and who have no say in decisions regarding their lives. Therefore, criteria for measuring poverty and identifying the most vulnerable groups, need to be adapted to each single context (6).

Social and cultural traditions can negatively influence the conditions of specific population groups such as children who are victims of sexual and labour exploitation, widows, single mothers, uneducated persons, wives of alcoholics, bonded (slave) labourers, prisoners, persons belonging to lower castes (like in certain parts of South Asia), etc. Poverty has a specific gender dimension.

Poverty among the minority groups is another important aspect. Persons belonging to ethnic or religious or linguistic minorities are also vulnerable to poverty and not only to economic poverty. A variety of historical, social, political and economic processes impose vulnerability on the powerless disadvantaged communities. And, at the core of their disadvantage and powerlessness is the absence or denial of certain basic rights (7).

DISABILITY

The industrial revolution and the advances in medical sciences are linked with the development of the medical model of disability (8). The medical model locates the disability

in individuals and proposes interventions for the individuals to improve functioning and decreasing impact of the disabilities.

Over the past few decades, organisations of persons with disabilities (DPOs) have proposed a social model of disability that focusses on a collective view of disability and the role of disabling barriers (physical, social, attitudinal and cultural) created by the society and proposes interventions for a more equitable, society, that dismantles disabling barriers and respects human rights of all persons.

The social model of disability has had a profound impact on the way disability issues are understood and analysed. It has also led to the development of “International Classification of Functioning, Disability and Health” (ICF, 2001) by the World Health Organisation (WHO). In the context of health, under ICF, isability is seen as an interaction, as a complex relationship between the health condition and the contextual factors (i.e. environmental and personal factors (8)).

NEPAL

Nepal, with a population of about 29 million persons, is one of the poorest countries in the world with a per capita income of US\$ 240 per year. More than 60 % (31% according to the government data) of the population lives in abject poverty, which affects different human development indices (9). Over the past decade, life in Nepal has been marked by internal strife and civil war with suspension of civil liberties, that have been reinstated only recently. This has worsened the general situation in the country.

Geographically, Nepal can be divided into three distinct ecological zones - high mountains, hills and the plains (Tarai). These three ecological regions show differing levels of well-being and poverty, as seen by the differences in the Human Development Index (HDI) in the 3 areas - hills have highest HDI, followed by Tarai and mountains respectively (10).

Nepal is populated by 103 caste and ethnic groups and the 2001 national census recorded 106 languages and dialects. While the geographical location determines the access to resources, there are hierarchical sub-groups in the population (caste based groups and tribal or *Janjati* groups), that also experience varying degree of obstacles to resources depending upon their position on the hierarchy. The exact number of the *Dalit* population (literally

“downtrodden or crushed” denote the caste groups lowest in the social hierarchy) is not certain, but one estimate is that they constitute 12.9% of the population, of which 55% live in the hills (10).

WATCH PROJECT

WATCH (**W**omen **A**cting **T**ogether for **C**hange) is a Nepalese non-Governmental organisation based in Kathmandu, that focuses on promoting empowerment of women belonging to marginalised and poor castes and ethnic groups in rural areas of different districts of Nepal.

In each project site, WATCH stimulates and supports setting up of self-help women groups in communities, that are encouraged and facilitated to undertake a number of developmental activities and to network with other women’s groups to establish district, regional and national level women federations.

METHODOLOGY

A survey was carried out in three geographical areas of Nepal, covering a total of 19,210 persons in 3,397 households of persons belonging to women’s self-help groups organised under different village development committees (VDCs), in three geographical areas of the country, as shown in Table 1.

Table 1. Districts and households covered under the survey in 3 geographical areas of Nepal

Area	Population / Household Covered
1. High Mountains covering parts of Okhaldhunga district (total population 156,702)	In following VDCs: Bigutar, Ragadip, Jantarkhani, Barnalu, Baruneshwor, Necha Batase, Mamkha, Ratmate, Patle, Shree Chaur & Biplate with a total of 37 women’s groups covering 700 households with a total population of 4,795 persons
2. In hills covering parts of Kathmandu and Lalitpur districts (total population 1,419,630)	In following VDCs: Devichaur, Dukuchhap, Chaimale and Sisneri with a total of 41 women’s groups covering 563 households and a total population of 2,733 persons

3. In the southern plains (Tarai) covering parts of Rupendehi, Nawalparasi and Kapilvastu districts (total population 1,753,265)	In following VDCs: Motipur, Majhuwa, Kerwani, Devdaha, Siktahan, Salajhandi, Salajhansi, Saljhanda, Banganga, Dudha Raksya, Karahiya, Makrahar, Jahada, Semalar, Makar, Butwal and Sunwal with a total of 152 women's groups covering 2,674 households and a total population of 11,682 persons
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All the households covered under the survey belong to poor communities according to the national criteria of poverty, with per capita incomes less than 1 US\$ per day. Almost all of them are composed of marginalised rural groups, usually belonging to specific caste groups.

WATCH has been active in these communities since 1992, for promoting the setting up of women's self-help groups and women's group federations. History of a long standing collaboration and mutual trust built in the communities, has been a key factor in ensuring the success of this initiative.

This survey was promoted for raising the awareness among the women members of self help groups and their families, about the situation of persons with disabilities in their communities and as a first step towards promoting setting up of community self-help groups of persons with disabilities.

The three health facilitators working for WATCH in the three site offices of WATCH, attended a three weeks training course on community-based rehabilitation (CBR) during which, they learnt about conducting surveys for identifying persons with disabilities in the communities.

At the same time, in collaboration with women's federations, village volunteers and other partners, focus group discussions were started with women's groups' members on criteria for wealth ranking for identifying the poorest among them. A basic set of wealth ranking criteria including kind of house-building, any land properties, material goods owned by the family, any family debts, jewellery and other valuables owned by the family, etc. was prepared by WATCH. These criteria were adapted through participatory discussions in the communities in each of the three geographical areas, to respond to the specific local contexts.

Finally, a questionnaire was prepared for collecting information about each household represented in the women's self help groups in each of the three areas covered by the project. This questionnaire was filled by WATCH facilitators with the support of women's groups and village volunteers, and provided the following information: number of households in each women's group, total family members of the households, economic status of the family according to wealth ranking criteria for their geographical area and the presence of any person with disability in the households.

For each person with disability, another questionnaire was compiled, providing the following information: age, gender, education, number of family members, economic status of the family, time of onset of disability, cause of disability, kind of disability, access to services, attitude of the person with disability and attitude of the family.

This information was collected over a period of three months in the beginning of 2006. Completed forms from each geographical area were collected and tabulated by WATCH staff in Kathmandu. These tables have been analysed for this paper.

FINDINGS AND DISCUSSION

The survey methodology for this study was based on participatory approaches where all the women belonging to the women's groups were involved in defining different study criteria and collection of different information with support from community volunteers and WATCH staff. While the blue print for the information to be collected was prepared by WATCH staff, each community had the option of discussing and influencing the decisions about what information was to be collected and how.

This had the advantage of ensuring that the information collected was meaningful to the communities and related to their local context. For example, it was important for collecting information on wealth ranking and poverty, as it took into consideration all the different local cultural and social factors, for defining the poverty rather than looking at an arbitrary amount of income for defining poverty.

However, the participatory process can also result in adoption of different criteria and definitions in the different geographical areas and thus the information collected in different areas may not always be completely comparable.

Prevalence and gender distribution of persons with disabilities

A total of 355 (55% men and 45% women) persons with disabilities were identified among the 19,210 persons surveyed, giving an overall disability prevalence of 1.84%. The prevalence of disability was highest in the Tarai region (2.19%) and lowest in the hills region (1.20%). The prevalence of persons with disabilities in the three geographical areas sub-divided according to gender is presented in Table 2.

Table 2. Prevalence of persons with disabilities in the three geographical areas

Area	Total study Population	Total number of persons with disabilities (Prevalence %)	Persons with Disability	
			Male	Female
High Mountain	4,795	65(1.35 %)	30(46.1 %)	35(53.9 %)
Hills	2,733	33(1.20 %)	20(60.6 %)	13(39.4 %)
Plains (Tarai)	11,682	257(2.19 %)	145(56.4 %)	112(43.6 %)
Total	19,210	355(1.84 %)	195(54.9 %)	160(45.1 %)

As far as gender is concerned, in the high mountains there were more women with disabilities as compared to disabled men, while in the hills and Tarai, the percentage of men was higher.

According to a national report, persons with disabilities constitute 1.63 % of the total population in Nepal. The principal causes of disability are malnutrition, congenital, non-communicable diseases, trauma, communicable diseases, mental problems, and alcohol and substance abuse (11). This national data compares well with the data collected during the survey.

However, the data collected in this survey is not based on standard definitions of different disabilities, but rather on how different existing conditions were judged as “disabling” in different contexts of three geographical areas (Tarai, hills and high mountains) involved in the survey. Some specific disabilities such as epilepsy and psychosocial disabilities (mental illnesses) were not counted.

It is also possible, that this data does not include persons with disabilities which do not affect the daily activities of the persons. For example, persons with grade 1 disability of leprosy (loss of skin sensation in hands/feet) or persons with partial vision loss or partial hearing loss may not have been included. Thus, it is likely that actual prevalence of disabilities may be higher.

Age Distribution of Persons with Disabilities

The prevalence of persons with disabilities according to different age groups was calculated in the three areas and is presented in Table 3.

Table 3. Age distribution of persons with disabilities

	< 5 Yrs	6-15 Yrs	16-40 Yrs	> 41 Yrs	Total
Mountain	2	16	23	24	65
Hill	4	7	12	10	33
Tarai	22	70	103	62	257
Total	28 (7.88%)	93 (26.19%)	138 (38.87%)	96 (27.04%)	355(100%)

To be meaningful, this data on age distribution of different disabilities needs to be correlated to the total population in each age group. However, this information was not available for analysis. From the available data, it appears that in the surveyed population, children below 15 years, together constitute about 34 % of persons with disability.

Prevalence of different kinds of disabilities

In the three areas, the categories of different disabilities were decided after discussions with the persons participating in the survey. These categories that were decided, were different from those used in the WHO manual on community-based rehabilitation. The prevalence of different disabilities in the three geographical areas is presented in Table 4.

Table 4. Prevalence of different disabilities

Kind of disability	Mountains	Hills	Tarai	Total
Movement	36(55.4%)	19(57.6%)	146(56.8%)	201(56.6%)
Hearing and speech	15(23.1%)	4(12.1%)	45(17.5%)	64(18.2%)
Vision	4(6.1%)	2(6.1%)	27(10.5%)	33(9.3%)
Intellectual	9(13.8%)	2(6.1%)	17(6.6%)	28(7.8%)
Multiple	1(1.5%)	6(18.2%)	22(8.6%)	29(8.1%)
Total	65	33	257	355

The categories of convulsions (epilepsy), loss of sensation (leprosy) and strange behaviour (mental illness) used in the WHO's CBR manual are missing.

Age at the Onset of Disability and Cause of Disability

The survey collected information about the time of onset of disability and the cause of disability, from all the persons with disabilities identified in the three geographical zones.

An analysis of this information shows, that for persons who developed disabilities after birth, the answers about age of the person at the time of the onset of the disabilities are not precise. Therefore, the data about "age of onset of disability" can only be analysed in terms of two categories – if the persons had disability at birth or did they develop it later.

The analysis of this data shows that 41.6% of the persons with disabilities covered in this survey had disability since birth. Data on age of onset of disability is presented in Table 5.

Table 5. Age at the onset of disability

Area	Persons with disability at birth	Persons who developed disability after birth	Persons for whom Information not available	Total
Mountains	31	33	1	65
Hills	13	20	0	33
Tarai	97	145	15	257
Total	141 (41.6%)	198 (55.8%)	16 (4.5%)	355

In the literature, it has been estimated that disabilities present at birth may constitute 15 to 25% of all persons with disabilities (12). However, this contrasts with the findings from this survey, where persons with “disabilities since birth” constitute more than 40% of all persons with disabilities.

Information about the opinions of persons with disabilities and/or their family members about the causes of disability, was not collected in a uniform manner in the 3 areas. Often, the causes were mentioned in a generic way (for example, “due to a sickness” was used frequently in the answers). Thus these answers have not been analysed for this paper.

Literacy levels among persons with disabilities

Data on level of education of persons with disabilities has been collected in different ways in the three geographical areas. For some persons, the precise number of years of school education are mentioned while for others, the answers are recorded simply as “literate” and “illiterate”.

Therefore, to compile this information, all the persons who had at least one year of school education have been calculated under the column “Lit.” (persons with basic reading and writing skills) in Table 6, without specifying the number of years of schooling. Therefore, this group of persons also includes some persons who have higher literacy levels.

Persons above 41 years and children below 5 years were excluded from this analysis.

The analysis shows that overall, among the 224 persons with disabilities belonging to the age group from 6 years to 40 years, 101 persons (45%) were literate and had at least basic reading and writing skills. Information on basic literacy for persons with disabilities subdivided for gender and age, is presented in Table 6.

Table 6. Basic Literacy for persons with disabilities subdivided for gender and age

Area	Male						Female					
	6-15 yrs			16-40 yrs			6-15 yrs			16-40 yrs		
	Lit.	Illit.	NA	Lit.	Illit.	NA	Lit.	Illit.	NA	Lit.	Illit.	NA
Mountain	2	5	-	5	7	-	5	4	-	7	4	-
Hills	3	1	-	6	2	-	1	2	-	0	4	-
Tarai	18	10	7	27	27	7	17	12	6	17	23	2
Total	23	16	7	38	36	7	23	18	6	17	31	2
%	50	34.8	15.2	46.9	44.4	8.6	48.9	38.3	12.8	34	62	4

Note: Lit.: knows basic reading and writing; Illit.: no reading and writing skills; NA: not known.

Since similar data about non-disabled persons according to age and gender is not available, this data cannot be compared with the situation in the remaining surveyed population.

However, these literacy levels compare well with the average national literacy levels in the general population in Nepal, that is 48.6% (13). This can also be a reflection of a long tradition of formal and informal education activities by the women's self help groups in the last 15 years and may not reflect the general situation.

Disability and Poverty

Wealth ranking of all the persons surveyed in the three areas was a key activity of this initiative. Though according to the official definitions, all the persons included in this survey fall under the definition of "rural poor", they were asked to identify the ones they considered the poorest amongst themselves. Communities in each geographical area discussed the wealth

ranking criteria, to fine tune them so that the criteria keep an account of their local context. Information on wealth ranking of all the survey population to identify the poorest among them is presented in Table 7.

Table 7. Wealth ranking of all the survey population to identify the “poorest of the poor” persons

Area	Total Population	Very poor population	%
Mountains	4.795	295	6.15 %
Hills	2.733	187	6.84 %
Tarai	11.682	1,138	9.74 %
Total	19.210	1,620	8.43 %

The survey showed that about 6 to 10% of the surveyed population were considered as “poorest of the poor” by their own communities.

At the same time, this information provided wealth ranking data for all the persons with disabilities identified in the surveys. This was analysed separately and situation is presented in Table 8.

Table 8. Persons with disabilities among the “poorest of the poor” persons

Area	Total Persons with disability identified	Wealth ranking not done	Very poor persons(%)
Mountains	65	-	42(64.6%)
Hills	33	-	21(63.6%)
Tarai	257	17	193(80.4%)
Total	355	17	256(75.7%)

In the total survey population wealth ranking, 6.15 % to 9.74 % of population (overall 8.43 %) was identified as “poorest of the poor”, while if one looks at the wealth ranking done for

persons with disabilities, about 64 to 80% of them (overall 75.7 %) are considered as “poorest of the poor”.

This finding confirms the strong links between poverty and disability in these communities and that poverty affects a disproportionately large number of persons with disabilities as compared to the general population.

Access to Services for Persons with Disabilities

Persons with disabilities and/or their families were asked if they had ever received any specific service for disabled persons (rehabilitation services, any aids or appliances, hospital visits, any training programme, etc.) from any institution or programme. The following Table 9 presents a summary of the answers about contacts with any specific services for persons with disabilities.

Table 9. Access to specific services for persons with disabilities

Area	Total number of persons with disabilities	No information available on access to services	Persons who received at least one service once in their lives (%)
Mountains	65	-	12 (18%)
Hills	33	-	5 (15%)
Tarai	257	5	21 (8%)
Total	355	5	38 (11%)

This means that around 80% of persons with disability did not have any contact with any disability related specific centre or services. The study shows that a very small percentage of persons with disabilities (8 to 18%) has any access to the different disability related services.

Issues of actual benefit from the services, details of different services accessed, quality of services received and level of satisfaction from the services were not tackled in this survey.

The issue of access to existing health services was also not tackled. Generally speaking, most of the areas covered by the project have inadequate coverage for basic health services. For example, in the mountain areas, out of the 18 health centres “planned” for the area covered by the survey, only 8 have any staff. However, none of these 8 centres were operative through out the year - majority of them functioned for about six months per year. Considering these difficulties, specific questions on access of persons with disability to existing primary health care services were not asked, but the access to the local primary health care services were likely to be very low. Access to more specialised rehabilitation services was likely to be even lesser or almost non existent.

Transport difficulties were common in all the three geographical areas covered under this survey. In the mountains, reaching a public transport service can require 2-4 days of walking. In the hills and Tarai, the walking distances to any public transport were lesser, but still can require hours of walking. These difficulties also influence the access to different services. However, specific roles of different factors including transport, in influencing access to different services were not tackled during the survey.

Other Information Collected During the Survey

The survey also provided descriptive information about attitudes of persons with disabilities, about their lives and their possibilities and the attitudes of communities towards persons with disabilities. This descriptive information is usually expressed in very generic terms and has not been analysed for this paper.

Impact of the Survey

The information collection initiative was carried out to promote awareness about the situation of persons with disabilities among the women involved in self-help groups and women’s federations. Preliminary discussions with the women’s groups had suggested that there were not many persons with disabilities in their communities. Therefore, community surveys provided actual information about the persons with disabilities who were often hidden and were invisible, and their needs were not considered.

Following the surveys, self help groups of persons with disabilities were formed in all the three geographical zones. Two federations of self-help groups of persons with disabilities

were also constituted in Rupandehi (Tarai) and Okhaldhunga (high mountains). There have been some contacts with national level organisations of persons with disabilities (DPOs). They have been able to demand resources from local government agencies and they have been able to establish contacts with national level organisations, but they are still neglected. At the same time, this initiative has been important in promoting inclusion of persons with disabilities in the development activities carried out by women's groups, but still a lot more requires to be done. A number of initiatives including community-based rehabilitation activities are being planned.

CONCLUSION

This study involved a community participatory survey in a relatively large sample of a population group of persons belonging to specific poor and marginalised caste groups, for creating awareness about the situation of persons with disabilities and as a first step for promoting setting up of community self-help groups of persons with disabilities.

All the households involved in this survey belonged to poor families according to the national definitions of poverty, as persons living on less than one US\$ per day. The participatory survey done by the women's self help groups shows that in these poor communities, a disproportionate number of persons with disabilities are among the "poorest of the poor". The participatory survey also showed that only a small percentage of persons with disabilities from these marginalised communities had access to any specific services.

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ACKNOWLEDGEMENT

This study would not have been possible without the active collaboration and hard work by a large number of persons including Mr. Sanjiv Shrestha, Mr. Sanchit Dangol, Ms. Bishnu Limbu, Ms. Kamal Magar (Chairperson of Okhaldhunga Federation), Ms. Shyam BK (Chairperson of Rupandehi Federation) and all the women's self help groups and their federations.

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BRIEF REPORTS

**HEAD INJURY REHABILITATION OUTCOME IN
RELATION TO THE CARERS' PSYCHOLOGICAL DISTRESS**

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ABSTRACT

Carers are the backbone in providing care in the community and in doing so, it takes a heavy emotional toll. Therefore, the psychological health of the carer is important for community rehabilitation of people with head injury. The present study was conducted to examine post head injury rehabilitation outcome in relation to psychological distress in the carers. It was hypothesised that carers' psychological distress would predict the functioning of affected people. People with head injury were recruited from the rehabilitation unit as well as outpatient clinics in Atkinson Morley Hospital, London. Brain Injury Community Rehabilitation Outcome (BICRO-36) was used for assessment of the physical, emotional, cognitive and social functioning, which was carried out by the carers. Psychological distress in carers was assessed using General Health Questionnaire (GHQ-28). Data was analysed using t-test, one way analysis of variance, correlation and regression analyses. Psychological distress in carers was significantly associated with rehabilitation outcome of people with head injury. The findings have important implications for policy makers, health care professionals, for people with head injuries as well as their families.

INTRODUCTION

Severe head injuries are the commonest cause of death in young men in UK and the USA (1). Head Injury (HI) can lead to numerous difficulties in areas that include activities of daily living, cognitive functioning, emotional and physical functioning. The longstanding residual effects of Traumatic Brain Injury (TBI) include cognitive, social and personality changes (2,3,4,5,6). Such implications of head injury not only have a significant impact upon the lives of survivors but also upon the lives of their family members and carers (7, 8)

Those discharged from hospitals and rehabilitation units following a TBI return to live mainly with their families (9). The informal care network of family and friends has become one of the most important elements in supporting individuals with brain injury, in their local community. Usually, it is one person (typically the wife or mother) who takes on the major responsibility of care.

Family members experience a high level of distress, guilt and burden (7, 10, 11) . Stress experienced by the carers may interfere with their ability to assist with the affected person's rehabilitation activities. It has been realised for more than a decade that families providing care to a person with head injury should be considered as an integral part of the rehabilitation team, as they are a source of motivation and adaptation for the person (12, 13). Moreover, family involvement, cooperation, and particularly their commitment to follow through with the rehabilitation process in the home setting are absolutely necessary to the long-term rehabilitation of head injury and the family system. There is a need to emphasise upon the carers' psychological functioning. Such studies would provide knowledge and assistance to those professionals involved in rehabilitation.

The main objectives of the present study were to assess: psychological distress in carers of head injured persons; to assess head injury outcome in terms of physical, psychosocial, emotional and cognitive functioning of the affected person and to examine relationship of carers' psychological functioning with head injury outcomes. It was hypothesised that: a.) the carers of head injured persons experience psychological problems such as anxiety, depression, somatic problems and social dysfunctioning; b. carer distress predicts rehabilitation outcome of head injured persons.

METHOD

Participants and Recruitment

The sample comprised 42 carers of a community dwelling former clients of a neurosurgery, neurology and rehabilitation centre. The clients were recruited through St George's Healthcare NHS Trust. Carers of these people who ranged in age from 18-65 years, lived in a non- institutional community setting and had acquired head injury 4-18 months prior to the assessment were included.

Head injuries in the majority had resulted from motor vehicle accidents (54.8%) and from falls (33.3%). A majority of the patients were male (76%) with the mean age of 38 years (SD = 12.37) and were single (40.5%). Most of them had been employed full time pre-onset (72.5%), whereas after head injury 25% were working full time and about 30% were unfit for work. Severity of injury varied from mild to severe and most of them had experienced mild head injury (54.8%). Carers mainly comprised of females (73.8%) and half of them were parents.

Measures

Psychological distress in carers was measured using General Health Questionnaire (GHQ-28) (14). Severity of head injury was estimated through Glasgow Coma Scale score as provided in the hospital records. Head injury outcome was assessed in terms of the patient's physical, psychosocial, emotional and cognitive functioning (memory) using the Brain Injury Community Rehabilitation Outcome (BICRO-36) scales. BICRO includes eight subscales: Personal Care, Mobility, Self-organisation, Partner and family contact, Parents and children contact, Socialising, Productive employment and Psychological Well-being. A relatives' questionnaire (15) was used to assess memory deficits and emotional problems in the affected person. High scores on all BICRO scales indicated either deficits or problems in respective areas of functioning, except for Psychological well-being scale where the high score meant better psychological functioning.

Procedure

Two packets, one for the person with head injury and one for the carer, were either mailed or handed over to them at out-patient clinics. The packet for the affected person contained a letter from the researcher explaining the nature and purpose of the study and consent forms. The person was requested to sign the consent form and pass on the carers' envelope to them if they themselves were willing for carers to participate. Carers were requested to complete and send questionnaires back to the researcher in Freepost envelopes provided to them. The response rate was 24.58%.

RESULTS

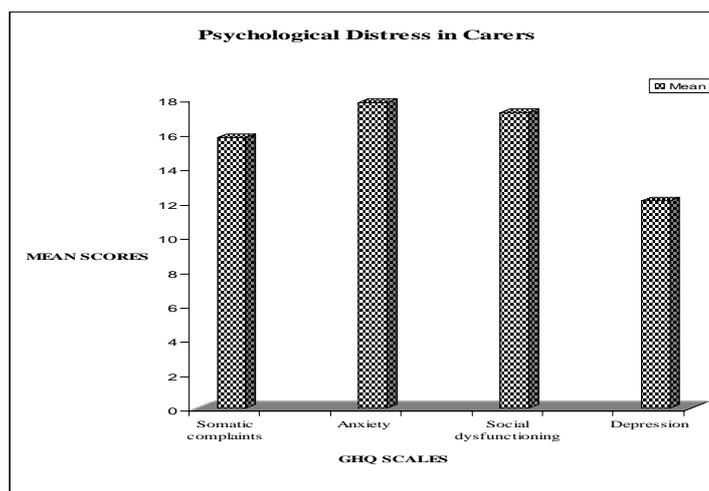
Psychological Distress in Carers

Mean scores on four subscales of GHQ showed that carers experienced anxiety followed by social dysfunctioning and somatic complaints (Figure.1).

Pearson Correlation analysis was used to examine relationship of head injury, and carer affected person variables, with carers' distress. Severity of head injury had positive correlation with somatic complaints ($g = .58, p < 0.001$), anxiety ($g = .36, p < 0.05$) and social dysfunctioning ($g = .36, p < 0.05$) in carers. Duration of carers' acquaintance with the person prior to the onset of head injury had negative relationship with depression in carers ($g = -.31, p < 0.05$).

One-way analysis of variance was carried out to examine whether distress in carers differed as a function of carers' relation with the patient. The carers' relation with the patient had a significant effect on depression in carers ($F = 5.94, df = 2(39), p < 0.001$). Post-hoc analysis revealed that parent carers were significantly less depressed than spouse and partner carers ($t = 3.34, df = 40, p < 0.002, M1 = 9.47, SD1 = 2.74, M2 = 14.66, SD = 6.55$ for both groups respectively). Partner and spouse carers did not differ in the psychological distress they experienced.

Figure 1. Psychological distress in carers (N = 42)



Rehabilitation Outcome in Affected Persons

Multivariate analysis of variance with repeated measures revealed significant differences in physical, psychological, social, emotional, cognitive and employment outcome ($F = 50.48$, $p < 0.001$). Emotional problems were reported as major ones followed by socialisation problems, psychological well being, productive employment, self-organisation and memory deficits. However, very few problems were reported in the areas of cognitive functioning, personal care, mobility and relations with family members.

Severity of head injury showed no relationship with any of the patient outcome variables, except for ability of personal care ($r = .34$, $p < 0.05$). Duration of carers' acquaintance with the person before the onset of head injury had negative correlation with the person's relationship with parents and siblings ($r = -.40$, $p < 0.01$). Time since onset of head injury had negative relationship with ability of personal care ($r = -.34$, $p < 0.05$) in affected persons.

Carers' distress and rehabilitation outcome in affected persons

Table I presents correlations between measures of rehabilitation outcome and carers' psychological distress. High scores on outcome variables indicate more problems in a particular area. Somatic complaints in carers had positive correlation with problems in areas of self organisation, parent family relations, productive employment and emotional problems. Carer anxiety was significantly correlated with emotional problems and memory deficits in the affected persons. Social dysfunctioning in had strong association with problems in self-organisation, parent-family relations, socialisation and productive employment. Carer depression had significant correlation with self-organisation, socialisation and productive employment. Psychological well being of affected persons had significant negative correlation with all carer distress variables.

Table 1. Correlation between current functioning of persons with head injury and psychological distress in carers (N= 42)

	Somatic Complaints	Anxiety Social-dysfunction			Depression
1.	Personal care	0.18	0.11	0.18	0.02
2.	Mobility	0.02	0.08	0.22	0.22
3.	Self-Organisation	0.49***	0.22	0.71***	0.58**
4.	Parent and family relations	0.31*	0.10	0.33*	0.10
5.	Parent and sibling relations	0.11	0.05	0.13	0.29
6.	Socialization	0.24	0.24	0.32*	0.52***
7.	Productive employment	0.34*	0.06	0.55***	0.31*
8.	Psychological well being	-0.51**	-0.46**	-0.45**	-0.33*
9.	Cognitive problems	0.11	0.23	0.00	0.17
10.	Emotional problems	0.38*	0.40**	0.12	0.29
11.	Memory deficits	0.30	0.38*	0.04	0.30

*p<0.05, **p<0.01, ***p<0.001

Further to correlation analyses, regression analysis was carried out to examine predictors of rehabilitation outcome. Severity of injury and carer distress variables were entered as predictors in a separate set of analysis for each outcome variable using hierarchical regression. Table 2 shows the steps in which the variables were entered, the standardised regression coefficients (betas) and the proportion of variance explained at each step. In all equations, severity of head injury explained very little variance, whereas addition of carer distress variables significantly added in variance explained for outcome variables i.e. self-organisation, parent family relations, socialisation and productive employment.

Table 2: Hierarchical regression of Patient current functioning on severity of injury and psychological distress in carers

Step	Out come variable	Predictor Variable(s)	?R2	Beta
1.	Personal Care	Severity of injury	.34*	.33
		Somatic complaints		.32
		Anxiety		.01
		Social dysfunctioning		.41*
		Depression		.06
R2			.11	.25
R2 change				.13
F change				1.41
2.	Self-oganisation	Severity of injury	.24	.03
		Somatic complaints		.11
		Anxiety		.27
		Social dysfunctioning		.56**
		Depression		.35*
R2			.06	.60
R2 change				.54****
F change				10.80**
3.	Parent family relations	Severity of injury	.04	.38*
		Somatic complaints		.72**
		Anxiety		.25
		Social dysfunctioning		.26
		Depression		.30
R2			.002	.25
R2 change				.25*

F change				2.70*
4.	Parent sibling relations	Severity of injury	.17	.42**
		Somatic complaints		.78**
		Anxiety		.16
		Social dysfunctioning		.25
		Depression		.79***
R2			.03	.41
R2 change				.38**
F change				5.17**
5.	Socialisation	Severity of injury	.13	.12
		Somatic complaints		.48*
		Anxiety		.67**
		Social dysfunctioning		.15
		Depression		.69**
R2			.01	.33
R2 change				.31**
F change				3.82**
6.	Productive employment	Severity of injury	.22	.02
		Somatic complaints		.31
		Anxiety		.34
		Social dysfunctioning		.52**
		Depression		.01
R2			.05	.40
R2 change				.35**
F change				4.71

*p<0.05, **p<0.01, ***p<0.001; Mobility, psychological well-being, memory, cognitive and emotional problems in patients were not predicted by any of the antecedents.

Severity of head injury predicted affected persons' ability of personal care when entered as a single predictor in the first step and the person's interpersonal relationship with the family only when entered in combination with carer distress variables in the second step of equation. Carer distress variables differentially predicted affected persons' functioning. Carer social dysfunctioning predicted ability of personal care, self-organisation and productive employment. Carer depression predicted affected persons' self organisation ability as well as their social and interpersonal relations.

Somatic complaints in carers emerged as significant predictor of affected persons' social and interpersonal relationships. Carer anxiety predicted the person's ability to socialise. None of the carer distress variables predicted mobility, psychological well-being, emotional problems, cognitive deficits and memory deficits in affected persons.

DISCUSSION

The present study examined rehabilitation outcome of head injury in relation to psychological distress in carers. Similar to other head injury family studies the primary caregivers in this study were predominately female and parents (7,11, 16).

Carers experienced psychological distress in the form of somatic complaints, social dysfunctioning and anxiety. Findings pertaining to distress reported in carers, are in line with existing literature which has extensively investigated psychological outcome of head injury care (17-18). Severity of injury showed positive correlation with carer depression. This finding substantiates earlier research (19) which revealed that more severe injuries were related to greater psychological distress and anxiety in relatives. Carers who had known the affected persons for a longer period were less depressed. Moreover, parent carers reported less depression compared to spouse and partner carers. Many researches have suggested that caregiving spouses in TBI population are at greater risk for distress, than caregiving parents (2, 17, 20, 21, 22). One possible explanation for the parent carers reporting less depression could be that parents had already been involved in caregiving to the person as their child, whereas for spouse and partner carers, assuming a new and different caregiving role is more difficult. The parents are likely to have more support and be less financially threatened (21). For spouses and partners, personality and emotional changes in affected persons would make it more difficult to cope with. Their needs for sexual and affectional

desires, intimacy and empathy in communication with spouses may be unmet, yet they would feel guilty about getting separated or divorced in such circumstances (23).

Carer distress showed positive correlation with rehabilitation outcome. Affected persons' ability of self-organisation, interpersonal problems, productive employment and psychological well-being seemed to be a major concern for carers as distress in carers showed significant correlation with deficits in these areas. Ability of self-organisation, interpersonal relationships and psychological well being are important factors for productive employment. Majority of the affected persons in this study were young adults who had been working full-time (69%) prior to the injury. However, after the injury their work status had either been changed or they had become unemployed and only 10 % could come back to their full-time work status. Carer anxiety had significant association with psychological problems in affected persons such as psychological well-being, emotional problems and memory deficits. These findings are consistent with the TBI literature which has emphasised that impact of psychosocial, emotional and cognitive sequelae on carers is more than physical complaints (11, 15).

Regression analysis revealed that except for ability of personal care, the severity of injury did not predict outcome. However, psychological distress in carers predicted affected persons' current functioning. Carer distress predicted the ability of self-organisation, productive employment and interpersonal relationships in affected persons. All these abilities are important for reinstating the work-status of affected person. Having considered that majority with HI in this study were young adults who were at the peak of their professional and practical life, this finding holds utmost importance from a rehabilitation point of view. There is extensive research which has looked at correlates of psychological distress in carers (24, 25), however, psychological distress as an antecedent of rehabilitation outcome has not been investigated. The findings of the present research emphasise the importance of carer psychological well being in rehabilitation of persons with TBI in the community.

One major limitation of the present study is that assessment of affected persons' current functioning was carried out by the carers and there was no objective measure used for this purpose. Carer assessment could be their subjective perception and not related to the actual deficits in the affected persons (26). Secondly, though an effort is made to establish that

carer psychological distress is a predictor of functioning in the affected person, cross-sectional research has an inherent limitation in establishing cause and effect relationship. Future research needs to adopt a longitudinal design and use objective assessment methods for studying psychological and physical functioning of persons with head injury.

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ACKNOWLEDGEMENT

This research was part of a post-doctoral project carried out at the Surrey University and the Wolfson Neurorehabilitation Centre, St. Georges' NHS Trust (London). This project was financially supported by the Association of Commonwealth Universities.

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**PERCEPTION OF PHYSIOTHERAPY AND OCCUPATIONAL
THERAPY STUDENTS SUPERVISION OF FIELD
ATTACHMENT IN ZIMBABWE**

Vyviennie RP M'kumbuzi *, Tamisayi PT Chinhengo, Farayi Kaseke

ABSTRACT

The field attachment for physiotherapy (PT) and occupational therapy (OT) students at the University of Zimbabwe has evolved since its inception in 1987. The new design places demands on local supervisors to ensure that all objectives are covered well. The purpose of this study was therefore, to evaluate PT and OT students' experiences of the quality of supervision of a rationalised field attachment programme.

A 4 - year (2004 – 2007) longitudinal survey was conducted by a direct questionnaire. Modal scores for the quality of local supervision were calculated for each broad objective of the attachment. The supervisors' mark was regressed against the field attachment average obtained by the student, as an indicator of the level of critical analysis of the student's performance by the supervisor.

One hundred and eight PT and OT students participated in the study. The modal total quality rating over the four years was 62.5% (IQR = 53.1% - 68.8%). Factors associated with a high total quality rating for supervision were constant supervision ($p < 0.01$), the year 2005 ($p < 0.01$). Occupational therapy students tended to rate their supervisors higher ($p = 0.03$). Local supervisors tended to overrate student performance contributing 49% variance to the field attachment average mark ($p < 0.01$).

Although students experienced good quality supervision, training of local supervisors in methods and frequency of supervision and in evaluating students were suggested to improve supervision. A review of the weighting of the field attachment evaluation components was recommended.

INTRODUCTION

Fieldwork prepares students to work in emerging practice areas and meet standards of accreditation. It also enables teachers to examine the current field work systems and give recommendations (1).

The field attachment programme is an important feature of all degree programmes (PT, OT, MBChB, Pharmacy, Nursing Science and Dentistry) in the College of Health Sciences at the University of Zimbabwe. It places significant emphasis on a social approach to health care which is increasingly acknowledged as a credible approach to decreasing morbidity and mortality(2), and is also being encouraged by the Ministry of Health and Child Welfare in Zimbabwe. The cost of health care, the burden of disease in a mixed epidemiological transition and the high burden attributable to HIV/AIDS has necessitated an increase in the quality of community care approaches(3). Health science students need to be exposed to best practice during community training. This can be ensured through adequate supervision. A Zimbabwean study demonstrated how supervised projects in a community based clinical pharmacy teaching, research and service programme enhanced pharmacy services, which in turn enabled the development of new clinical attachment sites for pharmacy students (4). Student feedback is said to be helpful and informative towards development of programmes and activities of medical education. It allows students to highlight the weaknesses and strengths of programmes resulting in provision of quality training and education (5).

There is a paucity of published literature on field attachment supervision. However, important inferences can be made from clinical and research supervision. In order for students to achieve a positive learning experience, it is vital that they receive adequate supervision and mentoring. The usefulness of the learning situation depends on several variables such as feedback to students, staff-student relationship, organisation of teaching, meetings with supervisors and supervisors' characteristics (6, 7, 8). The amount of feedback depends on the way students are supervised, and supportive supervision will redirect the students learning towards areas of efficiency as well as direct subsequent stages.

With regard to research, it was noted that postgraduate students wanted meetings and feedback to be regular and well conducted (8). In South Africa, reporting on undergraduate physiotherapy community based clinical teaching, Taukobong (9) further noted that these

students preferred supervisors who are there all the time without necessarily spoon feeding them, as this resulted in increased anxiety in the students. The quality of supervision is perceived by students to be an outcome of the supervisor's analytical skills. New graduates have been seen to be inexperienced supervisors who may not feel comfortable with community development activities if they have not received adequate training in the area (10). In their study to determine tutors performance rating, Dolmans et al (7) found that tutorial groups' productivity was an influencing factor in determining tutors performance. Thus groups with low marks rated the tutor low while those with high marks rated the tutor highly. Where the converse was true, it was attributed to some tutors being able to deal with unproductive tutorial groups, whereas others did not possess these skills(11). Tutors with strong group dynamic skills tend to regularly evaluate group function and work to improve cooperation within the group. Tutors' group dynamic skills contribute positively toward performance scores that they receive from tutorial groups regardless of group performance levels. This is however affected by students' problem based learning skills, students' level of prior knowledge and level of functioning in tutorial groups. This finding supports several authors recommendations on the need for training of supervisors in the area of interest and the need for well experienced supervisors who are well informed (6,8,10).

The field attachment programme for Physiotherapy (PT) and Occupational therapy (OT) students at the University of Zimbabwe is aimed at exposing students to the way of life of large scale commercial farming (LSCF), mining, and district, industrial, rural and urban municipal communities.

The field attachment constitutes a seven-week block during the third year of the B.Sc. OT and PT Honours programmes. Students attend formal lectures encompassing Sociology, Psychology, Primary Health Care (PHC), Community Based Rehabilitation (CBR) and Administration and Management in preparation for the attachment. Also, by the time the attachment takes place, students have completed their research methodology and biostatistics course and together with their increasing clinical experience are expected to use both quantitative and qualitative analytical approaches to study the communities. Students are also taken through the attachment objectives, and methods of achieving these are suggested and discussed. A pre-prepared handout containing all the relevant information as well as the methods of supervision and evaluation of the field attachment is given to each student prior to their departure.

The combined 3rd year class of PT and OT students is randomly allocated into groups of between three and six students each, and subsequently systematically distributed to provincial and district centres throughout Zimbabwe. The centres are selected on the basis of: 1). having experienced rehabilitation personnel who are willing and able to supervise students in situ, and 2). affording accommodation to students.

Rehabilitation personnel in this context include physiotherapists, occupational therapists and rehabilitation technicians (known as PT / OT assistants elsewhere). In addition to this local supervision, an academic member of the staff from the University's rehabilitation department visits the centres in a supervisory capacity, to give support to the local supervisor and to further their own knowledge of the area. This idea of supervision being necessary because it provides support and upgrades one's skills has been corroborated, as the supervisor has a threefold role, that of administrator, educator and supporter (10).

The Objectives of the Field Attachment are to:

1. Conduct a demographic and socio-economic survey.
2. Establish causes and distribution of conditions needing rehabilitation.
3. Identify and assess the organisation of health and rehabilitation services.
4. Assess characteristics and level of community involvement.
5. Describe and participate in Community Based Rehabilitation.
6. Participate in and assess the management of a rehabilitation department.
7. Describe the roles of staff in the provincial and district health organisation offices.

Students select and engage two or more communities and are expected to conduct a comparative analysis for all the objectives.

The techniques of gathering data are many and triangulation to saturate data is necessary. Data are obtained from many sources including government and specific health officials, traditional, administrative, informal and formal leaders, civic society and lay community members. While a clinical load is not a primary objective, students are encouraged to engage in clinical work and to observe methods of medical and rehabilitation management that are sometimes not a feature of the large academic hospitals where clinical OT and PT teaching occurs. Students therefore need to plan their time well.

Evaluation of the Field Attachment

The marks for the attachment form part of the continuous assessment mark for the course Rehabilitation II. For a student to be deemed eligible to sit for the final examination for this (12). The components of the evaluation include group file, group oral presentation, local supervisor's assessment and peer rating. The detailed criteria and schedule used to evaluate the student is given to the student prior to the field attachment.

Rehabilitation II is a barrier course i.e. a student cannot proceed to their 4th year of study if they fail to satisfy examiners in this course (12).

The field attachment programme for PT and OT students in Zimbabwe, in particular the combined placement of PT and OT students, seems to be a unique feature in the training of PT and OT students. There is therefore even less literature to draw from, in this respect. Taukobong et al reported that 65% of physiotherapy students expressed satisfaction with supervision of the community based clinical teaching at MEDUNSA (Medical University of South Africa) (9). Little can be drawn from this study, as the major component was clinical teaching, unlike the field attachment at the University of Zimbabwe. However, the challenges of supervision of community based activities may be similar in some instances, irrespective of the academic content of the activity being supervised.

Statement of the Problem

At inception of the PT and OT programmes in 1987 in Zimbabwe, the field attachment programme extended over 4 years as shown in Table 1.

Table 1. Original Field Attachment Programme Design

YEAR	BLOCK	DURATION
1	Village	2 Weeks
2	Rural	2 weeks
3	District	2.5 weeks
4	Provincial	2.5 weeks

The design of the field attachment in its present form (one seven week block in the 3rd year of study only), is thus the product of a gradual evolutionary process over time. This was intended to overcome the curriculum challenges, of fragmentation and duplication of some objectives, as well as to minimise the economic challenges particularly in transporting students and conducting academic supervisory visits to the countrywide centres for each part of the four year programme.

The new design relies heavily on local supervisors to ensure that all objectives are covered and covered well. The quality of supervision of a rationalised programme design needed evaluation, in order to determine the feasibility of the demands being made on the local supervisors. Use of student perceptions is important because they are the recipients of education and as such, are an important group of stakeholders (11).

AIM OF THE STUDY

To evaluate physiotherapy and occupational therapy students' experiences of the quality of supervision of the field attachment.

OBJECTIVES

1. To rate the quality of supervision of the field attachment for the seven field attachment objectives as reported by students.
2. To compare the students' rating of the quality of the field attachment supervision with each of the following variables:
 - a. Programme
 - b. Year of placement
 - c. Supervisor
3. To determine the supervisor's level of critical analysis of student's performance on field attachment.
4. To rate the social and emotional support and encouragement received by students during their field attachment.

METHOD

The survey was conducted at the University of Zimbabwe, College of Health Sciences in the Rehabilitation Department between 2004 and 2007. A 4 - year longitudinal survey of students' perceptions of their experience of supervision of the field attachment was investigated by direct questionnaire.

All students registered for the third year of training for the Bachelor of Science Honours degree in Physiotherapy, or Bachelor of Science Honours degree in Occupational therapy for the years 2004 to 2007 at the University of Zimbabwe, were included in the study.

A researcher-designed questionnaire was used to gather data from students. The instrument profiled participant demographics, field attachment variables, methods and frequency of supervision and rated the quality of supervision for each attachment objective.

The quality rating was measured on a likert-type scale. Each broad objective of the field attachment was rated separately. An eighth item - social and emotional support and encouragement was included for rating. Although this is not an objective of the field attachment, supervisors are given this responsibility and it has previously been reported as an area of concern(10).

The objectives and eighth item were scored and rated separately. Thus, a total score of 32 could be obtained. Table 2 shows the ratings obtained therefrom:

Table 2. Scoring and Rating of Instrument

Description	Score	Rating	Percentage (%)
Outstanding	4	25 – 32	>75 – 100
Good	3	17 – 24	>50 – 75
Unsatisfactory	2	9 - 16	>25 – 50
Poor	1	8 and 8<	0 – 25

The development of the questionnaire was influenced by the set objectives of the field attachment and the literature. It was piloted on 10 4th year PT and OT students in 2003, and

was found to have content validity. The results of the pilot study were not included in the analysis of data of the main study.

Routine preparatory seminars (objectives, supervision and evaluation) for the field attachment were given two days prior to students departing for the field attachment. A pre-prepared handout was given to each student containing the content of the field attachment preparation.

One day after the students returned from the attachment, a peer evaluation session was facilitated by the principal investigator with each group. Immediately after this session students were introduced to the purpose of the study. Verbal consent was sought and obtained and the questionnaire administered to individual students. Students completed the questionnaire whilst the researcher observed that each student reported their experiences independently. Questionnaires were collected immediately, for all participating students after this process in February 2004, February 2005, February 2006 and February 2007.

Finally a measure of each student's performance (local supervisors mark, presentation mark, peer rating mark and field attachment average) was entered onto a database.

Data Analysis

Data was entered into EpiInfo 2002. Descriptive statistics were generated to characterise the field attachment placements, describe the profile of the study participants and the frequency and methods of supervision.

A modal score was calculated for the quality rating of each objective, as well as for the item on emotional support and variability, calculated in terms of the inter quartile range.

Non – parametric tests were used to calculate the differences between the modal score of comparable groups as follows:

- a) Mann Whitney - U test for the OT and PT students;
- b) Kruskal Wallis test. for:
 - the four field attachment years
 - the supervisor (PT, OT or Rehabilitation Technician)

Spearman's rank correlation was calculated at the 0.05 level of significance for the:

- a) Field attachment average and supervisor's mark.

- b) Field attachment average and presentation mark (the presentation mark was considered to be the bench mark and most objective, because it is determined by three independent adjudicators in the presence of an academic audience and places high demands on students to present an analytical overview of the attachment).
- The supervisors mark and the presentation mark were then regressed against the field attachment average.
- c) Total quality rating score and the local supervisors mark.
- d) Total quality rating score and the field attachment average.

RESULTS

A total of 108 (100%) students participated in the study, 54 PT students and 54 OT students. The distribution of students by year was:

2004 – 34 students (31.5%)

2005 – 25 students (23.1%)

2006 – 21 students (19.4%)

2007 – 28 students (25.9%)

Students had been attached in districts in seven of the country's ten provinces over the years. Table 3 shows the trend in attachment sites over the study period.

Table 3. Attachment Sites Relative to Distance from the University, 2004 – 2007

Year of placement	Manical and 250-400km	Mash* central80 – 250km	Mash* East75 – 150km	Mash* West100– 200km	Masvingo 300 – 450km	Mat† North600- 900km	Midlands 250- 450km
2004	4	0	6	6	2	6	10
2005	2	4	5	2	4	0	5
2006	4	1	8	2	0	0	3
2007	0	4	17	7	0	0	0
Total	10(9.8%)	9(8.8%)	36(35.3%)	17(16.7%)	6(5.9%)	6(5.9%)	18(17.6%)

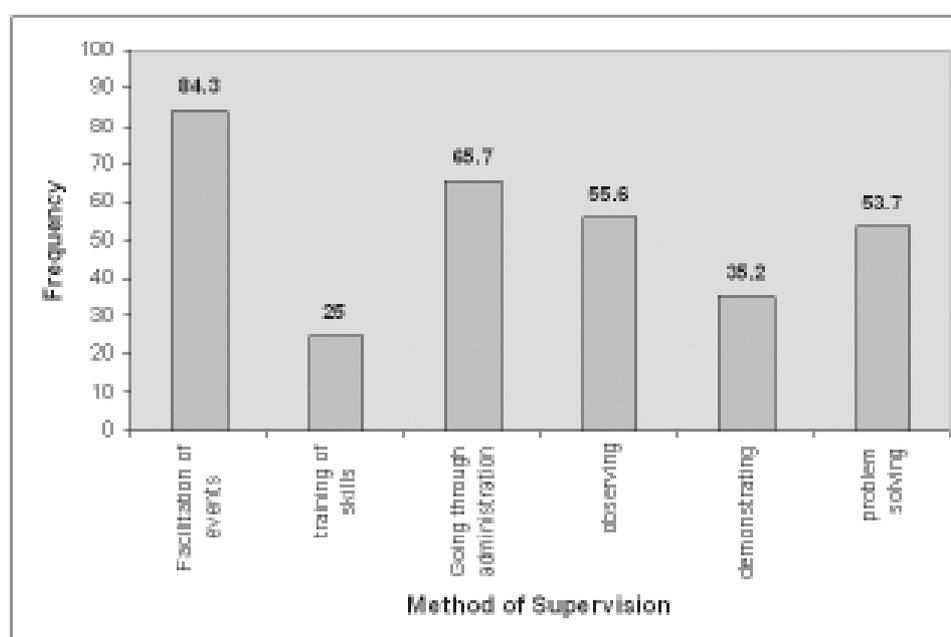
Note: n = 103 (some students did not indicate their attachment site) *Mash – Mashonaland, †Mat – Matebeleland

The more distant provincial attachment sites have had fewer or no students in recent years. The majority of students (60.2%) were supervised by a therapist (PT or OT), whilst 39.8% were supervised by a Rehabilitation Technician (RT).

Frequency and Method of Supervision

Over eighty percent (83.7%) of RT's were considered to offer constant supervision as opposed to 46.2% of therapists ($p < 0.01$).

Figure 1 . Frequency of Methods of Supervision



“Facilitation of events” was the most frequently cited method of supervision by 84.3% of respondents, whilst “training of skills” was the least cited by 25%.

Supervision of Objectives

Therapists and rehabilitation technicians were rated similarly on all objectives save for the objectives, on community involvement and CBR. Rehabilitation Technicians were rated better on supervision of the community involvement objective with 30% being rated

outstanding vs. 6% of therapist supervisors ($P<0.01$). On the CBR objective, 37% of rehabilitation technician supervisors were rated outstanding vs. 8% of therapist supervisors ($p=0.015$)

Students from 2007 rated all the objectives lower than the previous three years, whilst year 2005 rated all objectives higher overall as shown in Table 4.

Table 4. Overall Rating of Supervision of Objectives 2004-2007

	1. Demographic and social survey	2. Conditions needing rehabilitation)	3. Organisation of health and rehabilitation services	4. Community involvement	5.CBR	6. Managing a rehab department	7. Roles of staff	8. Emotional support
2004	3(2,3)	3(2,3)	3(2,3)	3(2,3)	3(2,3)	3(2,3)	3(3,4)	3(3,4)
2005	3(3,3)	3(3,3)	4(3,4)	2(2,3)	2(2,3)	4(3,4)	4(3,4)	4(3,4)
2006	3(3,3)	3(3,3)	3(2,3)	3(2,4)	3(2,4)	3(3,3)	3(3,4)	4(3,4)
2007	2(2,3)	2(2,3)	2(2,2.5)	2(2,3)	2(2,3)	3(2,3)	3(2,3)	4(3,4)
p-value	not sig.	P=0.013	P<0.01	not sig.	not sig.	P<0.01	p<0.01	not sig.

All values = Mode (IQR)

Over the four years studied, item eight - emotional support and encouragement was rated consistently good to outstanding.

None of the objectives was rated significantly different by PT students and OT students.

Total Quality Rating (TQR)

The modal total quality rating over the four years was 20 (62.5%) IQR = 17 (53.1%) – 22 (68.8%).

The PT students gave a modal TQR score of 19 (59.4%); IQR = 16 (50%) -21 (65.6%) which was significantly lower than OT students who gave 20 (62.5%); IQR = 18.5(57.8%) – 23.5 (73.4%), ($p=0.03$).

TQR was also statistically different among the four years, 2004 mode 20 (62.5%) (IQR=18 (56.2%) – 21 (65.6%)), 2005 mode 16 (50%) (IQR=19 (59.4%) – 24 (75%)), 2006 mode 19 (59.4%) (IQR=19 (59.4%) – 23 (71.9%)) and 2007 mode 16 (50%) (IQR=14 (43.8%) – 20 (62.5%)), ($p<0.01$).

Although RT supervisors obtained a higher modal TQR 19 (59.4%); IQR=18 (56.2%) – 23 (71.9%), TQR was not significantly different between them and therapist supervisors 19 (59.4%); IQR =18 (56.2%) - 22.5 (70.3%).

TQR was also significantly different among frequency of supervision, with constant supervisors having a higher modal TQR 20 (62.5%); IQR=18 (56.2%) – 23.5 (73.4%) than supervisors who supervised intermittently 20, IQR=18 (56.2%) – 21 (65.6%) or rarely 10 (31.2%), IQR=11(34.4%) – 14 (43.8), ($p<0.01$).

The student's final field mark was positively correlated to the student's TQR, Spearman's correlation coefficient 0.156 (SE=0.072), ($p=0.04$).

Critical Analysis of Student Field Attachment Performance by Supervisor

The field attachment average was positively correlated to the supervisor's mark, Spearman's correlation coefficient 0.54 (SE=0.106) ($p<0.01$). However, the supervisor's mark overrated student performance as it contributed great variance to the field attachment average ($r^2=0.49$) as compared to the variance contributed by the group presentation mark Spearman's correlation coefficient 0.522 (SE=0.128) and ($r^2=0.38$) ($p<0.01$).

DISCUSSION

A total quality rating of 62.5% (good) was recorded for supervision of the physiotherapy and occupational therapy student's field attachment at the University of Zimbabwe (UZ). Various social, environmental, academic and experiential factors are attributed to this finding.

A high rating for supervision was associated with constant supervision, the year 2005 and OT students tended to rate their supervisors more highly than PT students.

Other authors have previously reported student's appreciation for constant supervision, which too has been the finding in this study (7,10). This may suggest the students' need for constant guidance for community based learning and or in undergraduate learning. The community based teaching is not a routine approach in undergraduate health science programmes at the UZ, and it is possible that supervisors who themselves are graduates of the UZ programmes, lack the specific skills for community based teaching approaches. Whereas an increase in anxiety if supervision was given constantly so as to mimic spoon-feeding was reported (8), this element may be negated by the group nature of the attachment studied here.

A range of possibilities may account for OT students rating supervision more highly than PT students. The psychosocial focus of OT training may influence OT students to engender a more understanding nature when appraising the role of their supervisors. Alternatively, OT students may have a better predisposition to community based learning, thereby having less demands on the supervisor and subsequently rating them more favourably.

The good supervisor ratings by students from the year 2005 can be explained by the fact that it was in this year that the UZ academic department had a good staff complement. This, combined with a supportive faculty administration enabled 100% support follow up visits to attachment sites for the first time in many years. These events were timely in that, after rationalisation of the field attachment in 2004, the teething problems of 2004 were able to be addressed.

Subsequent attachment groups conducted their field attachment in an environment that was on a decline in many respects and came to be known as the economic melt-down in Zimbabwe (13). This was characterised by such socio-economic challenges as a high inflation rate, liquid fuel scarcity and thus transport non-availability, power and water supply interruptions, hence services and trade irregularity. Although these events had become evident prior to 2005, the escalation around this time became unbearable. The net effect of these occurrences that is immediately relevant to this study was the frustration of health professionals and the resultant mass exodus from the public sector, as well as from the country (14). In short the UZ had difficulty in finding supervisors for the field attachment. The few who held posts, were unwilling to take on student supervision duties, whilst those who were cajoled or coerced into student supervision had little or no resources to assist students to fulfil the

attachment objectives. Chief among these was transport. Transport and communication has been cited as a significant barrier to supervision (10).

Attrition of Rehabilitation Technicians (a lower cadre providing rehabilitation services, also known as PT / OT assistant elsewhere) has been marginal over the years. Although they are employed across the health system, their training was designed as a stop gap measure at independence (1980), to provide rehabilitation services in the absence of PTs and OT s. The focus of their training was for community based services while based at the district level. Most of the RT's are found at district level, and they have tended to serve their districts for longer periods of time. The higher quality rating for RT's in their supervision of the objectives on community involvement and CBR, are indicative of their background training and long experience in community work. They are thus well established and familiar with the structures, protocols and community development strategies. The field attachment programme would do well to recognise this advantage and capitalise upon it in order to enhance the learning experience for PT and OT students on field attachment.

The low frequency reported in "training of skills" as a method of supervision, raises concerns. It may in part, be because a clinical load is not a primary objective of this attachment or that supervisors lack the experience, or do not engage in continuing education and subsequently lack the confidence to "train skills" or to "demonstrate" (10).

Critical Analysis of Supervisors

This study has revealed that supervisors tend to overrate student performance on field attachment. This unfavourable finding may be attributed to the confidence levels especially where an RT is required to supervise a therapist student. Supervisors may lack confidence in supervising students and in evaluating them, as they may fear that a low mark given to a student may reflect their own inadequacies as a supervisor, rather than reflecting student performance.

Social and emotional support and encouragement were rated consistently good to outstanding, this despite the challenging environment described earlier. This finding is highly commendable as it implied that supervisors were able to respond appropriately in this aspect of their supervisory role from both a personal, social as well as professional work perspective.

There may be diminished ability by professionals to respond in this manner when challenged and demotivated, particularly if they work in isolation, or outlying areas where collegial support is rare or absent. In this instance however, the finding may support the idea that the social fabric of small, rural and district communities is strengthened in the face of adversity.

CONCLUSION

Supervision of the field attachment has been rated “good” by PT and OT students. A constant type of supervision was rated highly for the undergraduate field attachment, with OT students having a propensity to rating their supervisors more favourably.

Rehabilitation Technicians were rated “outstanding” for their supervision of the field attachment objectives on community involvement and CBR. However, all supervisors overrated student performance on the field attachment.

RECOMMENDATIONS

Strengthening of the field attachment can be achieved through the continued training and support of local supervisors from the UZ.

All supervisors need to be trained on a) Methods of supervision, b) Frequency of supervision, c) Evaluation of students.

Therapist supervisors need training on supervision of CBR.

RT supervisors need training on supervision of identification and assessment of health and rehabilitation services.

The College of Health Sciences administration should continue to provide resources to enable academic staff to conduct follow-up support and supervisory visits.

Attachment placement of mixed OT and PT students should be continued.

The weighting of the field attachment evaluation components need to be reviewed.

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ACKNOWLEDGEMENT

The authors would like to acknowledge the participation of third year Occupational therapy and Physiotherapy students from the University of Zimbabwe (2004 - 2007). Also, thanks to colleagues past and present, from the Department of Rehabilitation, University of Zimbabwe who over the years designed and supervised the field attachment programme. The contribution of rehabilitation staff at district and provincial health facilities country wide, who supervised students, and the support they have had from their District Health Executives and Provincial Health Executives year after year, is also recognised.

Last but not least the authors acknowledge the administrative support the programme has received from the College of Health Sciences University of Zimbabwe through the Dean's Office and the Field Attachments Office.

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