

**EDITOR'S COMMENT**

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Community based rehabilitation (CBR) has been in existence for over two decades now, started primarily to address needs of persons with disabilities in developing countries. During the first decade, there was little or no published literature available on different aspects of this new approach. Over the last ten years, however, there has been a gradually growing body of knowledge, based on experiential accounts and what Finkenflugel terms 'grey' literature, comprising of project evaluation reports, annual reports of programmes and some newsletters. Most of these reports are with donor agencies or governments, and not usually available for wider circulation. Scientific literature on CBR is still rare, and one finds that authors from the developed world

Over the last decade, the Asia Pacific Disability Rehabilitation Journal and associate publications like *Selected Readings in Community Based Rehabilitation* and *Manual for CBR Planners*, have been attempting to address the gap in information on CBR, by disseminating information on CBR from different parts of the world. It is now increasingly recognised that with a dedicated readership of about 20,000 from all over the world, APDRJ is a useful vehicle for dissemination of material related to CBR, not only by publishing in the journal, but also by co-mailing other related publications along with the journal. Of late, in addition to the APDRJ group publications, publications of work from other authors are being produced and mailed along with APDRJ.

The APDRJ team are now bringing out a CD-ROM with all back issues of the journal and associate publications, from 1997 to 2003. This will make available under a single source, all the material that is not available elsewhere, for easy reference and retrieval. The feedback received from readers indicates that such reference material would be of use to them, particularly for people in the field as they move from generating experiential information to more evidence based information. The feedback also indicates that it would also be more relevant to users at this point in time, with most field workers having access to computers.

All these publications are an effort at establishing a more scientific body of knowledge about different aspects of CBR, meant to build capacity of different groups such as policy

makers, donors, academics, researchers and people in the field. The aim of all these information dissemination efforts is to contribute to evidence based growth and development of CBR in the future.

The APDRJ team wishes all readers a happy New Year!

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**GUEST EDITORIAL**

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**AN ECLECTIC APPROACH TO DISABILITY RESEARCH: A MAJORITY  
WORLD PERSPECTIVE**

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**ABSTRACT**

*This paper argues that the "emancipatory paradigm", which is the research machinery commonly used to explore the social model of disability, provides a limited tool for investigating disability concerns. Although, this approach emphasizes greater control of disabled people over the research process and its production, examples on disability policy research in Afghanistan where the author works proved it to be not universal. This limitation, it is argued, is due to its inherent theoretical limitation when focusing merely on political issues, especially in developing world contexts. Also argued here, is the need for adopting a broader perspective in doing disability researches, such as a participatory one, which incorporates other relevant research approaches and theoretical views within its remit. In a participatory approach, issues of cultural diversity including contextual factors such as religion, political and economic systems are taken into account in the analysis of disability. On a larger scale, this may also call for the endorsement of an eclectic theoretical approach based on "Human Rights" ideals. A Human Rights perspective, with its near universal statements, will also incorporate other views on disability such as medical, social, feminist, and post-modernist analysis.*

*This paper attempts to answer the question of why research is important at all to disabled people and how the choice of a research method makes all the difference when dealing with disabled people for the purpose of planning policy and services.*

**INTRODUCTION**

In recent years, the re conceptualisation of disability as a socio-political issue has been coupled with changes in the practice of disability research, towards more of an interpretive "emancipatory" paradigm (1). This movement does not lessen the value of other approaches

to researching disability (e.g. positivist approaches). All approaches add important insights into the understanding of disability issues. Approaches with the non-emancipatory paradigm are, of paramount relevance to disabled people, especially in developing countries where disability policies and provisions are still highly dominated by medical approaches to rehabilitation. The value of the socio-political framework, which underpins research in such settings, is often in question.

### **CRITIQUE OF THE EMANCIPATORY PARADIGM OF DISABILITY RESEARCH**

Research is an essential part of the social inquiry concerning disabled people. In order to plan services for disabled people and in listing priorities, decision-makers require a research method to assess their needs. How best a method can then reflect the real needs in different cultural settings, becomes an important methodological concern in disability debate. All research methods have some flaws, and therefore, a relativist cultural approach, in researching and evaluating projects targeting disabled people in various contexts, seems more appropriate.

Research can be inherently political, and plays an important role in transforming and changing the world, and not only in describing it. In other words, the impact of research goes far beyond theoretical circles, into the life of society. The adoption of a particular research method for example, will influence the suggested solution put forward to deal with disability issues (i.e. influencing societal policies and provisions concerning disabled people). This is the reason why the choice of research method becomes a political decision and should be dealt with as such.

Generally speaking, there are two major approaches in doing disability research namely, the participatory and emancipatory paradigms. Both these approaches support a move away from the traditional methods of studying disabled people as respondents only, and signal a move towards permitting respondents to have more participation and control of the research process and its production. However, the two adopt different means in trying to achieve such a level of participation and control for disabled people, within the context of the research process.

While the "emancipatory approach" has widespread support in industrialised nations, this same approach has a number of limitations when applied to the majority world countries. Its limitation goes beyond academic debate into the life of society, as discussed below. This approach, which emphasises greater control by disabled people over the agenda, participation in the research, and gaining strength in the process, is not universal. The limitation of this model is especially true in developing countries.

Five areas of concern are identified here, where the emancipatory approach to disability research may be unable to provide a comprehensive understanding of disability issues. These are related to theoretical, contextual and methodological grounds, as described in the following sections.

At a theoretical level, emancipatory research has an inherent weakness related to its engagement only in political issues. This way, it tends to ignore other perspectives and views on disability, such as the analysis by feminists and postmodernists. Emancipatory researchers have been under increasing scrutiny by feminist writers and others, for not taking note of the experience of the body and pain, in their research (2, 3, 4). These are real experiences of many people with impairments and should not be neglected or ignored because of the political position of one theory, or research approach.

Postmodernist writers argue further that cultural norms and values should also be manifested clearly in disability research. Shakespeare (5) for example, contends that it is necessary to move away from society alone, for an account of the relationship between disabled people and the social construction of society's cultural values.

The emancipatory approach to disability and disability research has emerged and flourished within Western capitalist society and does not necessarily apply to many parts of the developing world, that are still witnessing early stages of development. In such countries, the needs and opportunities of disabled people are entirely different from those in the west and require different methods of enquiry, explanations and solutions.

Although, increasingly some western theorists argue the value of this approach for developing countries (6), recent debate supports the participatory approach to disability research in these countries (7, 8). This is so, for the reasons mentioned earlier, especially in the context of project evaluation (9).

Whether in developed or developing contexts, the medical needs of individuals will always remain even when social barriers are removed. Exposing such needs via medical research is as important as meeting them. This often makes a big difference to people with impairments, in terms of their functional abilities and subsequent life activities. In the context of post conflict zones such as in Afghanistan, where the author works, many people became disabled in war related activities and require immediate medical and physical rehabilitation.

Within a western welfare system, doing emancipatory research for policy making has proven to be successful in recent years, especially where social ideals dominate. Although this model has become a political privilege for people who identify themselves as "disabled", entitling them to extra support, this has often led to a positive discrimination in favour of

disabled people. This is because the social model is largely concerned with advocacy, lobbying and political activities.

In many countries of the majority world, such a view is a western luxury, as people (whether disabled or not) are struggling to survive and meet their basic needs. This is especially true, when no welfare system exists for support to those who cannot work and for other minority disadvantaged groups including disabled people.

This is also very true in the context of Afghanistan where there is almost no welfare system that exists to support disabled people (10). Those who are identified as war disabled, or the families of martyrs however, receive very small financial support equivalent to US \$ 6-14 per month. They have to go through complicated procedures to prove their entitlement to such support, which involves travel to central places that sometimes cost them more than the entitlement they would eventually receive.

Methodologically, the implication of this debate on doing disability research is that this model lends great support to independent research, carried out mainly by disabled researchers. While it is important to involve disabled people in disability research on an equal footing with other research partners in developing countries, this partnership might not be possible for a variety of reasons. Among such reasons for example, are existing oppressive political systems in society (i.e. the ex-communist regime in Afghanistan). Moreover, as Kitchen argues, disabled people might in fact, choose not to control the research process and production, on the grounds that able bodied researchers are being paid for doing the research (11).

By "over" doing emancipatory research and disseminating findings for policy-making purposes, disabled researchers are becoming their own worst enemies and marginalising themselves. This is likely to happen due to the fact that disabled researchers tend to force too many disability issues on society, when there are other equally pressing issues in that society. This may create a feeling of resentment among members of the public towards disabled people. This is particularly true in many developing countries including Afghanistan, where social ideals do not exist.

### **THE PARTICIPATORY APPROACH IN DISABILITY RESEARCH IN DEVELOPING COUNTRIES**

Traditional research in developing countries has conceptualised disability as an individual issue, thus fuelling the general negative attitudes towards people with impairments. Historically and until recently, disability research in these countries has been predominantly controlled by a positivist approach to research, such as survey methods, due to cultural and contextual factors. This has largely affected the way disability was perceived and dealt with, within society.

In many parts of the developing world, where democracy and human rights are not respected, one does not expect to find widespread support for emancipatory ideals. Therefore, a participatory approach to researching and evaluating disability issues seems more appropriate under these circumstances. Such an approach may have a particular relevance to local culture and could play an important part in stimulating awareness about disabled people, towards their disabling societal structure. Yet, there is room for improvement in the participatory approach towards disabled people being a major force in research enterprise.

Participatory research in this context, is an approach which emphasises a high level of involvement of research subjects, at all stages of the research process. This approach has been evolving in recent years, particularly in developing countries, and has been the subject of different interpretations. French (12) and Chambers (13) pointed out that the main aim of participatory research is to involve people in an active way at every stage of the research process. It also aims to educate decision makers and other research partners involved, in doing disability research. Thereby, they can learn about the local culture and specific circumstances of the community, which helps in a better understanding of the needs of these communities when making policy decisions.

Helander (7), favours the participatory approach when studying disabled people's needs in developing countries. He argues that researching and evaluating the needs of disabled people should be the starting point in any plan of determining the provisions required to meet those needs. As people's needs vary and each society sees its priorities differently, researching and evaluating disabled people's needs can best be done when taking into account the social structures and cultural traditions of the given society. Involving outside researchers as well as local disabled people and other research partners, could facilitate this.

Thus, participatory research appears to have a potential for making a discernable impact on disability issues not only in developing countries, but also to some extent in the developed world. This is because it allows a greater degree of participation by disabled people, along with other stakeholders including policy makers, in controlling the research process and its production. In this sense, this method is considered to be a democratic tool, which can accelerate social change.

## **PARTICIPATORY AND EMANICIPATORY RESEARCH: A COMPARATIVE VIEW**

In theory, there are four main differences between the emancipatory and participatory research methods. The first relates to the issue of control over the research process. Emancipatory researchers believe in giving disabled people full control over research production, or, as Oliver (1) and Barnes and Mercer (6) describe it, "ownership of research

production". The participatory method in contrast, is based on full participation, but without necessarily controlling the research production.

It has been proven extremely difficult though, to achieve full control by disabled people over the research process and its production, especially in research that involves academic work (14). In practice, research on disability issues in the academic field tends typically to involve collaboration between professional researchers and disabled people. This has been notable in developing countries where disabled people have often been treated as research objects only. Evidence from Jordan for example, supports such practices in disability research (8).

The second difference is the role of the researcher. Emancipatory research implies that the researcher's expertise should be put at the disposal of disabled people as a neutral resource (1, 15). In reality however, it is very hard to neutralise attitudes and skills as professional researchers. Further, disabled people may not be willing to take part in research at all (10), or might not consider this to be an issue altogether.

The participatory method on the other hand, implies that the role of the outside researcher is seen as that of an expert, although only in research skills, and that the local people or the target group, are the real experts in knowing their situation. Therefore, the role of the researcher here is to get involved in a learning process from and within the locality. Thus, the research acts as a means to facilitate greater involvement of disabled people in the research process.

The third difference relates to the issue of the source of initiative for undertaking the research. Emancipatory research, at least theoretically, encourages disabled people to decide what they need from research, on the basis of their awareness of the local situation. This however, might be possible in situations where social ideals exist and not necessarily everywhere. Participatory research in contrast, is usually initiated from outside the community, whether at national or international level. This may include those working in development and interested in having an overview of a given situation, such as professionals, government officials, and international aid agencies.

The fourth difference is that emancipatory research deals generally with individual and group aspects of liberation (2,16). Capitalist values prevailing in western society have greatly encouraged such notions of individualism in recent years. Participatory research on the other hand, deals with individual development, but within a group setting. Therefore, it is not the individual who is of central importance, but the community as a whole.

The similarity between emancipatory and participatory research methods however, applies in several respects. The first is that both of them have and use a package of methods for

data collection and analysis, which can sometimes be very similar. The second similarity is that both methods encourage the participation of disabled people in the production of research and so to some extent, challenge traditional research. In both approaches, the role of the researcher is changed, as far as possible, from that of controller to facilitator.

In brief, all research methods are flawed and have limitations. What is important here, is the move from treating disabled people as research subjects, into allowing them more power and control as research partners. Thus research becomes a political tool for eliciting social change.

### **TOWARDS A NEW DEBATE IN DISABILITY RESEARCH IN THE CONTEXT OF DEVELOPING COUNTRIES**

Unless there is recognition of all personal, social, and other aspects which influence the ways in which disability is experienced and manifested in research, prevalent views on disability research such as the emancipatory paradigm, will only offer limited scope to the understanding of disability issues.

The current debate on disability research suggests that it is necessary to consider elements of other perspectives such as those of the feminists and postmodernists, when discussing research issues. This is useful in drawing a range of insights from these debates and can help to arrive at conclusions for the basis of a new eclectic approach. Such an eclectic perspective on disability research is possible, because of the way in which contemporary politicised forms of discourse (i.e. emancipatory) have often failed to provide a more comprehensive understanding of disability issues.

While emancipatory research has been influential in shaping Western policy on disability in recent years, this however, did not eliminate existing discrimination against disabled people. This points out the need to go beyond the existing structure and into looking at new appropriate theoretical and methodological frameworks to researching disability issues, which are also sensitive to local contexts, including those of the majority world.

Every method entails implicit commitment to a particular theoretical understanding of the social world. This commitment more than anything, emphasises the importance of recognising the diversity of approaches in doing disability research. This is important in acknowledging the fact that the ways in which professionals engage in, and deal with people - within a methodological framework - contributes to the development of a certain theory and understanding about disability and disabled people. Theory itself is part of social action, a set of organising principles, by which social practices (in this case, research approaches) are understood. This understanding in turn, may either legitimise or challenge particular social practices.

Based on the previous analysis, there is an obvious connection between debates on doing disability research and social change in society. After all, disabled people do not live in a vacuum but in a dynamic and complex society. Therefore, it is crucial that debates become more accommodating to include other views on disability and also become culture sensitive. Debate on disability research can be instrumental in subsequent policies and provisions dealing with disabled people.

## CONCLUSION

Debate on disability research is a notion created by the west. However, recent discourse suggests that the value of such debate is under-developed within countries of the majority world. Debate on disability research is an under-researched aspect of disability and makes the subject of this paper. Given the obvious impact of research methods on disability issues, this analysis hopes to stimulate a debate and especially invites views on this subject from other writers in the majority world. The aspiration underlying such debate is to emphasise balancing power relations between research partners at both, the methodological and theoretical levels.

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**DEVELOPMENTAL ARTICLES**

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**PERSPECTIVES ON DISABILITY, POVERTY AND TECHNOLOGY**

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**ABSTRACT**

*The Knowledge and Research (KAR) Programme of British Department for International Development (DFID) has linked 'disability' with 'healthcare technology' and for this reason DFID has been interested in the potential role that 'technology' plays – and can play - in reducing (or possibly in increasing) disability. It is axiomatic that technology plays an important role in affecting the physical environment and the immediate physical circumstances in which disabled people live and work. It can produce built environments that constrain or offer facilities to disabled people, it can produce equipment and machinery, which also has the potential to provide opportunities or create restrictions for disabled people. Technology is rarely 'disability-neutral'. It is often argued that improvements in specific 'disability-related' technology can play a major role in improving the lives of disabled people. These improvements do not always imply more 'advanced' technology, but often technology that is '3A' – appropriate, accessible, and amenable to the needs of disabled people across the world – can improve their lives. For most poor and disabled people, however, appropriate technology is not accessible and what technology is available is not amenable to their needs. This paper is concerned with the relationship between disability, poverty and technology in the developing world.*

**A CONCEPTUAL APPROACH**

It is suggested, firstly, that the concepts of disability, poverty and technology are all best understood in terms of dynamic social processes and this paper sets out an approach to disability, poverty, technology and development based on the social model of disability. It argues that 'disability' is both different from and more comprehensive than 'impairment', and defines disability as the consequence of various forms of social discrimination and exclusion for people with impairments. For this reason, national and international statistics on the prevalence or incidence of physical and/or mental impairment are inadequate as a guide to the prevalence and incidence of disability. Furthermore, such data offer a partial and often misleading notion of social reality of disability in developing countries. It cannot, therefore, be used to gauge the specific needs of disabled people or as a basis for estimating the costs and

benefits of any particular programme. This paper argues the need to formulate an integrated strategy towards disability and development. It recognises the value of programmes like the Knowledge and Research (KAR) programme supported by DFID and recommends the funding of such initiatives in applied or action-research to examine further the relationship in different contexts of disability, poverty and technology.

### **DISABILITY, POVERTY AND TECHNOLOGY**

Although poverty and disability are often conceived as static and specific ‘states of being’ – a sort of ‘negative endowment’ - and technology as infrastructure or equipment, they are all better understood as the manifest and specific outcomes of dynamic social processes. Disability is not the same as impairment, and the problems and methods of dealing with impairment prevention and with disability are, therefore, often, although not always, significantly different. Disabled people have increasingly challenged the view that disability should be equated with impairment (the medical model of disability), arguing that what disables people are the various social and physical barriers and negative attitudes, which prevent equal participation in community life. Within this social model, disability is seen as the result of social exclusion and discrimination – as a dependent variable.

The social model offers a powerful framework for understanding the complex issues of disability, poverty and technology. It reveals disability as a crosscutting social issue, and the primary policy focus then becomes changing the conditions and circumstances in which disabled people are constrained or prevented from full participation as equal citizens – that is, reducing social exclusion. DFID’s statement on Disability, Poverty and Development tends to confuse the two approaches (medical and social), but leans towards the medical model, seeing disability as ‘long term impairment, leading to social and economic disadvantages, denial of rights and limited opportunities...’ thereby equating impairment and disability and characterising them as independent variables.

Poverty used also to be characterised very much as ‘a state of being’ requiring intervention and ‘re-habilitation’; increasingly, however, it is being defined as the consequence of social discrimination and social exclusion. Poverty in this sense needs to be understood as an outcome of social processes, which produce and reproduce it - oppression, subordination, exploitation and discrimination. Poverty is not only a dependent variable, and the consequence of social processes, it also is the root cause of many forms of impairment. But being poor is, even more significantly, a major factor in transforming impairment into disability. Poverty may generate impairment, through malnutrition, disease and inability to gain access to adequate health services; it also excludes those with impairments from many normal every-day activities and thereby increases disability. Disability exacerbates poverty, while having impairment makes being poor more gruelling and inexorable. Poverty, disability and impairment are clearly linked in a deadly mutual embrace.

Technology is best seen as the process of ‘the application of knowledge’ to find effective solutions to social problems. Technology and its outcomes (which may include buildings, transport systems, assistive equipment, etc.) can dramatically affect the environment within which people live and work and may itself significantly increase or decrease the barriers which prevent disabled people from participating fully in social life. Technology can be immensely liberating and empowering for disabled people if developed within a framework which prioritises their real needs as well as their genuine participation at all levels. The provision of appropriate technological solutions in a manner which empowers the users, should not be seen as outside or opposed to a social-model approach, but as a critically important element in this approach. For example, for millions of poor disabled people, the lack of low-cost, appropriate mobility aids and assistive equipment is a major barrier to social integration.

### **THE SOCIAL MODEL IN PRACTICE**

The social model has been the foundation for the disability movement, because it offers a true representation of disabled people’s experience and has proved a powerful lever for anti-discrimination legislation and other policy changes. It provides a protean challenge to the disablist paradigm so often associated with the medical model. The needs of disabled people (like disabled people themselves) have all too often been equated with ‘special’ – outside the ‘normal’ – and disability has all too often been equated with ‘abnormality’ and with ‘illness’.

There is a tendency for those concerned about ‘disability’ to speak and act ‘on behalf of’ disabled people. Charities and NGOs tend to be run by members of social and political elite groups, who may capture or divert programmes and projects. The need for disabled people and their organisations to be actively involved in defining their own needs and designing their own solutions is central for the social model approach.

Self-reliance does not necessarily mean ‘standing alone’; it does mean being in control of what kind of support is wanted and required, by whom or what, and when. This implies a ‘demand-led’ support system in which disabled people, together with specialists and others serving as facilitators can begin to work together to make judgements about what might prove to be appropriate and sustainable technologies with respect to disability in specific social contexts.

### **THE EXTENT OF DISABILITY IN DEVELOPING COUNTRIES**

Very little is known in detail about the nature, extent and severity of disability in developing countries; not much more is known about the prevalence and incidence of impairment. Social discrimination based on gender is widespread; so too is discrimination based on other socio-cultural definitions of identity – caste and ethnicity in particular – and on socio-economic

status, or class. These forms of discrimination affect the nature and severity of disability among people with impairments, according to their gender, caste or ethnic group, social class – or indeed age. But relatively little is known in detail about how precisely disability and social discrimination relate to other forms of social division – it may be that poor, low caste women are more severely disabled than wealthy, high caste men with the same physical or mental impairment, but this is not necessarily the case.

The nature of impairment is also poorly understood. Usually taken as a ‘given’, even in the social model of disability, impairment – like disability – is in fact socially defined and constructed. What is regarded as ‘an impairment’ in one social context, may not be in another. The registered prevalence of ‘learning difficulties’, for example, is rapidly rising as hitherto socially unrecognised ‘conditions’ (e.g., dyslexia) are diagnosed, or as new conditions arise (as in the case of HIV/AIDS, which now falls within the remit of ‘disability legislation’ in several countries).

Global statistics on impairment (often confused with disability) – because definitions vary, investigations are incomplete and people with impairments are often not recorded or identified as such - are unreliable and based on guesstimates. The figure of 600 million people or 10 per cent of the total population is often cited – but this too is a guess. Across countries, estimates vary from as high as 12-15 per cent (in some developed countries) to as low as 1-2 per cent (in many developing countries). This suggests that data are unreliable and misleading. Furthermore, although some of the reasons for this are, as indicated above, the result of deficiencies in definition or counting, there may be other, more important reasons which remain unclear. The apparently low incidence of impairment in many developing countries may simply indicate that mortality rates are very high among poor people with impairments, and they ‘disappear’ from the recorded population. It may also indicate generally lower rates of ‘recognition’ (where physical or mental impairment is more common, the ‘threshold’ for its definition as ‘serious’ may be higher). All too little is known.

The new International Classification of Functioning, Disability and Health (ICF) attempts to measure impairment and disability from a perspective that is somewhat closer to the social model (although it still emphasises the capacities and capabilities of the individual rather than the barriers and constraints of his or her social and physical environment) and was adopted by the WHO in May 2001. It will take some time, in any case, to implement. Attempts have been made to address the problem in a more systematic ‘objective’ fashion. The WHO has compiled figures on Disability Adjusted Life Years (DALYs) by region, to reveal some significant differences in the impact of impairment (and disability) on life expectancy and life expectations, but the measurement itself is based on essentially arbitrary, negative assumptions about the quality of disabled people’s lives.

The available global and regional data indicate that malnutrition, resulting from material poverty, is one of the most common causes of impairment and that many kinds of impairment are the result of specific diseases or conditions for which there exist relatively straightforward and inexpensive preventive measures. Poverty and poor access to simple remedies are thus key factors in the prevalence and incidence of impairment.

The identification and classification of impairment in a population is not the same as the analysis of the nature, extent and severity of disability in a society. Both are of major importance, but it is the latter that is crucial for the reduction of 'disability', but is even more difficult to identify and deal with. Such a task is best undertaken at the national, sub-national and local level where there is a greater opportunity for the specifics of 'disability' and 'impairment' to be recognised and understood and the appropriate forms of intervention (whether involving technology or not) devised.

#### **THE VALUE OF INTERVENTIONS**

The use of conventional benefit-cost analysis, with its emphasis on direct economic value within a specified (usually limited) time-frame is not really appropriate, as usually applied, in assessing the benefits of interventions designed to address disability issues. Nonetheless, broad social cost-effectiveness must be a consideration in the selection of policies, programmes and projects. If interventions (technological or other) are both appropriate and sustainable then they will tend to be cost-effective in the sense that they are likely to be widely adopted by relatively large numbers of disabled people and used over a relatively long period of time.

Ideally, the more disabled people are involved in debates on assessment and evaluation, in their local or national context, the more any debate about costs and benefits can be grounded in the social and political realities. This has already been recognised as effective in various forms of participatory evaluation, whether it is participatory action-research or participatory learning and action, of so-called poverty-alleviation policies, programmes and projects. There is a growing recognition that it is effective as well as appropriate to involve people at all stages in the formulation, design, implementation, monitoring and evaluation of policies, programmes and projects. Effective, inter-active participatory techniques for 'needs assessment', project appraisal, implementation, monitoring and evaluation, which include and involve disabled people must become part of the repertoire of all those working in the development field, particularly at the local level. A review of experience with disability projects and examination of specific case studies suggests that all projects should be firmly rooted in the expressed needs and demands of disabled people in a specific local social and physical context.

In most developing countries, the national level is where government and international (bilateral and multilateral) agencies are most likely to develop policies, programmes and even projects with respect to disability reduction. But it may be at the sub-national (regional, district and local community) level that such 'higher-level' agencies will need to work together systematically with local NGOs, organisations of disabled people, researchers and others with relevant skills and expertise, to develop appropriate projects, programmes, policies and legislation to reduce disability.

### **DISABILITY AND DEVELOPMENT: TOWARDS A GLOBAL STRATEGY**

Despite the undoubtedly vast number – hundreds of millions at least - of poor disabled people in the developing world, disability as an issue does not figure in either of the British Government's White Papers on International Development, and is barely mentioned in any of the key documents of the international development agencies over the last decade. There has been growing interest in, and concern about, disability – notably in specific agencies. The World Bank, for example, and USAID; JICA and the Asian Development Bank; NORAD and the other Scandinavian government aid agencies, and some of the international NGOs (like Save the Children) have turned their attention increasingly towards disability issues. Some have even begun to talk about policy to mainstream disability, just as 'gender' has been mainstreamed in recent years. Mainstreaming disability in a major development agency means that all policies, programmes and projects should include disability as a key issue, and that monitoring and evaluation should track both the involvement and empowerment of disabled people in the design and implementation of policies, programmes and projects and the impact of these policies, programmes and projects on disability reduction.

The authors believe that development agencies should increasingly integrate disability within the mainstream of their development policy and practice by adopting a social-model approach and by identifying disability as a major crosscutting issue. This would imply, in effect, adopting a twin-track strategy – already advocated by DFID in its paper on 'Disability, Poverty and Development' - and adopted with respect to gender issues. Several other development agencies have already moved quite a way in this direction. In order to implement such a strategy and policy for 'disability and development', it is essential that all development agency staff recognise the links between reducing disability and other development priorities, such as alleviating poverty. But for this to happen, they have to 'see' disability as a crosscutting development issue. One important way in which this can be facilitated is to introduce appropriate, social-model based disability equality training. Just as 'gender-blindness' has been identified even at the highest levels in international development agencies and NGOs, so too the risk is strong that 'disability blindness' may affect these agencies, unless strong preventive measures are taken.

There is a growing interest in, and concern for, disability issues in development among the major international agencies. Several international NGOs and some organisations specifically concerned with disability and development have already charted the broad direction in which theoretical and practical work should be moving. Greater effort needs to be put into disseminating new information and best practice with regard to disability and development between institutions and agencies. Publications such as *Asia Pacific Disability Rehabilitation Journal* produced by Action for Disability should be able to play a significant role by publishing ideas, experience and case material, examples of best practice and of innovations which can feed into what needs to be a fuller and more comprehensive international discussion and dissemination process. At the same time, those working in the field of disability and development should be aiming to write for publications in development studies so as to reach a wider and different audience, of development policy-makers, practitioners and professionals. On the other hand, those with experience and expertise in disability and rehabilitation should be equipping themselves with an appreciation and understanding of the latest thinking in development, bringing development and disability studies and practice closer together.

#### **PROPOSALS FOR THE DEVELOPMENT OF DFID'S DISABILITY STRATEGY**

In 2001, DFID produced a paper on 'Disability, Poverty and Development' in which an attempt was made, for the first time, to focus on disability as a significant development issue linked to poverty, and to develop a framework for addressing disability as a policy issue. The establishment and continuation of DFID's Knowledge and Research (KAR) Disability and Healthcare Technology Programme is another sign that DFID is beginning to address disability as an issue for action-research as well as for policy and practice. But while the establishment of the KAR Programme and the production of the strategy paper mentioned above indicate an emerging awareness within the agency of the need to address disability within the context of development policy and practice, there is as yet little evidence of an integrated and coherent approach to the issue. Disability remains institutionally as well as conceptually and practically marginalised, with responsibilities within DFID itself fragmented.

Recent re-structuring of DFID has meant that a certain amount of impetus has been lost as old departments and divisions have been replaced by new teams and focal areas. It is not at all clear where responsibility for disability issues and development 'sit' in the new DFID that is now beginning to emerge from its re-organisation. Perhaps it is a good time to define a new strategy. Such a strategy should be developed in collaboration with other like-minded international agencies seeking to integrate disability work with development priorities, whether these are essentially disability- or development- focused, and with the existing international organisations of disabled people.

The authors suggest that DFID establish a cross-sectoral, cross-thematic Disability and Development task force or team with a clear mandate to mainstream disability and to focus more attention on it as a specific development issue. In the new KAR Programme for 2003-2006 there is a specific 'project' to assist DFID in developing such a focus on disability and development. In terms of defining strategy for DFID, one possibility would be to commission the re-drafting of the short paper on Disability, Poverty and Development, to provide a more substantial and substantive document on which to base policy and practice throughout the organisation. Another would be to produce more focused papers showing how disability would be integrated into the work of specific teams and focus groups.

### **THE NEED FOR RESEARCH ON DISABILITY AND DEVELOPMENT**

One urgent priority is to increase knowledge about existing approaches to disability and development, both in theory and in practice, and to identify 'best practice' as regards disability and development, both in government agencies and in non-government organisations. This should be undertaken through an initial review of research and publications on 'disability and development', which could complement existing reviews of CBR and related programmes.

At the same time, a register or compilation of statements and policies on disability and development by international, bilateral and non-government agencies and organisations would be valuable, as would an international register of organisations and institutions with a proven capacity to design and implement innovative disability projects (including research institutions, NGOS, DPOS and private sector enterprises). Healthlink Worldwide under the previous KAR Disability and Healthcare Technology Programme has made a start on this. Thirdly, in the context of a stated concern with respect to technology for disability reduction, an international network of technology providers for disability reduction needs to be compiled.

The authors also argue that it would be useful to undertake a comprehensive study, which would involve a review of literature (and other sources) relating to disability and development, a review and analysis of significant programme or project initiatives (involving research and/or implementation), and a listing and discussion of country-by-country experience with respect to disability and development. This would constitute a fairly substantial project, but could be undertaken on a collaborative basis.

There are several areas in which new research should be carried out. The issue of disability and older people is becoming a matter of major concern in many developing countries as the demographic structure changes. Projects related to this issue, would be a priority. There is evidence to suggest that in developing countries many children with impairments die young or are ignored. We need to know much more about such children and their early lives. Finally, the relationship between disability and poverty requires more systematic investigation on a comparative basis across countries.

## **CONCLUSION**

This paper emphasises the need to recognise the importance of disability as a development issue, as a social issue, and as an issue closely linked to the stated priorities of the major international and bilateral development agencies and NGOs.

Technology generates outcomes and products which could be liberating and empowering for disabled people, but, like both 'disability' and 'poverty', it needs to be seen as essentially a social process, capable of generating negative as well as positive outcomes as far as disabled people are concerned.

More research is needed to identify examples of best practice as regards developing appropriate technology for disabled people. Access to technologies, which reduce barriers to inclusion and participation (not only assistive or specifically 'healthcare' technologies) should be seen as a basic human right.

Disability should be mainstreamed in the policies, programmes, projects and daily practice of development agencies and consideration given to the development of appropriate technologies as one component of a strategy for disability and development.

Development agencies, like DFID, need to recognise the importance of disability at all levels, and develop an appropriate institutional response, including the introduction of disability equality training and a greater degree of decentralisation in terms of policy and practice, given the importance of the specific social context of disability.

Each country development strategy should include a section on disability and development, as an integral part of their overall vision for the development of the country concerned; and country level staff should also receive disability equality training.

DFID and other development agencies should promote a twin-track approach to disability, as has been done with gender. All development initiatives or projects should be able to demonstrate that they are truly inclusive of disabled people.

Significant additional funds should be made available to support disability-specific initiatives.

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## **ACKNOWLEDGEMENT**

This paper is based on a Report produced by a team of specialists engaged by the Overseas Development Group at the University of East Anglia, in response to terms of reference drawn up by Healthlink World-wide and GIC Ltd., based on a concept note produced by the British Department for International Development (DFID). Other contributors included Ken Cole, Roger Cozens, Victoria Daines, Ray Lang and Indumathi Rao.

### **CROSS-LINGUISTIC STUDY OF ACQUIRED READING DISORDERS IMPLICATIONS FOR READING MODELS, DISORDERS, ACQUISITION AND TEACHING**

Author: Prathibha Karanth

The study of acquired reading disorders has served as a touchstone of research on language and the brain. Researchers believe that an in-depth analysis of reading disorders could lead to comprehensive models of the representation of reading skills and its subcomponents in the human brain. Significantly, in the past decade, there has been an increase in the research on learning to read and write and on the factors affecting reading within broader cross-linguistic and cross-cultural perspectives.

This volume focuses on cross-linguistic studies of the acquired disorders of reading and what they can tell us about the models of reading and the human brain. The author has compiled a source-book on cross-linguistic studies of reading disorders with data from the alphasyllabaries of India, in addition to showing the implications of these findings on the understanding of reading, its acquisition, and the developmental and acquired reading disorders and their management.

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## **POSITIVE PERCEPTIONS IN PARENTS OF CHILDREN WITH DISABILITIES**

Ashum Gupta,\* Nidhi Singhal \*\*

### **ABSTRACT**

*A lot has been written about the stressors in the lives of parents of children with disabilities. Studies have been done to understand the types, causes and the effects of these stresses. Most often, only the negative aspects of this situation are highlighted. The work is primarily addressed towards understanding and measuring the negative attitude and adverse consequences of having a child with disabilities. This article examines the existing research done on this aspect. However, the article takes a step forward and focuses on the cognitive processes as a result of experiencing a traumatic event. The authors move away from the negative outcomes and highlight the process of developing positive perceptions in these parents. The focus is on the process of coping that generates positive perceptions and the ways that these positive perceptions are used as an effective coping strategy.*

### **INTRODUCTION**

It has been well documented that the parents of children with disabilities experience chronic stress. The recent research evidence has evaluated the types, degree and determinants of the stress faced by the families in caring for their disabled members (1, 2, 3). The literature is uniform in reporting that families do experience high levels of stress. It is also noted that having a child with disabilities affects not only the parents, but also siblings and the relationships among the family members (4).

The nature of stress has been shown to span over several aspects of family life such as daily care demands, emotional distress (e.g., maternal depression), interpersonal difficulties (e.g., parental discord), financial problems and adverse social consequences (e.g., social isolation). Stress experienced by the families is influenced by child specific variables like age, sex and severity of the problem; socio-demographic variables such as social class, family income and domicile; and family coping resources and strategies like acceptance of the child's diagnosis and perception of stigma associated with the disorder (5). Additional stress is also created due to marital conflicts associated with rearing the handicapped child, extra financial burdens to obtain the necessary services, and fatigue and loss of leisure time due to care-taking responsibilities (6).

Added to these is the extent of behaviour problems exhibited by children and adults with disabilities. Not only do child characteristics influence parental stress levels, but negative reactions from others can also serve as a source of stress for the families (7). Parenting a child with a disability increases stress in the areas of everyday management of disruptive behaviours, heavy caregiving responsibilities, and concerns about the future of the child when the parents are no longer able to care for him or her.

### **PARENTAL ATTITUDE TOWARDS THEIR CHILD WITH DISABILITIES**

An enormous amount of research has been done to explore the stressors associated with caring for a disabled child and the deleterious effects these stressors have on parents' well-being. There is research evidence that the family attitude contributes to the prognosis. Family stresses associated with limited financial resources, lack of appropriate services, and insufficient support systems are examples of family system risk factors that can contribute to poor prognosis (8). Environmental risk factors such as lack of services and negative attitudes can also have an adverse influence on the prognosis of the child with disability.

Existing studies reveal that very often the parents have a negative attitude towards their child with disabilities. The parents are plagued with feelings of pessimism, hostility, and shame (9). Denial, projection of blame, guilt, grief, withdrawal, rejection, and acceptance are the usual parental reactions (10). Some parents also experience helplessness, feelings of inadequacy, anger, shock and guilt whereas others go through periods of disbelief, depression, and self-blame. The siblings also experience feelings of guilt, shame, and embarrassment (11).

In India, disability is still viewed in terms of a "tragedy" with a "better dead than disabled" approach, the idea being that it is not possible for disabled people to be happy or enjoy a good quality of life. Cultural beliefs about disability play an important role in determining the way in which the family perceives disability and the kind of measures it takes for prevention, treatment and rehabilitation (12). Studies report that parental expectations from their disabled child were mostly negative and unrealistic. Dalal and Pande (13) investigated cultural beliefs and attitudes of a rural Indian community towards physical disability. The results revealed fatalistic attitudes and external dependence in families with disabled children. In India, there is a very strong belief in the metaphysical causation. Also, most of the respondents felt that the disabled member in their family could not do anything and just needed help and sympathy.

One such instance is the belief in the theory of karma, which is often invoked to explain major life events, including the occurrence of disability. It has also been shown that people tend to accept their own disability as something which has resulted from their past karma or due to God's will and thus often show low motivation to overcome the limitations (14). A

belief that prevails very strongly is the perception of disability as a punishment for past karmas. Any form of disability is looked upon as a curse that has been bestowed upon the family to atone for the sins committed by the person or the family members in their previous lifetimes. In stark contrast, it is the duty of the “non-disabled” to give away food, money, and clothes in charity to the disabled, as a religious responsibility to attain moksha, the ultimate liberation (15).

Studies reveal that this negative attitude adversely affects the parents. Family members of children with disabilities are often perceived to experience harmful psychological effects (16). These extreme stress levels heighten negative health outcomes like depression and marital dissatisfaction (17). Parents are found with unstable emotionality, constant grief, psychological ill health, and unsatisfactory social health. Studies have found them to be at a higher risk for marital discord and social isolation. The commonest psychiatric disorder that was found is dysthymia followed by generalized anxiety disorder and moderate depression (18). It is also found that the parents of children with disabilities perceive more problems in themselves and their family.

The majority of literature has highlighted the stresses and the subsequent negative consequences in caring for a child with a disability. The primary focus in this literature seems to be on stress, strain, grieving, and other negative issues. In fact, researchers have even proposed that when a child is diagnosed as having a severe disability, the parents may experience similar cognitive processes to those individuals who have experienced a traumatic event (19). Although many researchers have found that the families of children with disabilities report more stress than do other families, recent research shows that there is no clear evidence that they also report fewer positive feelings or perceptions. In fact, data are suggestive of no differences or even reports of more positive perceptions in families of children with disabilities.

### **COPING THAT GENERATES POSITIVE PERCEPTIONS**

There is evidence in the recent research that has shown that stress need not be an inevitable consequence in a family with a child with a disability. Mullins (20) presented themes arising from a content analysis of 60 books written by parents of children with a variety of disabilities. He identified significant demands and emotional stress, but the majority of the authors also felt that their lives had increased meaning and enrichment as a result of their experience with their children. In a similar analysis of fathers’ published accounts, Hornby (21) noted stressful experiences and negative feelings but also strong positive feelings and claims of personal growth. Furthermore, it has been found that relatives who have been studied less intensively by researchers, such as siblings and grandparents, anecdotally reported positive views about their relative with a disability.

The functional role that positive emotions serve in the context of stressful events was considered by Lazarus, Kanner, and Folkman (22). They hypothesized that under stressful conditions, when negative emotions are predominant, positive emotions may provide a psychological break or respite, support continued coping efforts, and replenish resources that have been depleted by the stress. Positive perceptions could be viewed as a factor ameliorating the impact of a child's disability on family members. Essentially, positive perceptions are different outcomes to stress and other negative experiences but they occur in concert with the negative or stressful experiences. Positive affect might help to bolster psychological and physical resources during stress, act as a buffer against the adverse physiological consequences of stress and help to protect against clinical depression (23).

Existing individual and family focused theories suggest that positive perceptions play a central role in the coping process. It has been proposed that positive perceptions may assist us to cope better with the traumatic and stressful events (24). Cognitive adaptation model of responses to threatening events posits that we attempt to adapt to threatening events by searching for meaning, trying to gain mastery, and enhancing the self. A key mechanism by which this adaptation is achieved is termed as cognitive illusions (24, 25). When these illusions are challenged, different perceptions will be generated in order to maintain meaning, mastery, and/or the self-system. Setting achievable goals and engaging in problem-focused coping in order to achieve them, leads to feeling of control and mastery.

Problem-focused coping refers to efforts directed at solving or managing the problem that is causing distress. It includes strategies for gathering information, making decisions, planning, and resolving conflicts. It also includes efforts directed at acquiring resources (e.g., skills, tools and knowledge) to help deal with the underlying problem, and instrumental, situation-specific, task oriented actions (26). In a stressful situation, it is possible to identify goals and experience efficacy, mastery, and control even in situations that appear uncontrollable and even worsening. However, this often requires relinquishing previous goals that are no longer tenable and turning to new, realistic goals (27).

Under stressful conditions, individuals may bring about, note or remember ordinary events and in fact often infuse ordinary events with positive meaning (28). It may be that when a negative event occurs, the individual creates a positive event or interprets an otherwise ordinary event as positive as a way of offsetting the unpleasant affective consequences of the negative event. Hobfoll (29) commented that people are often keyed to respond to the adverse sequelae of loss by turning their attention to their resources and looking for positive aspects of their lives.

A further coping approach is that of positive reappraisal – cognitive strategies for reframing a situation in order to see it in a more positive light (23). Positive reappraisal enables the

individual to appraise a difficult situation more positively. It often involves deeply held values that are activated by the stressful situation. This kind of coping encourages people to focus on the value of their efforts and is especially important in helping people sustain efforts, such as those associated with caregiving, over long periods of time.

Coping basically involves creating, reinstating, or reinforcing meaning in the midst of stress. This aspect has long been implicated in the appraisal of stress (30) where it helps determine the personal significance of a stressful situation in relation to the individual's beliefs, goals, values, or commitments. This appraised or situational meaning shapes the emotions that the person experiences in the stressful encounter. This is in contrast with the global meaning which refers to a more abstract, generalized meaning related to people's fundamental assumptions, beliefs, and expectations about the world and the self in the world (31).

Because stress by definition is something that an individual cannot contend with through his or her usual means of coping, a traumatic event may actually force an individual to choose a different strategy for resolving a crisis. Dabrowski's (as cited in Hague) (32) psychological model of positive disintegration suggests that once psychological development reaches equilibrium, any further development occurs very gradually. Before rapid development and significant change can occur, disintegration of that equilibrium must take place. Moreover, he suggests that only a life crisis or a major challenge results in that disintegration.

In her study, Janoff-Bulman (33) also maintains that it usually takes an event of traumatic proportions to serve as a catalyst for any positive transformation. Furthermore, she asserts that since this change is largely a result of the interpretation or appraisal of the event rather than the event itself, it can occur simultaneously with the event or even a long time afterward. Palus (34) concurs that such changes are the precipitators of self-growth. This generally happens in two phases: initial disequilibrium and reorganization, i.e., the characteristic way of "doing things" is interrupted, and is substituted by a new and a superior way of acting.

Recent focus has also been on the factors that differentiate families who adapt successfully to the birth of a child with disabilities. It is important to study the impact of a disability on the coping effectiveness of the family unit and extend the concept of positive perceptions as a coping mechanism at the level of the family. The focus here is on family as an interacting system. Meichenbaum and Fitzpatrick (35) affirm that recovery from a traumatic event is predicated on the ability of an individual or a family to adapt in a manner that restores faith in the goodness and inherent value of self and of life. This is accomplished through the construction of narratives, or stories, by the individual or family unit that enables them to interpret the stressful life event in a positive way.

McCubbin and Patterson (36) discovered that some families might adapt well to raising a child with developmental disabilities; a state called “bonadaptation”. Patterson’s family adjustment and adaptation response model (37, 38) is focused on the processes by which families restore the balance between demands and capabilities and minimize their experience of stress. Thus, parents might attend to the positive and emphasize growth and development of the self and the family unit while minimizing limitations of the child and problems caused for the family. A further concept is that of a family schema. A positive outlook may also be a part of such a schema: the shared beliefs, meanings, and values that a family develops in order to coordinate their interaction patterns and consequently, cope or adapt to their situation.

This notion of family schema has also been discussed in the resiliency model of family stress adjustment and adaptation (39). Family schemas within this model are hypothesized to help maintain family stability. They are also the filters through which all experiences, including the appraisal of potential stressors, are evaluated. Having positively focused schemas assists families to maintain a more general positive view of events and, thereby, cope or adapt to challenges. Dunn (40) studied children’s close relationships and suggested that a family’s response to this type of stress influenced the siblings’ perception of the situation. If parents react positively to their child with special need, then the sibling relationship tends to be more positive. If the parents took an optimistic and caring view, then the sibling was more likely to do the same. Thus the parent’s ability to accept their child’s difficulties influences the ways in which a family functions.

There is research evidence that the families benefit when instead of totally depending on external agencies for rehabilitation, parents take charge of the situation and educate and train themselves. Basu and Deb (41) observed significant improvement in the behavior, study habits and prosocial behavior of children with Attention Deficit Hyperactivity Disorder (ADHD) as a result of training parents of children with ADHD. Similarly, in their study Bhan, Mehta and Chhaproo (42) found that irrespective of the economic status of families with a child with cerebral palsy, intervening factors like mother’s personality, optimism, and religious support were found to alleviate the degree of stress. Positive attitude, social support and faith in God helped mothers generate psychic energy to cope with the physical, emotional, and financial aspects of care giving.

Poyadue (43) maintains that there is a stage of adaptation that is beyond acceptance that might be called “appreciation” or the “all right” stage. Parents at this stage may be a resource to families facing difficulties. One effective way of doing this could be through parent support groups. In their study, Singer et al. (44) found that parents involved in a parent-to-parent support group reported an increase in their positive perceptions of their

child with a disability. In effect, one of the key factors of success was a positive outlook on the part of supporting parents. It is imperative that the families adopt a constructive approach of sharing to promote self-confidence and urge for self-reliance to the maximum. In another study, Russell, John and Lakshmanan (45) examined the efficacy of interactive group psycho-education on measures of parental attitude toward intellectual disability. Results indicated a significant clinical improvement in the attitude of parents, their orientation towards child rearing, knowledge of intellectual disability and the attitude towards management of intellectual disability.

### **POSITIVE PERCEPTIONS: AN ADAPTIVE COPING STRATEGY**

It has been shown that positive emotions promote creativity and flexibility in the process of thinking and problem solving (46). Positive affect also facilitates the processing of important, relevant information even if that information is negative and may potentially damage self-esteem (47). Another route through which feeling positive may offset the deleterious physiological effects of stress is through the neuroendocrine system.

The possibility that positive feelings may prevent adverse physiological effects of stress is reinforced by findings that positive and negative affects are associated with different neural structures (48). Studies indicate that the women's positive affect, as a result of meaning-based coping in response to traumatic events, may have made them more physiologically resilient in the face of subsequent stress and may have protected them from the maladaptive neural, endocrine, and immune responses to chronic stress that can lead to diseases (49).

A number of studies have examined positive outcomes of stressful events. Even though the events themselves may not have had favourable resolutions, outcomes include the perception of benefit from the stressful encounters (50), the acquisition of new coping skills and resources (51), the perception of growth related to their stress (52), and the spiritual or religious transformation that results from the stressful experiences (53).

Scorgie et al. (54) did a qualitative analysis of the mechanisms that led parents to achieve positive transformations in their perceptions of their child with a disability. This analysis revealed that parents arrived at a more positive state through three processes: (1) the need to form new identities, (2) attempts to derive meaning from the situation, and (3) the development of a sense of personal control. Many parents find meaning through acquiring new roles like parent – group leaders, conference speakers, or members of advisory councils for schools, hospitals or agencies representing people with disabilities.

Some other parents have focused on acquiring new traits like becoming more compassionate and less self-focused, learning they could achieve rather than remain powerless, developing endurance or greater personal strength in the midst of their feelings of weakness, progressing from depression to being able to view life as worthwhile and of value, and facing life with new boldness rather than capitulating to fear. Though not being able to ‘grin’ and be ‘happy’ overall in life, they were however, able to cultivate a sense of humor and increase the ‘happy times’ in life (55). Some parents have also reported loss of friendships as a result of having a child with disabilities but also cited other parents of children with disabilities, personnel from agencies serving people with disabilities, and caring health professionals as primary members of their new friendship networks. They intimated that they might not have had relationships with such a depth if they had not had a child with a disability.

One of the acquired traits rated highest by the parents was the ability to speak out on behalf of their children. Though for some it is a long and difficult learning process, it stemmed largely from their desire to protect and support their child with disabilities. This was often done to fight against the discrimination and difficulties associated with accessing equal services. Parents have reported the exhilaration of knowing that through advocacy they have “made a difference” in someone else’s life. While there have been reports of disintegration of marriage with the diagnosis of a disability, some parents have also reported that their marriage had emerged stronger as a result of parenting a child with disabilities, citing that the need to find solutions to complex situations and work together as a team required them to improve their communication skills and reinforce their marriage (55).

Research has also been done to understand the themes of positive perceptions. Behr, Murphy, and Summers (56) used exploratory factor analysis to study more than 1200 families and identified nine positive factors: (1) a source of happiness and love, (2) a contribution to family strength, (3) a stimulus for personal growth and development, (4) a source of pride and contribution, (5) a path to learning and contribution, (6) a key to understanding life’s purpose, (8) a guide to understanding future issues, and (9) a stimulus for career growth.

In a review of published research on positive perceptions of families with children with development disabilities, Hastings and Taunt (57) compared themes, items and factors in various research studies and found some key themes about the nature and structure of parents’ positive perceptions and experiences of their child with a disability and the caregiving experience. These can be summarized as: (1) pleasure/satisfaction in providing care for the child, (2) child as a source of joy/happiness, (3) sense of accomplishment in having done one’s best for the child, (4) sharing love with the child, (5) child providing a challenge or opportunity to learn and develop, (6) strengthened family and/or marriage, (7) giving a

new or increased sense of purpose in life, (8) development of new skills, abilities, or new career opportunities, (9) becoming a better person (more compassionate, less selfish, more tolerant), (10) increased personal strength or confidence, (11) expanded social and community networks, (12) increased spirituality, (13) changed perspective on life (e.g., clarified what is important in life, more aware of the future), and (14) making the most of each day and living life at a slower pace.

## **CONCLUSIONS AND IMPLICATIONS**

The identification of a disability in a child most often comes as a shock. Changes in home routines, vocational life, and relationships with family and professionals are typically required. Basic life assumptions are challenged. The stage may therefore be set for changes to occur. The need of the hour becomes disintegration or abandonment of one's previous life in favor of a new and clearly, a better way of living. These positive indicators do not mean that parents are naïve about, or are blind to the difficulties they face or are in the state of denial. These studies are, but an indication of how the families have been able to successfully weave their lives around the successes in their lives, versus the sorrows in every day living. They have been able to find a meaning in their life by reframing their original appraisal to emphasize on the positive outcomes, such as their abilities to reach out to others in need.

There is ample evidence that parents of children with disabilities do go through prolonged periods of stress than do parents with typically developing children. Like any other child, the family and environmental systems also affect a child with disabilities. A negative attitude towards disability from the family members, relatives, friends and/or the society, not only impacts the child directly, but also adds on to the existing stress levels of the family. Lack of public awareness about the potential of disabled people, often acts as a barrier to their acceptance and participation of the disabled. Awareness raising activities need to be particularly focused upon and formation of self-advocacy groups, which is still at the initial stage, needs to be hastened (58). Mainstreaming disability typically requires a supportive environment and social participation to reduce negative ideas associated with anxiety, insecurity, depression as also education, counseling, and vocational training to develop the capabilities of the individuals.

Though it cannot be disputed that parents of disabled children face a great deal of stress, it is now important to move away from describing these stressors and their adverse effects. Instead, research should now focus on exploring the ways that such families cope with varying degrees of success. Several studies have been done which recognize that many families have been successful in developing positive perceptions regarding raising a child with disabilities. Recent studies have consistently reported that families with a child with disabilities can and in fact do have positive perceptions which leads to better quality of life

for the family, and scope for maximizing the child's potential. Though precipitated by a specific event, formation of positive perceptions is usually a process, which can occur simultaneously or a longtime after the event.

Existing research suggests that positive perceptions play a central role in the coping process and assist us in dealing with the traumatic and stressful events. Not only do they benefit the parents and the siblings in coping with the child, the disability, and the difficulties associated with it; but it also helps the family unit as a whole. The way in which a family functions, is influenced by the parent's perception of their child's difficulties.

This leads to three main implications. Firstly, given this framework, the situation calls out for more extensive exploration. Research on this aspect is virtually missing in the Indian context and thus more studies should be carried out exploring the positive adaptations of parents. It is rather important to understand the conditions that facilitate these positive changes in the perceptions. Also, the focus should move towards collecting longitudinal data. If a research explores only the early reactions to a child with disability, the families could still be recovering from the shock of the diagnosis. Investigators who have examined families at later points in time have frequently concluded that parents are better characterized by commitment rather than sorrow.

This is accompanied with the second implication. It is imperative to look at the tools being used, and whether they provide space and opportunity to give positive responses. If we do not ask positive questions, we would rarely get a positive answer. Chances are that a positively framed question will encourage a positive response from the family. Helff and Glidden (59) analyzed publication trends in research on adjustment in families of children with disabilities from 1970s to 1990s. They suggest that though negativity in published research has decreased over time, however, there has been no increase in positivity over the same period. Criticism has been given regarding structuring of the research, where no space is provided to include positive feelings of parents with a child with disability. They state that investigators still assume primarily negative versus positive assumptions and hypothesis in their research endeavors, which are not likely to yield any positive answers.

Finally, helping families develop a positive outlook might be the serving point of intervention by the clinicians themselves. Although, the research in this area is limited as yet, there is a possibility of developing practical interventions to help families to adapt. Most often the intervention is done at the level of the child and addressing the disability per se. Therapists might want to concentrate on this aspect and facilitate families' coping processes by encouraging and supporting positive outlook on self and life. This can be executed through the course of family therapy, marital therapy, or individual counseling. A very effective way would be moderating self-help or support groups for parents with children with

disabilities. Parents with positive perceptions can help the other parents in the early stages of adjustment develop positive but realistic expectations.

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**KEY ISSUES AT GLOBAL AND REGIONAL LEVELS  
IN THE PROCESS TOWARDS THE INTERNATIONAL CONVENTION  
ON RIGHTS OF PERSONS WITH DISABILITIES**

Kozue Kay Nagata\*

**ABSTRACT**

*This paper is a review of the background and issues related to the decision by the international community to draft a new human rights convention for people with disabilities, at the 2<sup>nd</sup> session of the Ad Hoc Committee on an international convention to protect and promote the rights and dignity of persons with disabilities, held at New York in June 2003. It also includes a discussion on the recent initiatives taken by United Nations Economic and Social Commission for Asia and Pacific (ESCAP) at the regional level. The paper attempts to provide a link between recommendations and a new regional policy for action by governments and concerned stakeholders entitled 'The Biwako Millennium Framework for Action towards Inclusive, Barrier-free, and Rights-based Society for Persons with Disabilities in the Asia and Pacific Region (BMF)'. It introduces policies and priorities of the Bangkok draft that was adopted by ESCAP regional workshop for 'Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities' (Bangkok, 2003).*

**INTRODUCTION**

A historical momentum is being witnessed this year in the global disability movement because of the following reasons. Firstly, the new Asia and Pacific Decade of Disabled Persons (2003-2013) has been initiated. Secondly, the international community after 15 years of efforts has taken a decision about drafting a 'Convention text' on rights of persons with disabilities and commissioned a 'Working Group'. Lastly, the Arab Region, under the auspices of the League of Arab States, will declare the 'Arab Decade of Disabled Persons' (2003-2012) at the end of this year. It follows the 'Asian and Pacific Decade' and the 'African Decade of Disabled Persons' (2000-2009).

**WORLD PROGRAMME OF ACTION CONCERNING DISABLED PERSONS**

The proclamation by United Nations General Assembly of the 'United Nations Decade of Disabled Persons' between 1983-1992 provided a time frame to implement the objectives of

'World Programme of Action' concerning disabled persons. Three main objectives of the Programme of Action were prevention, rehabilitation and equalisation of opportunities. This programme defined 'equality of persons with disabilities' as provision of equal opportunities. Equality is a dynamic concept that often develops in accordance with overall social development. Equalisation of opportunities is the process of promoting accessibility for people with disabilities to the systems in the society. The most fundamental element of accessibility is to promote full participation of persons with disabilities in decision-making. This that can be achieved by promoting self-help groups of persons with disabilities who can then lobby and influence governmental policies that affect their life.

### **DISABILITY PERSPECTIVE ON DEVELOPMENT AND HUMAN RIGHTS**

The World Programme of Action provides the basis for a disability perspective to be integrated into development, in contrast with the earlier charitable approach towards persons with disabilities and the medical model with an emphasis on medical treatment and rehabilitation. The World Programme of Action represents a movement towards a human rights and development perspective. Equality is the fundamental concern of the Programme of Action and is strongly reflected in its objective of equalisation of opportunities. The Programme of Action does not see persons with disabilities as vulnerable, but as development agents for positive change. It directs special attention to social and environmental factors, that hamper progress in equalisation of opportunities including accessibility. When the World Programme of Action was formulated, protection of rights of persons with disabilities included relevant sections from 'Universal Declaration of Human Rights' and 'International Covenant on Human Rights', namely the 'International Covenant on Economic, Social and Cultural Rights' and the 'International Covenant on Civil and Political Rights'.

Parallel to this development, in June 1983, the ILO General Conference passed a sectoral convention on employment promotion (Convention No. 159 of the Vocational Rehabilitation and Employment of Disabled Persons) that came into force on 20 June 1985. It has been ratified by 68 ILO member states. This sectoral convention aims to ensure that vocational rehabilitation measures are made available to all categories of disabled persons and employment opportunities are promoted for disabled persons in the labour market. Based on the work of United Nations Educational, Scientific and Cultural Organisation (UNESCO), the Salamanca Statement and Framework for Action on Special Needs Education, was adopted by the World Conference on Special Needs Education: Access and Quality. This statement urges that governments adopt inclusive education as a policy or a law. Its framework for action defines special education needs as needs arising from disabilities or learning

difficulties and recommends that schools accommodate all children with child-centred and individual pedagogical methods.

## **HISTORY OF EVENTS LEADING TO THE NEW INTERNATIONAL CONVENTION**

The first recommendation to elaborate on the rights of persons with disabilities was submitted at an international expert group meeting, held at Stockholm in August 1987. The meeting reviewed and evaluated the progress, achievements and barriers in implementing the World Programme of Action at the mid-point of the United Nations Decade of Disabled Persons (1983-2002). It then recommended that the General Assembly convene a special meeting on rights of persons with disabilities with the mandate to draft an international convention on elimination of all forms of discrimination against disabled persons and to protect their human rights. It was later ratified by its member states by the end of the Decade.

Both the 42<sup>nd</sup> session in 1987 and the 44<sup>th</sup> session in 1989 of the General Assembly had a draft text of convention of human rights of persons with disabilities that were submitted for consideration. But a majority of member states suggested that further studies and information gathering were needed before they were considered. However, in the light of the expert group's recommendations and the views expressed by non-governmental organisations and governments, the General Assembly decided that the 2<sup>nd</sup> half of the Decade should emphasise equalisation of opportunity as a major concern.

Simultaneously intergovernmental action on promoting equalisation of opportunities was considered in the 1990 session of Economic and Social Council of the United Nations. Thus, in May 1990, United Nations Commission of Social Development initiated work on standard technical rules on equalisation of opportunities for disabled persons. Effort to elaborate the rules was funded by voluntary contribution and included technical teams from all regions. These efforts resulted in the General Assembly resolution 48/96 on 20th December 1993, titled 'Standard Rules of the Equalisation of Opportunities for Persons with Disabilities (Standard Rules)', a UN document which ensures rights of persons with disabilities. While not legally binding, the Standard Rules incorporate human rights and reflect strong moral commitment of member states to achieve equalisation of opportunities for persons with disabilities. The 22 rules provide normative guidelines for policy-making and formulating a national policy. The Standard Rules have 4 chapters that include preconditions for equal participation, target areas for equal participation, implementing measures and monitoring mechanisms.

The monitoring mechanism is among the most radical aspects of the Standard Rules. Monitoring aims to ensure effective implementation of the rules. Monitoring also identifies

barriers and obstacles against successful implementation of Rules. Mr. Bengt Lindqvist (the special rapporteur appointed by the Secretary General of UN in March 1994) in his monitoring reports marked the need for a more focussed human rights perspective in the context of the Standard Rules, and directed greater attention to issues related to children with disabilities, gender and housing. He presented his views on options to complement the Standard Rules further with attention on human rights of persons with disabilities. A major development during his mandate was the decision of General Assembly in the resolution, 56/168 of 19 December 2001, to establish an Ad Hoc Committee to consider a comprehensive international convention to promote and protect rights and dignity of persons with disabilities. The report of the special rapporteur also noted that the process towards a convention might take several years and hence it was important to develop the disability dimension with regard to human rights of disabled persons within the existing United Nations human rights monitoring systems.

During the 56<sup>th</sup> session of the General Assembly in 2001, Vicente Fox Quesada, President of Mexico, presented a proposal to initiate a comprehensive and integral convention on the rights of persons with disabilities. The Mexico draft called for the international community to combat poverty and social exclusion of people with disabilities. He reaffirmed the interest of Mexico to lead the process and as a result the government of Mexico hosted an international expert group meeting at Mexico City in 2002. The Mexico Draft containing elements of the convention was then submitted at the first session of Ad Hoc Committee on 'Comprehensive and Integral Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities' in New York in July - August 2002. The first session of Ad Hoc Committee considered the Mexico draft and position papers for the convention submitted by China and the European Union. The outcome of the first session of the Committee was another General Assembly resolution 57/229 adopted by the 57<sup>th</sup> session of the General Assembly in 2002. The General Assembly resolution 57/229 provided guidance for further elaboration of a comprehensive convention at all levels. It invited all regional commissions of United Nations, such as ESCAP and ESCWA, and intergovernmental organisations such as Organisation of African Unity, or the League of Arab States, as well as non-governmental organisations and other stakeholders, to present suggestions and papers to the Ad Hoc Committee to be considered during the convention.

At the regional level, governments, ESCAP and non-governmental organisations worked together to implement the 'Agenda for Action' for the 'Asian and Pacific Decade of Disabled Persons' from 1993 to 2002. Through its resolution 58/4 of 22 May 2002, entitled 'Promoting an Inclusive, Barrier-free and Rights-based Society for People with Disabilities in the Asian and Pacific Region in the Twenty-first Century' the Commission extended the 'Asian and Pacific Decade' to 2003-2012. The Decade's action-oriented guidelines for ESCAP Member States, 'The Biwako Millennium Framework for Action towards Inclusive, Barrier-free and

Rights-based Society for Persons with Disabilities in Asia and the Pacific (BMF) urged governments in the ESCAP region to support and contribute to the work of the Ad Hoc Committee. In pursuance of the United Nations General Assembly resolutions and the regional mandate, ESCAP organised an expert group meeting in June 2003 to discuss the 'International Convention to Protect and Promote the Rights and Dignity of Persons with Disabilities'. The meeting's outcome was the 'Bangkok Recommendations', a comprehensive set of recommendations on the proposed convention. The 'Bangkok Recommendations' were presented at the second session of the Ad Hoc Committee, which was held at New York in June 2003.

During the 2<sup>nd</sup> session, the Ad Hoc Committee agreed to elaborate on the convention on disability and to establish a working group composed of 27 selected governments, 12 non-governmental organisations and 1 national human rights commission. This working group would prepare a draft for the convention to be the basis of negotiations at the next session of Ad Hoc Committee in 2004. Seven governmental positions were allocated to the Asian block excluding Australia and New Zealand that were included in other blocks. To date, 7 governments (China, India, Japan, Lebanon, Republic of Korea, Philippines and Thailand) had self-nominated for membership of the working group and were approved. From the Asian Block, two women representatives were nominated and approved for membership of the working group (Ms. Anuradha Mohit, Human Rights Commission, India and Ms. Venus Ilagan, President, Disabled Peoples International). Both attended the ESCAP regional workshop on 'Women and disability: Promoting full participation of women with disabilities in the process of elaboration on an international convention to promote and protect the rights and dignity of persons with disabilities', at Bangkok in August 2003. As gender was among the key issues in the Bangkok Recommendations, a group of women experts, most of whom were disabled, critically evaluated the recommendations from a gender perspective and developed a 'Statement of Recommendations'. This 'Statement of Recommendation' was used as a background paper along with the 'Bangkok Recommendations' during the regional expert group workshop in October 2003.

The regional expert group was held in order to formulate a full text version of the convention for people with disabilities, based on the Bangkok Recommendations. The draft text will be submitted to the working group to be held early next year, with copies forwarded to the United Nations Department of Economic and Social Affairs (UNDESA) and the Special Rapporteur on Disability. The draft of the convention is a well-formulated complete text, ready to be used by any government in the Asian and Pacific region with their own revisions if necessary. It is one of the few complete text versions of the draft convention like the Mexico draft. Already the Government of the Philippines has fully endorsed both the Bangkok Recommendations and the Bangkok Draft, instead of elaborating its own national version. The Bangkok draft was formulated by a group of regional experts on disability issues and

international human right lawyers. Representatives from all 7 countries of the working group participated in the process, as well as representatives of most of the region's major non-governmental organisations. A set of general recommendations about the principles of the Bangkok Draft will be submitted together with the Draft to the Working Group commissioned by the Ad Hoc Committee for their consideration. A full text of this Draft is available at <http://www.worldenable.net/bangkok2003/>

Furthermore the Bangkok Draft was critically evaluated and commented upon, by the forum of governmental delegates in Beijing in November 2003. This regional seminar on 'International Convention on Disability' was co-organised by ESCAP and the China Disabled People's Federation (CDPF) with financial support by the Chinese Government. This seminar invited governmental opinions on disability from the Asian and Pacific region, increased public awareness on the process towards the Convention, evaluated, commented on and supported the draft Convention text prepared by the October 2003 expert group from Bangkok. Over a dozen of governmental participants from the Asian and Pacific region attended it and developed a joint political statement entitled the 'Beijing Declaration' for expressing a collective determination and willingness to support the process towards the Convention. Non-governmental organisations and other civil society members also participated in the Seminar as observers.

About 50 participants from 22 countries and territories of the Asian and Pacific region attended it and adopted a joint Policy-oriented statement entitled "Beijing Declaration on the Elaboration of and iNternational Convention to Promote and protect the Rights and Dignity of Persons with Disabilities" for expressing a collective determination and willingness to support the process towards the Convention. NGOs and other civil society members also participated in the Seminar as observes. The Beijing Declaration will be submitted together with the Bangkok Draft to the Ad Hoc Committee and the Working Group

#### **ELEMENTS OF THE BANGKOK DRAFT**

The elements of draft convention include a preamble, basis of the convention and special articles. It highlights issues and priorities to be included in the Convention. Unlike existing human rights instruments, such as 'Convention on the Elimination of All Forms of Discrimination against Women' and 'Convention on the Rights of the Child', the proposed Convention involves populations defined based on disability. Unlike gender and age, disability has to be defined to identify who is disabled and who are to be covered under the convention. The Bangkok Draft adopted the conceptual framework of WHO's International Classification of Functioning, Disability and Health, that was endorsed by World Health Assembly in March 2002. In the International Classification of Functioning, Disability and Health, 'disability' is an umbrella term for an impairment of body's structure or function, limitation of activities or

restriction in participation. Disability is conceived as a dynamic interaction between health conditions and environmental and personal factors. The Bangkok Draft adopted more or less this concept.

The structure of the Bangkok Draft is very holistic covering all kinds of rights that are to be enjoyed by persons with disabilities, including civil and political rights, and socio-economic and cultural rights, as well as the principle of non-discrimination and equality. The structure of the draft is composed of a preamble, statement of objectives and general principles, scope/definitions, general obligations of the state, such as guarantee for equality and non-discrimination, guarantee of specific rights, other state obligations, monitoring mechanisms and miscellaneous provisions.

The main principles of Bangkok Draft are:

- the Convention should build on human rights laid down in the existing UN human rights treaties;
- Human Rights are universal, inter-related and inter-dependent and fully apply to people with disabilities;
- Pro-active state obligations to take legislative and administrative measures to ensure equality;
- The role of international cooperation in implementation of the Convention;
- Independent community living the inclusive services (e.g. inclusive education, etc)

The Bangkok Draft defines discrimination in all forms including direct, intended and unintended, hidden and systemic discrimination. Equality of opportunities was defined as freedom from any relevant restrictions or any limitations caused directly and indirectly by a disability, and include appropriate modifications, adjustments, or assistance, including affirmative actions, reasonable accommodations or special measures to provide barrier free access. The Draft also includes provision for full participation of people with disabilities in monitoring mechanisms, at international and national level.

#### **LINK BETWEEN THE CONVENTION AND BIWAKO MILLENNIUM FRAMEWORK**

As mentioned before, the 'Biwako Millennium Framework' was adopted as a set of policy guidelines for implementation of the new Asian and Pacific Decade of Disable Persons (2003-2012). It is a rights-based approach to disability issues in this region. In paragraph 53, it mentions that civil, cultural, economic, political and social rights of persons with disabilities

should be addressed and protected. In the same paragraph, it recommends that governments should support and contribute to the work of Ad Hoc Committee and they should include persons with disabilities and their organisations at the national, regional and international levels, for drafting and adopting the Convention. It is hoped that passing the Convention will ensure a strong consumer-influenced monitoring mechanism on the rights and responsibilities of persons with disabilities. By ratifying the Convention, governments are to adopt national laws and policies and review existing laws to protect the rights of person with disabilities, to ensure non-discrimination. Persons with disabilities will have equal access to their rights under such national laws or under the International Convention itself. Currently, more than 40 countries globally have adopted non-discrimination laws on disability, but only 9 countries in Asia and Pacific region have done so.

#### **AFRICAN DECADE OF DISABLED PERSONS (2000-2009) AND ARAB DECADE OF DISABLED PERSONS (2003-2012): SOUTH-SOUTH DIALOGUE**

The African Decade of Disabled People was an initiative of non-governmental organisations of Africa, in co-operation with governments and 'Organisation of African Unity'(OAU), now the 'African Union'. In a way, it replicates the practice of the first Asian and Pacific Decade of Disabled Persons, with the purpose of furthering the equalisation of opportunities of persons with disabilities. The period 2000-2009 was formally proclaimed the African Decade of Disabled Persons at the 72<sup>nd</sup> session of the OAU 'Council of Ministers' and at the 36<sup>th</sup> session of 'Assembly of the Heads of States' respectively, held in Lome, in June 2002. The goal of the decade is promoting awareness and commitment to full participation, equality and empowerment of persons with disabilities in Africa. Following the proclamation of the Decade, responsibility for organising the Decade was handed to the African Rehabilitation Institute (ARI) in Harare, in collaboration with the non-governmental Pan African Federation of Disabled Persons, the African Union of the Blind, and other regional entities of persons with disabilities.

The question of proclaiming the period 2003-2012 as the Arab Decade of Disabled Persons was first seriously considered at a meeting hosted by ESCWA in Beirut in October 2002, though the history of this Decade dates back to almost 10 years like the International Convention. A conference on 'Towards an Arab Decade of Disabled People' was co-organised by ESCWA and the League of Arab States, in collaboration with the government of Lebanon, Arab Organisation of Disabled People and other non-governmental organisations concerned with disability. More than 200 people attended the conference, including officials from 18 Arab countries. Plenary and workshop sessions identified recommendations that were unanimously adopted later at the closing session. They will be presented to the League of Arab States and

the Arab Ministers of Social Affairs for adoption and proclamation at the Arab Summit. It is envisaged that the Decade will be launched from the end of 2003 or early 2004.

As these parallel events indicate, a historical momentum is now evident in developing countries. It is also reflected in the fact that there was unanimous support to the Convention during this year. For the first time it also included a lot of support from many member states from less developed regions. As the process towards the Convention requires a consensus at global level, this kind of 'South-South' dialogue and collaboration will become more important for generating a unified stance. At the UN level, ESCAP and ESCWA are working together closely. Just prior to the ESCAP expert group meeting on the Convention in June 2003, a similar meeting was organised by ESCWA in May 2003 at Beirut and views from different regions were exchanged.

This review suggests that elaboration of an international convention on rights and dignity of persons can facilitate development of policy for people with disabilities in the context of national policies and existing laws and regulations. The process towards the Convention itself will contribute to boosting public awareness in line with proclamation of regional Decades, empower people with disabilities and enhance South-South dialogue among stakeholders. One is entering the new decade at regional and global level with a historical momentum. It is imperative for all to use this occasion to promote further advancement of persons with disabilities and create a truly barrier-free and rights based society for all people with and without disabilities at regional and global levels.

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## CHALLENGES IN LEPROSY REHABILITATION

Maya Thomas\*, M.J. Thomas\*\*

### ABSTRACT

*'Multiple drug Therapy' (MDT) has transformed the outcome of leprosy in people affected by it. Leprosy affected persons develop much less disfiguring disabilities after use of MDT. As a result leprosy services are now becoming integrated into general health services. When this integration becomes stronger, leprosy rehabilitation is also likely to adopt methods followed by general health services. Vertical, stand-alone services, based on single aetiology like leprosy, will require some adaptation to fit in with the environment of general health services. The authors speculate that changes in leprosy rehabilitation could make 'community based rehabilitation' (CBR) an important method for the vast majority of leprosy patients who need rehabilitation. This paper discusses some of the concerns regarding the suitability of CBR for leprosy rehabilitation.*

### INTRODUCTION

With the use of 'Multiple Drug Therapy' (MDT), leprosy affected persons now develop less disfiguring disabilities compared to a decade earlier (1) and as a result, stigma attached to leprosy has diminished considerably. In the past, leprosy was viewed as a severely stigmatising condition that progressively devalued and marginalised the affected persons; finally to culminate in segregation, away from homes and society in colonies of similarly deformed people. During this process not only did society devalue them, but they also rated themselves lower on the value chain.

The scenario is different today. The integration of leprosy services into general health services has initiated a transformation in leprosy rehabilitation from being a vertical, stand-alone service, based on a single etiological factor, to an integrated service along with other general health services (2). As the process of integration has picked up pace of late, leprosy rehabilitation has started using strategies adopted by other health services, such as 'Community Based Rehabilitation' (CBR). The recent changes in management of leprosy have also led to changes in rehabilitation and its philosophy. It has changed from a medical model where prevention and reversal of deformities were the prime focus of interventions, to a psychosocial model with emphasis on integration, economic rehabilitation, and access to services and human rights. Interventions in leprosy rehabilitation have shifted beyond traditional prevention, treatment and surgical reconstruction to others such as community based rehabilitation, socio-

economic rehabilitation and formation of self-help groups for affected persons and families. Thus, leprosy rehabilitation has refocused its emphasis from a purely 'client-centred programme' to a 'client and community centred programme' (3).

### **CHANGING SCENARIO OF LEPROSY REHABILITATION**

Even though the strategies in leprosy rehabilitation have been modified to suit the present situation for sometime now, it is still unclear as to who needs rehabilitation and which services are best suited for different groups of patients (4). In an analysis of studies on leprosy, Srinivasan reported that 21% to 45% of all persons affected by the disease deteriorated economically. A high proportion of this group had deformities. Yet, not all persons with deformities deteriorated economically. Conversely, some persons without deformities also deteriorated economically. The dilemma is to identify 'who amongst leprosy affected persons need community level rehabilitation to address the economic and other psychosocial impact of the illness'. Are they persons with deformities? Or are they leprosy affected persons with some other parameters that are not yet identified? Likewise, it is yet unclear what kind of rehabilitation is most acceptable to leprosy affected people. For example, only a very small number of people with deformities are finally fit and willing for reconstruction surgeries. Similarly, a substantial number of economically deteriorated leprosy affected people show no interest in seeking available rehabilitation schemes. Objective evidence pertaining to acceptance and appropriateness of rehabilitation services in leprosy is scanty and is an area of concern.

The transition of leprosy rehabilitation from medical to psychosocial and from institutional to community based processes require certain changes in governance. Traditionally, health care institutions used a 'top-down' approach in service delivery and governance. In some cases the systems became so autocratic that 'needs' of clients were ignored and they never became empowered to choose their goals. In contrast, 'community based organisations' do not have highly differentiated structures or systems of communication that are imposed on clients. They use a 'bottom-up' approach that allows client participation in strategy development. The major difference between institutions and community-based organisations is that institutions discouraged people from accessing services if they disagreed with the institutional goals. In community-based organisations any such differences are settled through a change in programme plan to make it more client-centred. Leprosy rehabilitation until recently was more institutional and top-down. However of late, some programmes have become 'bottom-up' in approach, and as a result have started using 'participatory needs analysis', 'participatory decision making' and so on. These are approaches that are quite different from what these institutions were used to earlier.

## **COMMUNITY BASED REHABILITATION AND LEPROSY**

Among the strategies adopted for rehabilitation, 'community based rehabilitation' (CBR) is of special interest for leprosy because general health services in many countries have already adopted this strategy as a viable alternative to reach disabled persons from rural areas. Planners can no longer ignore the strategic importance of this method that has evolved over the past two and a half decades (5,6). Over the years, there have been many changes in the way CBR is conceptualised and implemented. The major changes have been the transition from an individual orientated focus to a community orientated one, and from the medical model to the social one. It has now moved away from being merely a form of 'therapy in community' to an approach that promotes community participation and ownership of programmes. The emphasis is on equal access to disabled people to all services that are accessible to others in the community. More recently equal opportunities, protection of rights, advocacy and formation of self-help groups have also become major areas of interest for CBR. The goals of CBR are now widened to include enhancement of activities of daily life; creation of awareness, achievement of barrier free environment, attainment of human rights; and a context where community can participate and assimilate the process of their development.

Now that CBR has become a community development process, the debate whether it should be initiated by outsiders or started by the community has been of interest. Votaries of the former view advocate starting delivery of services without waiting for the community to participate. Because community ownership, where people take responsibility for planning, implementing, monitoring and risk sharing, is a slow process. The alternate view is that concerned groups themselves should initiate CBR because it is a developmental process. If CBR is externally initiated, communities can remain passive and do not develop capacity to manage their own affairs. 'Community participation' is the central and essential tenet in the social model. However, communities are often quite heterogeneous, with wide differences in socio-economic, educational, religious and ethnic status. This diversity can cause friction, because some groups have different needs and priorities compared to others. Similarly, needs and priorities of people with disabilities are not always at the forefront when competing issues occur simultaneously. People in some developing countries also expect benefits from their governments as doles, and as a result show a reluctance to take charge of their affairs. Decentralisation and 'bottom-up' strategies become difficult to implement in these circumstances.

The emphasis in CBR today is on integrating disability into the development processes. Votaries of integration conclude that it is cost-effective, promotes better social integration and ensures access to people with disabilities as much as others in the community. Besides, community participation is greater when the majority rather than only a minority share its

benefits. At the same time, unplanned integration of disability into development can ignore 'real rehabilitation' needs of people with disabilities and segregate them further. During the last few years, integration of disability into community development programmes have shown some tangible benefits and some problems. Poor organisational capacity to integrate two functionally different streams of interventions and lack of familiarity with rehabilitation on the part of community development organisations, have acted as major barriers for integration. Lack of mobility, education and other skills also prevent disabled people from being part of the broader development process. In addition, people with disabilities expect doles and are poorly motivated to assume responsibilities. Integration of rehabilitation into development programmes needs a high degree of co-ordination and collaboration between different sectors such as health, education, employment and others. Barriers in this process have to be removed before such collaboration can succeed and make the social model of CBR effective.

CBR was promoted to gain wider coverage at affordable costs. In order to reduce costs many interventions were shifted to families of disabled persons and community. Although CBR appears to be cheaper, in reality much of the costs are transferred to the consumers. If the consumers' costs are also included in computing the expenditure, it may turn out to be much higher than what is generally assumed. Many families in developing countries do not have the means to support their disabled members. In an environment of increasing difficulty to access resources, these families are more likely to choose their 'normal' members to support than their disabled relatives.

About 30% of people with disabilities in CBR have severe and multiple disabilities. Sometimes severely disabled persons get neglected while CBR focuses on issues such as 'community participation' and equal 'rights'. When they are neglected, programmes tend to gloss over their shortcomings as a 'limitation of CBR'. Women with disabilities are another group whose needs are not adequately addressed. They face unique disadvantages simultaneously, such as difficulties in performing traditional gender roles, participating in community life, and accessing rehabilitation services provided by male service providers.

The problems of community volunteers illustrate how difficult it is to translate a theme like 'community participation' into practice. Volunteers are difficult to find, their turnover is high, large resources are required to train them continuously, they lack motivation and do not perform if incentives or small salaries are not paid. However, there are programmes that have successfully used volunteers, though they are the exceptions.

## **CONCLUSION**

'Community based rehabilitation' evokes different perceptions in different people. Many feel that it is the only hope for the majority of people with disabilities in developing countries.

Others see CBR as a process of development with ill-defined boundaries. Some feel that CBR would disappear after a while. If one ponders for a moment on alternatives to CBR for people with disabilities, including people affected by leprosy in poor countries, it would be clear that it is difficult to ignore the role of CBR in leprosy rehabilitation.

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**ORIGINAL ARTICLES**

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**THE DIAGNOSTIC TEST OF READING DISORDERS (DTRD)**

Dharmishta H. Mehta\*, Smriti Swarup

**ABSTRACT**

*The Diagnostic Test of Reading Disorders (DTRD) has been designed to identify deficits in the sub-processes leading to a reading failure in children. The sub-processes identified in the DTRD, cover areas in phonemic skills and linguistic skills, through its eight items. The DTRD is clinical - prescriptive in nature, whereby the child's performance in the test forms a base for intervention.*

*The DTRD has been standardised based upon on a sample of 1100 children, between the ages of 8-11 yrs. The mean age of the subjects was 9 yrs. and 2 months. The data was collected from English Medium schools in Mumbai, as well as the Assessment Unit of the Centre of Special Education, SNDT Women's University, Mumbai. The reliability and the validity of the test, has been determined using appropriate statistical techniques.*

**INTRODUCTION**

For every child, reading has many connotations. It is the key to success in school, in the development of interests outside school, to the enjoyment of leisure time, and to personal and social adjustment. It helps the child in adjusting to others in the same age group, to become independent of parents and teachers, to select and prepare for an occupation and to achieve social responsibilities (1). Aldous Huxley pointed out 'every man who knows how to read has it in his power to magnify himself, to multiply the ways in which he exists, to make his life full, significant and interesting'. In the modern school, effective reading is the most important avenue to effective learning. Difficulty with reading is, by far, the most common characteristic of a student with learning disabilities. It is estimated that 90% of all children identified as learning disabled, are referred for special education services because of reading problems (2).

**THE READING PROCESS**

"Reading can be compared to the performance of a symphony orchestra" (3). Reading is a holistic act. Even though reading is sometimes characterised by specific skills such as discriminating letters, identifying words, and understanding specific vocabulary; performing

the sub-skills one at a time, does not constitute reading. Reading can take place only as an integrated performance. Therefore, deficits in any of these sub-skills will affect the reading efficiency.

Reading is meaning-based. It entails the active construction of meanings, and requires the reader to be strategic, and interact with the text. Reading is a language learning that is socially mediated.

In order to read, a person must acquire a number of basic perceptual linguistic skills.

- The ability to focus attention, to concentrate and follow directions
- The ability to understand and interpret spoken language in daily life
- Auditory memory and sequencing
- Visual memory and sequencing
- Decoding and word attack
- Structural-contextual analysis of language
- Logical synthesis and interpretation of language
- Vocabulary development and expansion
- Fluency in scanning and referencing

Children with LD experience serious difficulties with learning even in basic skills such as reading, writing and doing math, despite having normal intelligence.

They also manifest problems in listening, reasoning, perception, memory, selecting, and focusing attention on relevant information. These perceptual and cognitive deficits, assumed to be the underlying causes for reading and writing problems, have provided the basis for the development of the Diagnostic Test of Reading Disorders (DTRD). Children experiencing reading difficulties consistently are said to have dyslexia and no, one causal factor seems to explain all cases of dyslexia. Therefore it is imperative to diagnose the cause of the reading disorder for which the Diagnostic Test of Reading Disorder has been developed. This Diagnostic test uses a "Clinical Inferential" approach against the 'statistical approach', in the diagnosis of a dyslexic. The general cognitive hypothesis of both the approaches, hold that distinct patterns of reading and spelling reflect the weakness and strengths of broadly defined cognitive processes, auditory and visual perception and memory in particular. In a language class, initially the child "learns to read", then "reads to learn". Children having deficits in the learning process will find difficulty in "reading to learn" and comprehend text.

Recent research suggests that children with severe reading disabilities, particularly those who are resistant to intervention effective for the majority of struggling readers, may also have process deficits, besides the deficits in phonological awareness (4).

### **THE RATIONALE FOR DTRD**

In the DTRD, the authors have focused on those processes which will assess the child (from 8-11 years) for fluency and accuracy, the two major aspects of reading. The test identifies and diagnoses the process deficits that cause disorders in both fluency and accuracy.

The DTRD aims at measuring the following process through its eight items.

### **ITEMS**

#### Level-1

- I) Sound-symbol Association (SSA)
- II) Blending of Sounds.(BS)
- III) Phonic Analysis (PA)
- IV) Visual Conditioning (VC)
- V) Semantic Closure (SC)
- VI) Lexical Processing (LP)
- VII) Language Internalization (LI)
- VIII) Copy Writing (CW)

#### Level-II

- I) Grapheme Phoneme Association (GPA)
- II) Verbal Phonetic coding (VPC).
- III) Phonemic Synthesis (PS).
- IV) Verbal Visual Correspondence (VVC).
- V) Verbal Memory (VM).
- VI) Listening Comprehension (LC).

VII) Reading Comprehension-ALoud (RCA).

VIII) Reading Comprehension Silent (RCS).

## **STANDARDISATION OF THE TEST**

### **Sample**

DTRD Level-I and Level-II was standardised on a sample of 1100 school-going boys and girls in the age range of 8-11 years. The mean age was 9 years and 2 months. The data was collected from schools in Mumbai and the Assessment Unit of the Centre of Special Education of SNDT Women's University, where children coming from various parts of India are assessed for reading problems, besides other learning problems.

For Pilot testing, an equivalent sample of 278 (boys and girls) was selected from 4 schools in Mumbai, which are not included in the final sample.

### **Procedure**

#### **a) Item : Preparation and Selection**

All the sub-processes required for proficient reading were identified and the items were prepared to measure each of the sub-processes. In the first draft of the test, the number of sub-items was double the number of sub-items in the final test. This was done to avoid repeating preliminary data collection for selection of the items. After preparation of the final test, it was given to 10 experts working in the field, to judge from appropriateness of the content of the items to the sub-processes to be measured. On the basis of their comments, the items were modified and deleted when necessary, from the test. The second draft of the test was administered on a smaller sample of 20 children, in the age range of 8-11 years.

On the basis of observation of the children's task behaviour, the items and instructions were further modified.

The selected items were subjected to Pilot Testing:

#### **b) Item : Try-out/ Pilot Testing**

After item selection the second draft of the test was used for pilot testing. 278 boys and girls in the age range of 8-11 years from standard III and IV were selected for pilot testing. A close observation was made with regard to the children's understanding of the instruction task etc. All kinds of ambiguity were recorded and later removed from the items. Items which did not seem to discriminate between the good and the poor performers and ambiguous items, were deleted after the pilot testing.

**c) Final Testing**

After pilot testing and modification of the second draft, a final draft of the test was administered on the combined sample of 1100 boys and girls. The data thus collected on the sample, was used for determining reliability and validity of the test.

**d) Reliability of DTRD**

The Reliability coefficient was computed using the Test-Retest Reliability method. The test was administrated twice with a time gap of 20 days. The reliability coefficient for each time was computed by correlating the scores obtained by the students, on the two administrations. The reliability co-efficient and reliability index for the test (Level-I and Level-II) are presented in the following table.

**Reliability Co-efficient of DTRD**

**Level-I**

**Table 1.**

Item	I	II	III	IV	V	VI	VII	VIII	Total
Sub-Areas	SSA	BS	PA	VC	SC	LP	LI	CW	N=550
Test-Retest Reliability Co-efficient	.68	.76	.81	.61	.72	.61	.58	.62	.71
Reliability Index	.81	.86	.84	.77	.89	.75	.83	.76	.81

**Level-II**

**Table 2.**

Item	I	II	III	IV	V	VI	VII	VIII	Total
Sub-Areas	GPA	VPC	PS	VVC	VM	LC	RC(A)	RC(S)	N=550
Test-Retest Reliability Co-efficient	.78	.62	.68	.72	.71	.73	.64	.70	.70
Reliability Index	.71	.89	.73	.84	.88	.75	.88	.79	.78

**e) Validity of DTRD**

The validity of the test items was established by applying the procedures of item analysis. Item analysis determined the discriminatory power of each item with regard to delineation of students with, and without reading disorder.

**f) Item Analysis**

Item analysis was done to find out the internal consistency of the test, which would lead to the diagnosis of the reading disorders. Biserial co-efficient of correlation were calculated between the top 27% and the bottom 27% of the scores on each item. The difficulty index was calculated by averaging the percentage of the two extreme groups. The validity index and the difficulty index for each item were calculated. The rbis ranged from .20 to .57 for Level-I and .21 to .36 Level-II. The difficulty index ranged from .48 to .64 for Level-I and .55 to .70 for Level-II.

Cross validation of the items was done on another parallel sample of children with reading problems Level-I (N=146) and Level-II (N=126).

The biserial co-efficient of correlation thus obtained ranged from .24 to .53 for Level-I and .19 to .46 for Level-II.

**Table 3.**

Difficulty - Index (DI) and Validity - Index (VI) of the test items of DTRD :

**Level-I**

Item No.	Sub-Test	DI	VI
1	SSA	.82	.20
2	BS	.56	.37
3	PA	.58	.42
4	VC	.48	.20
5	SC	.64	.57
6	LP	.50	.33
7	LI	.52	.20
8	CW	.58	.25

**Level-II**

Item No.	Sub-Test	DI	VI
1	GPA	.55	.21
2	VPC	.68	.23
3	PS	.70	.36
4	VVC	.63	.22
5	VM	.68	.23
6	LC	.55	.25
7	RC(A)	.58	.33
8	RC(S)	.64	.21

*Items having validity index below .20 were not included in the test.*

**g) Quality - Control Procedure**

To eliminate the effects of the tester's bias, the authors of the DTRD personally administered the test on the children, scored and analysed the data. To maintain consistency in administration, the instructions were read out from the booklet to the subjects. Care was taken to make the subjects feel comfortable before and during the testing.

**DISCUSSION**

Scot and Clinton (5) state that reading is a "psycho-linguistic" process. According to them, the reader relies on three types of information to read adequately - a) the graphic information b) the semantic information and c) syntactic information. The authors of DTRD through its eight items (Level I and Level II) have sought to assess the child in each of these types of information.

Phonemic awareness is believed to be critical to any success in reading. It has been observed that most children diagnosed as dyslexics have performed poorly on items measuring the phonemic process. The ability to segment and synthesise sounds, are tested through items on phonemic awareness. A lack of familiarity with the sounds of the language and the way they are represented in its alphabetic code, cause children to fail in developing any reading skills and create severe problems in learning how to spell as well. This explains, why a lot of these children were unable to reads words like "baby" or "nation" or even non words like "sool" or "jugar".

Reading is a skill superimposed on a well developed language (6), and so, a sound language base is imperative for adequate reading. This is because reading is not just the deciphering of the sound symbols, but is meaning based too. It is language proficiency that makes possible

the comprehension of matter that is read. A child must somehow assimilate the complex rules governing the language system embodying the underlying linguistic structures for assessing meaning from print. This is why a subgroup of poor readers were unable to read or comprehend sentences like, "Tie your tie and untie it again" and "Prakash puts pen and pencil in his pocket". Poor performance was also observed in the test of Language Internalization (Level 1, No. VII). Many felt that the sentences needed no blanks to be filled, and when filled, it was generally incorrect.

The authors of the DTRD have identified two sub groups emerging amongst the Dyslexics. One with adequate oral language skills, where reading failure has been attributed to purely perceptual process, and where children perform reasonably well on tasks involving listening comprehension. The other sub group exhibited deficiencies in both, the perceptual process, as well as the process involving the development of language skills. Poor language skills interfere with comprehension, for they fail to provide the necessary background, so necessary for adequate comprehension (7). Children, especially in cities in India, learn through English which is the medium of instruction, and most often this is not the child's mother tongue. Bilingualism, another characteristics feature of the Indian educational system, also aggravates the problems for dyslexics in India. A sub group of dyslexics in the country, are faced with a dual problem - one dealing with perceptual problem and the other dealing with the language aspect. Because of Bilingualism the problems in semantics, syntax, monophology and pragmatics, all get doubly complex. (8). This test has been standardised on the bilingual population of children.

## **CONCLUSION**

The DTRD aims at pin pointing the deficient areas responsible for the child's reading failure. The analysis of the child's performance on the DTRD would result in forming the base for effective remediation. It has been the observation of the authors of the DTRD, that 80% of children with Dyslexia need remediation in both perceptual as well as language areas.

A highly motivating environment with enriched language and structured reading programmes would serve to remediate, circumvent problems in reading for the dyslexics and even prevent a reading failure in one "at risk", if early and intensive remediation is resorted to.

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The Spastics Society of India's National Resource Centre for Inclusion and the Centre for International Child Health, London offer a 12 week certificate course entitled "Community Initiatives in Inclusive Education" (CIIE) for master trainers and planners of community services in the Asia Pacific Region. The course commencing on the 9th of February 2004 is supported by the Women's Council, UK who are willing to fund the tuition and stay of deserving women candidates. Interested individuals as well as organization who wish to propose a woman candidate may contact Dr. Sharmila Donde, Coordinator CIIE at [sharmiladonde@hotmail.com](mailto:sharmiladonde@hotmail.com).

**A SURVEY OF KNOWLEDGE AND OPINION ON RIGHTS  
IMMUNITIES AND PRIVILEGES FOR PERSONS  
WITH MENTAL RETARDATION**

S. Venkatesan\*

**ABSTRACT**

*The present study was undertaken to develop and standardise a questionnaire for assessment of contemporary knowledge and opinion on rights, immunities and privileges of person with mental retardation. A sample of 150 respondents, including parents, rehabilitation professionals and medical practitioners were administered a fifty item questionnaire exclusively developed for this purpose. The results of the study indicate that most respondents have been able to correctly answer only half of the items in the questionnaire-an indication of the serious need for stepping up awareness and sensitisation programmes for rehabilitation professionals themselves. These findings are consistent across variables like education, occupation and sex of the respondents. Item analysis was carried out to delineate specific trends in positive attitudes, misinformation or misconceptions of respondents. The available interpretative norms for this standardised tool will be of use in attitude change programmes being undertaken by service agencies for persons with disabilities or their caregivers and professionals in the country.*

**INTRODUCTION**

There are various schemes and programmes for disabled persons that have been sponsored by central/state governments and union territories in India. They cater to the complex educational, vocational and living requirements of persons with disabilities (1,2,3,4). The available data reflect that only 5-10 per cent of children with disabilities in the age group of 6-14 years actually avail some kind of benefits from government sponsored measures (5). In general, most consumers, caregivers, parents, medical practitioners and even rehabilitation professionals are unaware of the facilities, benefits, schemes or programmes initiated by the government.

**AIMS OF THE STUDY**

The study aimed to:

- (i) to develop and standardise a questionnaire for assessment of the prevailing knowledge and opinions on rights, immunities and privileges for persons with mental retardation;

- (ii) to administer the questionnaire on a representative sample of parents/caregivers, medical practitioners and rehabilitation professionals, to survey their knowledge and opinions on rights, immunities and privileges for persons with mental retardation; and,
- (iii) to determine the influence of related variables like sex, educational qualifications, occupation, etc., in formation of their knowledge and opinions on rights, immunities and privileges for persons with mental retardation.

## **METHOD**

The study was conducted on a total sample of 150 respondents, including parents (N: 25) of children with handicaps, rehabilitation professionals (N: 53) and medical practitioners (N: 72). The rehabilitation professionals included psychologists, special educators, social workers, speech therapists and audiologists. The medical practitioners were doctors manning Primary Health Centres across Karnataka, who were deputed for the National Programme on Orientation of Medical Officers Working in Primary Health Centres on Disability Management, sponsored by the Rehabilitation Council of India and conducted periodically at All India Institute of Speech and Hearing, Ministry of Health and Family Welfare, Government of India, Mysore. The sample included 86 male respondents and 64 female respondents with a mean age of 28.81 (SD: 6.91). Among the respondents were postgraduates (N:67), graduates (N: 37) and undergraduates (N:46).

The procedure of data collection involved the use of a fifty item "Knowledge and Opinion Questionnaire On Rights, Immunities and Privileges of Persons with Mental Retardation" (KNOQ\_RIP\_MR), prepared exclusively for the purpose of this study. The questionnaire comprised of 50 questions related to government policies, programmes, schemes and rights of persons with disabilities; and items on concessions, benefits and privileges of persons with mental retardation in India. The questions were randomly distributed to avoid any purposeful classification of the items. Each item in the questionnaire was to be responded either as: "Right", "Wrong" or "Don't Know".

The correctness of responses for individual items in KNOQ\_RIP\_MR was considered as the basis for giving appropriate weight scores either as zero or one point. The correct answers were given one point and incorrect, or "don't know" responses were given zero points respectively. A high score on the questionnaire indicated better knowledge and positive attitude, while a low score meant poor knowledge and negative attitudes of respondents on rights, immunities and privileges of persons with mental retardation. The maximum possible numerical score on this questionnaire for a given respondent is 50. Data were collected, compiled and computed for descriptive and interpretative statistical inferences by using SPSS/PC Version 3.0 (6, 7).

## RESULTS AND DISCUSSION

For the overall sample (N: 150), it is seen that respondents maintain an almost average knowledge-attitude towards rights, immunities and privileges available for persons with mental retardation (Mean: 24.32; SD: 7.24). On an average, male respondents show a single point difference in their scores (N: 86; Mean 24.80; SD: 7.02) as compared to female respondents in this sample (N: 64; Mean: 23.67; SD: 7.54); even though these differences are not statistically significant ( $p > 0.05$ ; NS)(Table One). The finding that most respondents in this study have been able to correctly answer only half the items in the questionnaire, indicates a serious need for stepping up awareness/sensitisation programmes for rehabilitation professionals themselves. Professional service providers are lacking in knowledge-awareness on contemporary rights, immunities and privileges for persons with mental retardation, which therefore calls for an urgent update in optimising rehabilitation services for persons with disabilities in the country.

**Table 1. Distribution of Mean & SD scores on KNOQ\_RIP\_MR.**

SlNo.	Items	N	Mean	SD	Probability
1.	<b>Overall:</b>	150	24.32	7.24	
2.	<b>Sex:</b>				
	(a) Males	86	24.80	7.02	t: 0.952
	(b) Females	64	23.67	7.54	p: > 0.05 (NS)
3.	<b>Education:</b>				
	(a) Undergraduates	46	21.67	5.67	t: 1.954
	(b) Graduates	37	24.64	7.00	p: > 0.05 (NS)
	(c) Graduates	37	24.64	7.00	t: 0.0354
	(d) Postgraduates	67	24.32	7.24	p: > 0.05 (NS)
	(e) Undergraduates	46	21.67	5.67	t: 0.3171
	(f) Postgraduates	67	24.32	7.24	p: > 0.05 (NS)
4.	<b>Occupation:</b>				
	(a) Medical Practitioners	72	24.81	7.42	t: 0.252
	(b) Rehabilitation Professionals	53	25.16	6.65	p: > 0.05 (NS)
	(c) Rehabilitation Professionals	53	25.16	6.65	t: 0.528
	(d) Parents/Caregivers	25	24.32	6.64	p: > 0.05 (NS)
	(e) Medical Practitioners	72	24.81	7.42	t: 0.295
	(f) Parents/Caregivers	25	24.32	6.64	p: > 0.05 (NS)

{\*p: <0.05 (S);\*\*p: <0.01(HS); \*\*\*p: <0.001(VHS)}

### Relationship with various variables

With regard to education variable, respondents with post-graduation and above, (N: 67; Mean: 24.32; SD: 7.24) do not seem to differ significantly from graduates (N: 37; Mean: 24.64; SD: 7.00) and/or undergraduates (N: 67; Mean: 21.67; SD: 5.67) ( $p > 0.05$ ; NS). The influence of respondent-occupation in determining the favorable/unfavorable knowledge-attitude towards contemporary social-legal status of individuals with mental retardation does not also show any significant differences between medical practitioners (N: 72; Mean: 24.81; SD: 7.42), rehabilitation professionals (N: 53; Mean: 25.16; SD: 6.65) and parents/caregivers (N: 25; Mean: 24.32; SD: 6.64) respectively ( $p > 0.05$ ; NS).

### Item Analysis

An item wise analysis of respondent scores on KNOQ\_RIP\_MR was carried out by calculating the weighted ranks of correct answers (Table Two). This was done by a simple calculation involving conversion of the number of correct respondents to single digit ratio. For example, if there were 104 correct respondents for item one out of the 150 respondents, the item's weighted rank would measure 0.69. The analysis of weighted ranks (Mean: 0.49; SD: 0.192) for all the items in the questionnaire closely approximates the measure of central tendency for the whole sample. Some of the questionnaire items with low weighted ranks that reveal negative opinion-attitude valence, includes their belief that school fees for children with mental retardation should be higher than those of normal children, since special teachers put in extra efforts in teaching them (Item #14; WR: 0.11). They believe that a heavy dose of tranquilisers can be given to mentally retarded children for controlling their disruptive

**Table 2. Item wise analysis of scores on KNOQ\_RIP\_MR .**

SI No.	Item/s	WR
1.	MR persons have similar rights/privileges as normal human beings.	0.69
2.	MR child is eligible to receive same life saving remedies at birth or later, like other children.	0.88
3.	MR infants cannot be put up for adoption like other normal babies in our country	0.25
4.	MR children cannot claim educational entitlement for same number of years like other normal children	0.38
5.	MR adult is also qualified and permitted to stand/vote in general elections	0.35
6.	MR person is eligible to receive the same help and protection from the police like other normal persons	0.93

**Table 2. Item wise analysis of scores on KNOQ\_RIP\_MR . (Cont'd).**

Sl No.	Item/s	WR
7.	MR person is considered incapable of realistically comprehending his rights and responsibilities despite advising as in case of normal citizens.	0.57
8.	When a MR person is charged with a crime, he must be presumed innocent unless proven otherwise.	0.80
9.	Not all MR persons are permitted to use all public utilities like playgrounds, buses, hotels, banks, etc., at all times.	0.39
10.	There is no agency to oversee and assure the enforcement of all basic rights of persons with MR in our country	0.28
11.	Overdose of tranquilizers can be given to MR individuals for controlling their disruptive behaviors.	0.15
12.	When a MR person is hospitalized, obviously, he cannot claim the same quality of attention, comfort, privileges of having visitors, etc., like other patients.	0.17
13.	The informed consent of a MR person is not required before any proposed hospital treatment programme.	0.51
14.	The school fees for children with MR can be kept higher than normal children as anyway teachers have to put up with extra effort for teaching them.	0.11
15.	The MR worker could be paid lower than his non-retarded peers since his production/quality of work is likely to be inferior or lower	0.19
16.	The Government has provided for some economic allowances like pension, invalidity allowance, etc., from taxpayers' money to parents of MR children.	0.66
17.	MR persons can be segregated from their families by placing them in institutions, residential homes, etc	0.43
18.	There are still no laws in our country to ensure that MR persons make use of same recreational/leisure time facilities like swimming pools, play clubs, etc., along with his non-disabled peers.	0.48
19.	There is legal provision to house natural homes and foster homes of MR persons in places away from residential areas .	0.33

**Table 2. Item wise analysis of scores on KNOQ\_RIP\_MR . (Cont'd).**

SI No.	Item/s	WR
20.	There are still no laws to ensure "barrier-free" environment/architecture for public utility buildings visited by persons with MR in our country	0.46
21.	There is, at present, no law to guarantee guardianship rights for MR persons, especially when they are abandoned, orphans or destitute	0.39
22.	There are, still, no legally authorized government agencies to intervene on behalf of MR persons when their welfare is threatened	0.39
23.	There are no laws to prevent exhibition or exposure of MR persons to visitations by members of public or press under circumstances, which could be considered inappropriate in a regular institution.	0.38
24.	There are no laws that prohibit depiction of MR persons as comic figures in films/mass media with an intention of entertainment or ridicule.	0.43
25.	Marriage with MR spouse is declared null and void since they do not anyway understand their attendant duties and responsibilities	0.49
26.	MR persons enjoy 75 % concession along with an escort for rail travel by train	0.66
27.	MR persons are allowed 50 % concession for travel by air in domestic flights.	0.53
28.	Concessions are allowed up to an extent of 50% for travel by road in KSRTC buses for persons with MR and their single escort	0.57
29.	Government of Karnataka grants MR persons owning motorised vehicles exemption from road tax.	0.27
30	There is also a scheme to refund up to 50 % of expenditure incurred by MR owners of motorized vehicles on purchase of petrol/diesel from recognized dealers subject to certain ceiling limits.	0.16
31	There is a scheme to reimburse conveyance allowance for employees of Central Government incurred on their MR children subject to certain maximum limits	0.55
32	There is provision for preferential allotment of Public telephone booths for persons with MR	0.55
33	Excise duty exemption has been given to equipment imported/purchased for requirement of MR persons subject to certification from competent authority	0.49

**Table 2. Item wise analysis of scores on KNOQ\_RIP\_MR . (Cont'd).**

SI No.	Item/s	WR
34.	There is a scheme for providing scholarships to a tune of Rs.100/- per month for lower income groups of persons with mental retardation in Karnataka.	0.71
35.	Under the scheme for "Integrated Education for Disabled", uniform allowance of Rs.50/- per annum has is permitted for MR children attending schools.	0.62
36.	Under Section 80 DD of Income Tax Act, deduction of Rs.40, 000/- is allowed in addition to standard deduction for income tax assesses having children with moderate-profound MR.	0.51
37.	Parents can claim preferential allotment of house sites through Urban Development Authorities in the name of their MR children	0.38
38.	Central Government employees having children with MR can secure preference in their place of posting subject to consideration on humanitarian grounds	0.61
39.	There is provision for special leave subject to a maximum of two weeks per annum for Central Government employees having children with MR in order to facilitate them to seek medical assistance for their wards	0.41
40.	A MR person is ineligible to secure a driving license	0.55
41.	MR persons have an opportunity to participate in a "Special Olympics" held at National/International Levels	0.75
42.	MR persons have an opportunity to participate in a "Special Arts" held at National/International Levels	0.81
43.	Just as there is a "National Health Policy" (1982), "National Policy on Education" (1986), there is as yet, no "National Policy on Disability Rehabilitation" in India.	0.41
44.	The Government has established Special Employment Exchanges across the country through which MR persons can register to seek employment in government/public sector undertakings	0.42
45.	One per cent jobs are reserved in government/public sector undertakings for each category for physically, visually, hearing & MR persons respectively	0.79

**Table 2. Item wise analysis of scores on KNOQ\_RIP\_MR . (Cont'd).**

SI No.	Item/s	WR
46.	Repayable-low interest loans are available for cooperatives of MR adults through a scheme introduced by National Handicapped Finance & Development Corporation	0.59
47.	A recently introduced scheme provides for free distribution of anti-convulsion medication to persons suffering from epilepsy along with mental retardation	0.53
48.	According to a government scheme to promote voluntary action for persons with disabilities, registered societies/charitable companies/trusts can seek grant supports up to an extent of 90 % for starting or continuing services for MR persons.	0.47
49.	MR person is eligible to receive life long pension under Central Employees Pension Scheme (1995) even after the death of his/her parents in or out of service	0.55
50.	The Department of Posts (India) has a scheme to subsidise on postal charges incurred for letters/materials in or for the service of persons with MR	0.30

**(WR: Weighted Ranks)**

behaviours (Item #11; WR: 0.15). They share a negative opinion that when a mentally retarded person is hospitalised, he cannot claim the same quality of attention, comfort or privileges of having visitors like other patients (Item #12; WR: 0.17). Other negative attitudes indicate that mentally retarded workers could be paid lower wages than their non-retarded peers, since their production/quality of work is likely to be lower or inferior (Item #15; WR: 0.19).

A majority of respondents are misinformed in believing that there is scheme for a refund of 50 % on the purchase of diesel/petrol by mentally retarded owners of motorised vehicles. (Item #30; WR: 0.18). They presume that mentally retarded babies cannot be put up for adoption like other normal babies in India. (Item #3; WR: 0.25). It is also seen that a majority of the respondents in this study are unaware of the Office of Commissioner of Disabilities in the country, under whose purview all the basic rights of persons with mental retardation are safeguarded or guaranteed (Item #10; WR: 0.28).

The items on which respondents show positive opinion-attitude valence includes the correct knowledge that mentally handicapped persons are eligible for monthly scholarships (Item

#34; WR: 0.71). They are aware that parents of these children are eligible for income tax exemptions under section 80 DD of the Indian Income Tax Act (Item #41; WR: 0.75). It is paradoxical that the majority of respondents who believed erroneously that there is a scheme for refund of petrol/diesel expenses, also identify that mentally handicapped persons are ineligible to secure a driving license (Item #45; WR: 0.79). Many respondents agree that when a mentally handicapped person is charged with a crime, he must be presumed innocent unless proven otherwise (Item #8; WR: 0.80). They are aware that there is "Special Arts" for persons with mental handicaps (Item #42; WR: 0.81), or that mentally handicapped persons are eligible to receive the same life saving remedies (Item #2; WR: 0.88) or help/protection from the police, like other normal persons (Item #6; WR: 0.93).

### Interpretative Norms

The raw scores derived from this study were normalised to Z scores in order to derive interpretative norms. Since none of the associated organismic variables were found to be statistically significant, only overall interpretative norms are given (Table Three). As per the criteria adopted for deriving interpretative conclusions for individual respondents in the use of this questionnaire, the conventional criteria of the population between +1.00 SD and -1.00 SD (68.27 %) was designated as "Average". The Z values between +2.00 SD and -2.00 SD (surrounding 27.18 % of population) was designated as "Above Average" and "Below Average" in their knowledge-opinion valence. Only those scores which fell beyond +2.00 SD and/or -2.00 SD (remaining 4.55 % of population) was designated as either "Good" and/or "Poor" in their knowledge-opinion on rights, immunities and privileges for persons with mental retardation.

**Table 3. Interpretative Norms for KNOQ\_RIP\_MR**

Sl No.	Interpretative Description	SD Range	Raw Score Range
1.	Superior	+2.00 and above	>38
2.	Above Average	+1.00 to +2.00	33-38
3.	Average	- 1.00 to +1.00	18-32
4.	Below Average	- 2.00 to -1.00	10-17
5.	Inferior	Below -2.00	<10

### Reliability and Validity

An in-house two week test retest reliability check for KNOQ\_RIP\_MR on a sub-sample (N: 39) showed a correlation coefficient of 0.91. The face validity for the questionnaire as confirmed by experts, was also rated as high. A series of inter item correlation carried out to ascertain Kuder Richardson 20 (KR-20) estimates an internal consistency coefficient of 0.82; thereby confirming the homogeneity of item pool included in this questionnaire.

## CONCLUSION

The KNOQ\_RIP\_MR is expected to be a useful instrument for:

- (a) Ascertaining the content of parents/caregiver and/or professional opinion-knowledge on rights, immunities and privileges for persons with mental retardation in India.
- (b) Determining the attitudinal valence of parents/caregiver and/or professional opinion-knowledge on rights, immunities and privileges for persons with mental retardation in India.
- (c) Formulating, planning, implementing and evaluating knowledge-information based training programmes for target groups of rehabilitation professionals as well as parents of children with mental disabilities.

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**BRIEF REPORTS**

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**NEEDS ASSESSMENT OF PROGRAMMES INTEGRATING  
COMMUNITY BASED REHABILITATION INTO HEALTH ACTIVITIES**

Johnson Raj S\*, Prema Latha, Metilda

**ABSTRACT**

*This study assessed the needs of voluntary, non-governmental organisations (NGOs) in Tamil Nadu for effective integration of community based rehabilitation (CBR) in their health promotion activities. Alongside, resources for CBR integration available with organisations working with persons with disabilities (PWD) were also identified. Questionnaire, interview schedule, semi-structured interview guide and field observation schedule were used to collect primary data from respondents. The study showed that personnel involved in health promotion activities had little understanding about issues faced by PWDs. Chief functionaries with higher qualifications and more years of experience had better understanding about disability. Eighty percent of the respondents were interested in learning how to integrate CBR into their programmes and 74% of the chief functionaries expressed a desire to undergo orientation on CBR. A majority of respondents could not distinguish between impairment, disability and handicap. They reported consanguineous marriage and malnutrition as major causes of disability. Less than 1% of community health workers (CHW) were aware of the 'Persons With Disability Act – 1995'. However, most CHWs knew about Government schemes. Their training needs included topics such as 'overview of disability issues, classification of disability, causes and prevention of disability, importance of early intervention, concept of CBR and role of CHWs in promoting CBR'. Eighty seven percent of respondents expressed the need for 'information, education and communication' materials (IEC) to promote CBR. The study revealed that NGOs were favourably disposed towards integration of CBR in the ongoing health activities.*

**INTRODUCTION**

Over the years, the concept of rehabilitation of persons with disability (PWDs) has undergone several changes especially in developed countries. There has been an expansion of definition

of rehabilitation, ranging from helping PWDs to survive, to ensuring equal human rights to PWDs. Today rehabilitation services for persons with disability aim to reach the largest proportion of this population, utilising readily available resources within the community in a cost-effective way, through community based rehabilitation (CBR). The voluntary sector in India, which is known for its innovations and pioneering ventures, has not however paid adequate and appropriate attention to CBR. This study was undertaken to explore possibilities to enable NGOs working in rural areas of the state of Tamil Nadu in southern India to integrate CBR within their ongoing health activities.

## **METHOD**

The objective of the study was to identify 'needs' of voluntary organisations, with regard to integration of CBR in their health programmes and to identify 'resources' available for this purpose with other organisations working with PWDs.

The specific objectives were to:

- Assess interest of voluntary organisations to integrate CBR into their health programmes and estimate the level of strategic guidance required for this purpose.
- Estimate the level of knowledge and attitude of chief functionaries of NGOs about disability issues and to identify areas that need further introduction.
- Assess the level of awareness of community health workers and to identify training inputs required by them.
- Identify the information/education/communication materials (IEC) required by NGOs to create awareness on disability and related issues.
- Identify other resources available with them and explore how they can be utilised.
- Identify disability issues that require further campaigning, lobbying or advocacy.
- Identify existing networks of NGOs working for PWDs and explore methods to strengthen these networks.

Data collection was carried out using questionnaires for information from NGOs, interview schedules for interviews of chief functionaries, semi-structured interview guide for focus group discussions of CHWs, field observation schedule to identify resources and IEC materials, and case study method to identify issues faced by health workers. The questionnaire had two parts, the first to collect general information about voluntary organisations and the second to assess needs.

**RESULTS AND DISCUSSION**

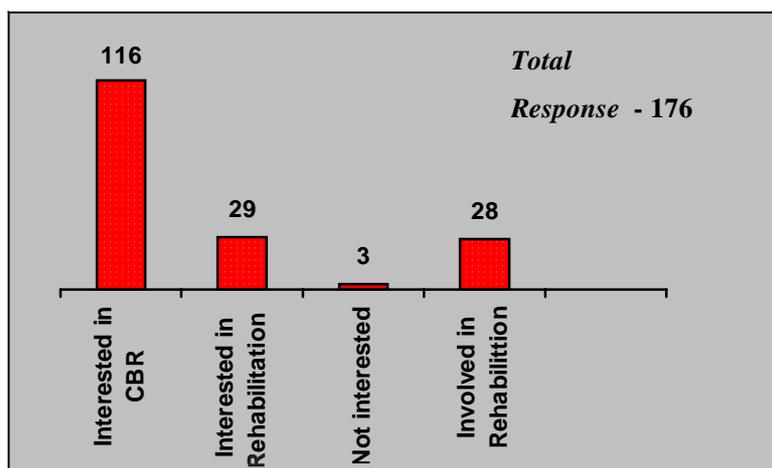
Questionnaires were sent to 570 NGOs of which 176 responded. Five focus group discussions were conducted with community health workers from various voluntary organisations in which 107 CHWs participated. In depth interviews were conducted for 30 chief functionaries of voluntary organisations. Data were collected over three months.

**Table 1. Category of institutions that responded to study (n=176)**

No	Category	No. of Respondents	%
1	Hospital	24	13.7
2	Dispensary	7	3.9
3	Community based organisations	145	82.4
<b>TOTAL</b>		<b>176</b>	<b>100</b>

Thirty four percent of the chief functionaries had postgraduate degree, 19% were undergraduates, 13.6% had doctorates and 33.4% had other educational qualifications. All of them had participated in training programmes on different issues related to disability.

**Figure 1: Specific needs of voluntary organisations interested in integrating CBR**

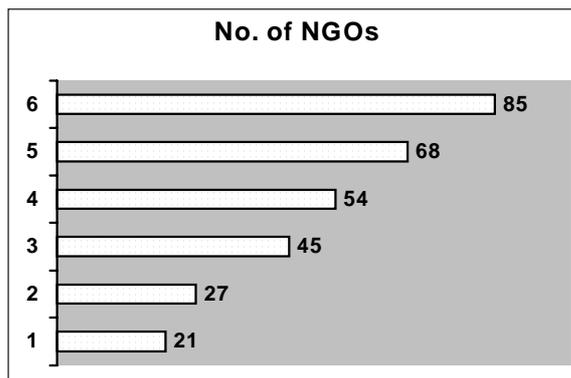


Sixty six percent of respondents were interested in starting a CBR programme and 16 % were already involved in rehabilitation activities.

**Figure 2: Areas of specific interest of voluntary organisations that are interested in integrating**

**No Areas of Interest**

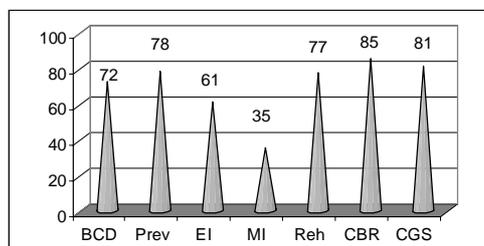
- 1 New Born screening
- 2 Medical intervention
- 3 Early intervention
- 4 Establishment of Schools/Home
- 5 Prevention of disability
- 6 Components of CBR



Chief functionaries expressed a desire to integrate activities to prevent disability and promote CBR after they gained conceptual clarity on disability and CBR. They also identified areas that would require further familiarisation.

**Figure 3: Topics listed by chief functionaries for further orientation**

- Basic concepts of disability      BCD
- Prevention                              PREV
- Early intervention                      EI
- Medical intervention                  MI
- Rehabilitation                          REH
- CBR strategies                          CBR
- Accessing Govt. Schemes            CGS

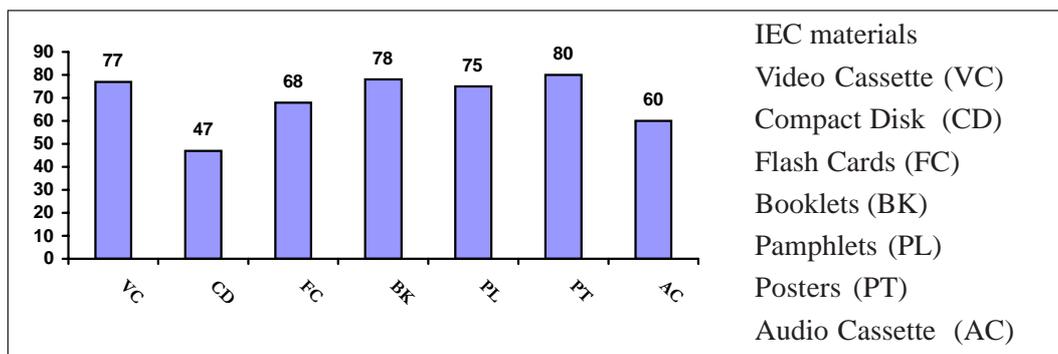


Ninety five percent of the chief functionaries reported that they could depute 2-3 staff for CBR work and training. Regarding current knowledge level of community health workers, it was found that these workers could not differentiate between impairment, disability and handicap. They divided disability into two groups, namely physical and mental disability. They identified causative factors as consanguineous marriage, malnutrition and improper parental care. They could not link these causes to any specific type of disability. Almost all CHWs expressed that disability could be prevented by immunisation. They were not aware of 'Persons With Disability Act 1995'. They listed a few Government schemes for persons

with disability, like bus pass, provision of maintenance grant and wheel chair, but they did not know how to access them. They were aware of institution based rehabilitation strategies such as educational and vocational training. However, they were not sure how to choose different categories of persons with disabilities for training or when to refer them. The concept of CBR was new to 90% of them and the remaining had only heard about CBR, but did not know what it implied.

Eighty percent of CHWs who were interested in integrating CBR in their programmes identified their training needs. These needs included basic understanding of disability, early identification and intervention, strategies to implement CBR and procedures to access government schemes.

**Figure 4: IEC materials required by CHWs**



Thirty-five NGOs reported that they were already working with PWDs. They also reported that they had enough manpower for this work. Trained staff, recognised by the Rehabilitation Council of India was working in 67% of these NGOs. Fifty five percent of the NGOs who were already involved in disability issues were willing to depute their staff to assist other NGOs.

Hundred and sixteen NGOs were interested in networking with other NGOs. Twenty two were already members of existing state level or national level networks, while 17 were members of district level networks.

There were few other needs expressed by different sections during the study. A majority of chief functionaries reported that they lacked authentic information on prevalence and incidence of disability. They also expressed a need for survey forms to undertake baseline surveys in their working areas. Nearly half of the chief functionaries wanted to visit a few agencies implementing CBR. They also felt that since CBR was a relatively new area with new techniques, they would need continuous improvement in their knowledge level. A vast

majority of CHWs felt that unfriendly transport systems and environmental barriers were major hurdles for full participation of persons with disabilities in mainstream activities. They wanted to learn about strategies to be followed to remove these barriers. Another need expressed by CHWs was for information on facilities for education and vocational training of children with disabilities. They observed that the integrated education system did not provide the appropriate barrier free environment for it to succeed. They wanted to develop skills to motivate school authorities to provide appropriate barrier free education for children with disability. CHWs wanted existing government schemes to be more accessible and to learn how to influence policies of the government. CHWs also wanted to know ways of imparting sex education to women with disability, to conduct campaigns on themes such as abortion of foetus with disability, early identification and intervention, and modifying teachers' training curricula to include teaching strategies for handling children with disability and barrier free environment.

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#### **ACKNOWLEDGEMENT**

This study was part of a project implemented with support from CBR Forum, Bangalore to improve capacity to integrate CBR in voluntary organisation's health activities.

## MANAGEMENT OF MASS SCALE DORSO-LUMBAR INJURIES FOR EARLY REHABILITATION

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### ABSTRACT

*This report is a prospective study of 72 cases on treatment for dorsal and lumbar spine injury resulting from the earthquake in Gujarat state in western India in January 2001, from the point of early rehabilitation. The purpose of the study was to assess results of surgical intervention with regard to rehabilitation, in selected patients of mass scale spinal injuries following a major catastrophe. Posterior instrumentation and laminectomy were used to treat sixty patients of dorsal and lumbar spine injury with neurological deficit. Mobilisation was started as early as possible so that rehabilitation was faster and better. The remaining 12 patients had normal neurological findings and stable type of spinal injuries and hence were treated conservatively with bed rest, bracing and gradual mobilisation. Regular follow up was carried out and some patients were also followed up at their residence. None of the patients had neurological deterioration following surgery. At 2 years follow-up, 53% patients have a functionally useful motor power based on Frankel's classification. Physical, psychosocial, vocational, and sexual rehabilitation was better. There were no cases of late neurological deterioration or mechanical failures in the conservatively treated group. The authors conclude that dorsal and lumbar spine injuries can be rehabilitated much faster and better if treated with posterior stabilisation and decompression when there are large numbers affected after a major catastrophe. Chances of neurological improvement are also good because 53.3% of patients gained functionally useful motor power. Seventy three percent could perform their daily activities independently and were vocationally independent.*

### INTRODUCTION

Disaster has always co-existed with mankind and no community is immune to it. Many civilisations have been buried under the wrath of nature. Kutchh district of Gujarat, in India has always been prone to natural disasters and has been devastated twice before the 2001 earthquake. On the morning of 26<sup>th</sup> January 2001 at 8:46 A.M. an earthquake of the magnitude of 6.9 on Richter scale rocked the state of Gujarat. The epicentre was located at Lodai, 20 kms. from city of Bhuj of Kutchh district of Gujarat. Millions were directly and indirectly

affected by this killer quake. 1,66,000 people were injured, 13,811 died and 8,68,000 houses were damaged. In the days to follow, 800 patients were received at Paraplegia Hospital, Ahmedabad of which 500 had to be admitted. There were in all 78 (15.6%) spinal injuries of which 72 were with dorsal and lumbar level injuries.

## **METHOD**

To manage this large patient overload the authors adhered to the following protocol very rigidly:

- Resuscitation of the patient was done wherever required.
- Neurological status was accurately noted using Frankel's classification.
- Patients were subjected to X rays, blood investigations and MRI (to know the cord status).
- Associated injuries were managed simultaneously.
- Twelve atients with normal neurological findings and stable spines were treated conservatively with adequate bed rest, bracing, muscle strengthening exercises and mobilisation as and when the pain permitted them to move.

Sixty patients with dorsal and lumbar spine injuries with neurological deficit were treated in the following manner:

- Parental methyl prednisolone was administered to patients with spinal injury in the following dose (1). A bolus dose of prednisolone, 30 mg. /Kg. body weight was administered over 15 minutes followed by 45 minutes pause and then in next 24 hours continuous infusion of 5.4 mg. /kg. /hour was administered.
- Posterior stabilisation was done using appropriate instrumentation and decompression was done with laminectomy. The retro-pulsed fragments were pushed anteriorly after retracting the cord wherever possible. The status of the dura was noted (whether pulsatile, non-pulsatile, crushed or continuous). Anterior decompression and fusion was done at 3-4 weeks time where the canal was compromised more than 40% (2,1). or where there was a retro-pulsed fragment with persistent neurological deficit.
- To manage this heavy overload of patients 8 operation theatres worked round the clock maintaining strict aseptic precautions.
- Routine postoperative management of dressing, antibiotics, analgesics and others was followed in all patients.
- Care was taken to prevent bedsores by using waterbeds, frequent change of posture and back care.

Post operative rehabilitation included:

- Bedside physiotherapy
- Fast tilt table mobilisation (TTM)
- Upper limb strengthening
- Passive mobilisation of lower limbs
- Deep breathing exercises
- After finishing TTM at 70 degrees, sitting with backrest on the cot was carried out.
- After finishing TTM at 90degrees, depending upon the neurological status, patients were made to walk using parallel bars with or without support.
- Progression from parallel bar to walker/ elbow crutch/ stick/ independent walking was done later.
- Bladder training was given to all patients.
- Vocational, psychosocial and sexual rehabilitation was also carried out.

### **Follow-up**

All patients of spinal injury were meticulously followed up at 3, 6, 9, 12, 18 and 24 months. Detailed neurological examination, rehabilitation status and x-rays were done at each follow-up. A team of orthopaedic surgeon, physiotherapist, nurse, orthotist, medical social worker and occupational therapist examined those patients who could not make it to the hospital, for follow-up at their residence.

### **RESULTS**

Twenty-four patients were males and 48 patients were females. They are classified into different age groups in table 1.

**Table 1. Age distribution**

<b>Age</b>	<b>1-15</b>	<b>16-30</b>	<b>31-45</b>	<b>46-60</b>	<b>&gt;60</b>
No. Of patients (total 72)	1	8	28	22	13

**Mode of injury**

- Wall falling on the patient: 40 patients
- Heavy object falling on the patient: 19 patients
- Fall from height: 13 patients

**Mode of transport from the site of injury**

Eight patients were air lifted, 29 patients were transported by bus, 13 by truck, 15 by ambulance, and 7 by other means.

**Table 2. Admission pattern**

Day	1	2	3	4	5	6	7
No. Of patients Total (72)	5	19	23	21	2	1	1

**Table 3. Level of injury**

Level of injury	No. of patients
Dorsal	10
Dorsolumbar (D11- L2)	52
Lumbar	10
<b>Total</b>	<b>72</b>

**Preoperative neurological status using Frankel's classification (only dorsal and lumbar spine patients):**

46 patients belonged to Frankel's A and B, 18 patients to Frankel's C and 8 patients belonged to Frankel's E.

**Treatment offered**

Twelve patients were treated conservatively because 8 patients belonged to Frankel's grade E, in 2 patients there was local infection and 2 patients were medically unfit. Sixty patients were treated surgically, of which 54 were treated only by posterior surgery and 6 by both anterior and posterior surgery.

**Table 4. Dura status and recovery pattern (in 60 operated patients of dorsal and lumbar spine injury)**

Dura intact				Dura crushed	
Pulsatile		Non pulsatile		12	
14		34			
NR: 0	R: 14	NR: 16	R: 18	NR :12	R: 0

NR = no neurological recovery

R = neurological recovery

### Complications

There was no immediate postoperative mortality or neurological deterioration. Infection was found in 4 patients (6.7%).

### Average hospital stay

Average hospital stay was 20 days and further rehabilitation was done at the attached specialised paraplegia unit.

### Neurological status according to Frankel's grade at 24 months at follow-up

Twenty patients' belonged to Frankel's grade A and B, 8 patients belonged to Frankel's grade C, 22 patients belonged to Frankel's grade D and 10 patients belonged to Frankel's grade E. Thus, 32 patients (53.33%) belonged to Frankel's grade D and E, thereby having functionally useful motor power.

### Rehabilitation status

44 (73.3%) patients perform their daily activities independently. 26 (43.3%) patients ambulate independently with or without support and 18 (30%) patients lead a wheelchair life independently. Six (10%) patients are bed-ridden. 44 (73.3%) patients are vocationally independent. Bowel and bladder control was normal in 20 (33.33%) patients, indwelling catheter was present in 7 (11.6%) and self-catheterisation was practised in 33 (55%). Superficial bedsores were found in 20 (33.33%) and deep bedsores in 8 (13.33%).

## **DISCUSSION**

The patients received at the institute were mainly from rural Gujarat. Females were more affected because most men were out in the fields working in the morning. As patients were from distant places most were received on the 2nd, 3rd or 4th day after the earthquake depending upon the availability of transport and speed of evacuation.

Most injuries were at thoraco-lumbar junction as this area is most mobile. Most injuries were also due to fall of a heavy object or a wall that concentrated forces at thoraco-lumbar region. Methyl prednisolone was administered to all patients of spinal injury with neurological deficit to decrease cord oedema (3,1). Posterior fixation and decompression were the treatment for patients with dorsal and lumbar spinal injuries with neurological deficits, so that compromise of the canal is removed early, facilitating axonal flow and reducing cord ischemia. This was done as early as possible so that permanent changes did not develop in the cord (3). Due to stabilisation of spine, rehabilitation could be started earlier and progress could be made much faster despite the large number of patients. Anterior surgery in the form of decompression and fusion was done in 6 patients after 3 to 4 weeks where the canal was compromised more than 40% or when there was a retro-pulsed fragment. Improved neurological function has been associated with early (4) and late anterior decompression (5,6,7,8). However, current literature on timing of anterior surgery is still inconclusive.

Four patients developed infection that was controlled with debridement and antibiotics. No patients required early implant removal. At 24 months follow-up, 53.3% of patients had functionally useful motor power that made them independent. Review of literature shows recovery rates in routine circumstances varying from 50-90% using various forms of treatment (9,10,11,12,13,14,15,8). For a major catastrophe like the earthquake in Gujarat, 53.3% recovery to a functionally useful status seems most satisfying. Because of vigorous physiotherapy 73.3% of patients could perform their daily activities independently. Vocational assistance was given to these patients after analysing their rehabilitation status and aptitude on an individual basis. Because of this process these patients were also vocationally independent. About 6 (10%) patients were bedridden and 8 (13.33%) patients had deep bedsores. This was mainly due to their poor socio-economic status, illiteracy, hot, dry and dusty weather and unwillingness of family members to treat them further.

## **CONCLUSION**

In conditions leading to large-scale devastation like earthquake where large number of spinal injuries may have to be treated in a very short period of time the following guidelines may be helpful.

- Early evacuation of the patient.
- Immediate transfer to a centre with facilities.
- Sufficient organisation of the centre to avoid chaos arising out of the large number of patients.
- Short course steroids.
- Early stabilisation of spine and decompression of the spinal cord.
- Proper postoperative rehabilitation.
- Good psychosocial support.
- Vocational and sexual rehabilitation.

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## **SCREENING PROGRAMME FOR HEARING IMPAIRMENT IN NEWBORNS: A CHALLENGE DURING REHABILITATION FOR ALL**

M. Shamim Ansari\*

### **ABSTRACT**

*Reduced hearing acuity during infancy and early childhood not only interferes with development of speech and language skills, but also adversely affects the developing auditory nervous system. It can be harmful for social, emotional and cognitive growth, and continues to plague the individual for the rest of his/her life. Current clinical methods to identify hearing loss are convenient, cost-effective, accurate and valid and can be easily employed for early identification and intervention of hearing loss. This paper attempts to convince public health experts, administrators and policy makers that hearing loss is a public health issue. It also discusses the relevance of screening criteria for screening hearing loss in new-born babies.*

### **INTRODUCTION**

Hearing impairment has a devastating, detrimental and an invariably adverse impact on the development of new-borns and the psychological well-being of their families. Neonates having mild to profound hearing loss bilaterally or unilaterally, hearing loss of varying degrees above 1000Hz, or auditory deprivation due to recurrent otitis media, develop significant and long term effects on speech and language skills. Reduced auditory input also adversely affects development of the central auditory nervous system, and can negatively impact speech perception that interferes with growth in social, emotional, behavioural and cognitive spheres, academic achievement, vocational options, employment opportunities and economic self sufficiency. Indeed, such problems may trouble these individuals for the rest of their lives, if not attended in time.

In a recent survey, 4 out of every 1000 children born in India were found to have severe, to profound hearing loss (1). It is indeed a big challenge to provide special education, vocational training and employment to this large population. There are only 540-550 special schools that cater to 3% of children with hearing impairment. There are also only 17 vocational rehabilitation centres, 22 special employment exchanges and over 40 special cells in ordinary employment exchanges, catering to their needs. At present, only blue collar jobs are available to hearing impaired persons. The gravity of this problem can only be tackled if available infrastructure is used to mainstream hearing-impaired people in regular education, vocational training and employment, by attending to hearing loss on time and instituting appropriate remedial measures.

The concept of early identification and intervention though not new, is yet to gain a foothold in India. Nikam and Dharamraj attempted infant hearing screening in 1971 (2). Basvaraj et al. (3) carried out screening for hearing impairment in Bangalore in 1984. AYJNIHH (4), Mumbai, in 1985, conducted a 3 year project on screening pre-school children for early identification and intervention of hearing loss, using the high risk register (HRR) approach. Hearing screening of neonates admitted in neonatal intensive care units (NICU) are also under way at the Wadia Children's Hospital, Mumbai (5) and AIIMS, New Delhi (6). The effectiveness of these techniques, to identify early hearing impairment is however, questioned. Literature reveals that 50% of hearing impaired children are likely to be missed in HRR. and NICU approaches (7). Moreover, their application requires a team of specialised professionals and adequate time to record risk indicators, making the process expensive.

Professionals agree that hearing loss in infants should be recognised in time and appropriate otological and audiological rehabilitation should be instituted early, to take advantage of the plasticity of developing the sensory system (critical period is 0-3 years). This effort can lead to normal speech and language development, social, emotional and cognitive growth, and academic achievement in the child. In addition, identifying hearing loss before it is clinically apparent, provides a baseline on which subsequent evaluation can be made and compared. Also, medical and surgical treatment can be initiated for conductive hearing loss and progression can be controlled. Timely information also provides acceptance of hearing impairment and improves the parents' readiness to initiate a family centred rehabilitation programme. Moreover, early identification and intervention is guaranteed by the People with Disabilities Act (8).

### **NATION-WIDE NEWBORN HEARING SCREENING**

Hearing loss causes severe developmental damages. But surprisingly, no dedicated national programme has been carried out so far, in India, for early detection of hearing loss in newborns. Screening is a process of applying certain rapid, accurate, valid and simple tests to a large population, to identify individuals with a high probability of having the target condition. It should have least requirement of time, cost and should be convenient to carry out. The condition to be screened should have serious and/or long-term consequences. The occurrence of the condition should be sufficiently frequent. It could be diagnosed on clinically established signs and symptoms. Preventive measures and effective treatment for the condition must be available. It must respond to appropriate interventions. There should be an advantage with early identification.

Normal auditory integrity within the early years of life is essential for quality development of the child. Hearing loss of any degree, results in substantial and long term damages in all spheres of human life. The prevalence and incidence rate in India is quite alarming. Studies

show varying prevalence rates from 1%, to as high as 40%. The Indian Council of Medical Research (9) in 1983, reported the incidence of conductive hearing loss of about 48% in rural areas. However, the National Sample Survey Organisation (NSSO) reports of 1986, showed that India had a 3.02 million deaf population, and in 1991 showed 3.24 million in the age group of 5-14 years (10,11). The Human Development report of 1999, estimates a 0.3 million hearing impaired population between 0-4 years age group and 1.5 million in the age range of 5-12 years (12). WHO in 1998, estimated 123 million people in the world with a hearing loss of 41 dB or more, in the better ear, and a majority of them were living in Asia.

The signs and symptoms of auditory deficit and otological pathology can be clinically established in new-borns and infants. Otoacoustic Emission and Auditory Brain Response Audiometry (ABR) are the diagnostic auditory assessments in infant hearing screening. These electro-physiological methods are efficient, cost effective and accurate for identifying any degree of hearing loss. ABR is the method of choice for hearing screening in infants less than 5 months of age, as it does not require child participation and can be done without sedation (13). Hall et al. (14) have reported specificity and sensitivity rate in excess of 96% for ABR screening in new-borns. Automated ABR screener (AABR) has high sensitivity and low failure rate, and it is more time and cost effective also. Otoacoustic emission (OAE) represents another promising, quick, cost effective and valid method of testing cochlear function. The most direct application to date, is the use of OAE for screening sensory loss in new-borns. Wherever these instruments are not available, behavioural observation audiometry can be employed for screening.

**Table 1. Summary of hearing screening approaches and their rationale**

APPROACH	SCREENING RATIONALE
1. AUDITORY BRAIN RESPONSE	<ul style="list-style-type: none"><li>·It is objective measurement of auditory system.</li><li>·It provides ear specific information.</li><li>·It is independent of subject's state (sleeping, awake).</li><li>·It does not require sound booth for evaluation.</li><li>·ABR is independent of cerebral status.</li><li>·ABR has a valuable contribution to cross check principle.</li><li>·AABR and innovative analysis is cost effective.</li></ul>

APPROACH	SCREENING RATIONALE
2. OTOACOUSTIC EMISSION	<ul style="list-style-type: none"><li>· Normal OAE is recorded in normal cochlea.</li><li>· OAE can be recorded reliably from new-borns.</li><li>· OAE is abnormal even in person with mild hearing loss.</li><li>· Non-audiologic person can perform it.</li><li>· OAE recording requires relatively brief time.</li><li>· OAE provides frequency specific information.</li><li>· Helps in identifying Auditory neuropathy along with ABR</li></ul>

The obvious objective of any screening programme is to provide appropriate treatment. Fortunately for hearing loss, ranges of effective treatment modalities are available. Hearing losses resulting from bacterial or viral diseases, due to otitis media with effusion or congenital defects of head and neck, can be prevented and treated medically and surgically. The most common intervention in congenital hearing loss is audiologic rehabilitation, such as hearing aids with well-structured auditory stimulation. Technologically advanced hearing aids are available to suit individual needs. With the use of computerised probe mike, real ear measurement, selection and evaluation, fitting of hearing aid in new-borns has become easier. Advances in ear mould technology, like the use of non-shrinkable material for impression and soft material for casting, has made it possible for local people to take an impression and send it, to distant labs for casting.

The relevance of a screening programme is to provide effective treatment at the earliest, thereby sufferings due to the disorder can be alleviated or minimised. The value of screening may lie in identification of mild to moderate hearing losses that are amenable to treatment. Furthermore, otitis media with effusion, bacterial and viral diseases can also be prevented and treated at primary health centres. In a longitudinal study of 10 years, Markides (15) reported that children identified with hearing loss between 0-6 months of age with immediate audiological and family centred programmes, have achieved significantly higher developmental function than those with delayed identification, in terms of increased expressive vocabulary and language. They have also improved syntactic comprehension / receptive vocabulary. They gained good speech intelligibility and acquired larger number of vowels and consonants.

Children who received early intervention, demonstrated significantly better language, speech, social and emotional development, than children who were identified late. They had language

development similar to non-verbal cognitive development and it was maintained in the low average range through 1-5 years of life. It resulted in better speech intelligibility, better personal-social development, less parental concern and stress. Four-fifths of the identified neonates with hearing loss had language development in the low average range through 1-5 years of life, as compared with one-fifth of the number of children identified later. In general, children identified early, tend to have better communication skills that lead to better academic performance, better career opportunity, psycho-social adaptation, a better quality of life and increased life time earnings, as compared to children identified late.

## **CONCLUSION**

A substantial number of new-born babies suffer from congenital hearing loss, which results in severe difficulties to both infants and families. Hence, it is necessary to secure normal, social and holistic development of the child by detecting hearing loss at birth and providing remedial services at the earliest. Unfortunately, there are no national policies for early identification of hearing loss as yet. Neonatal-screening for hearing loss can yield high returns. Moreover, the screening programme is cost effective, as, the child who receives early interventions for hearing loss requires less of expensive special education later. The true value of screening may lie in identification of mild to moderate hearing losses that are amenable to treatment and if left unattended, may manifest like a severe impairment. Hence, detection of hearing loss in the first month of life as well as mild hearing losses is necessary, through a 'Newborn Hearing Screening Programme'. Some suggestions to implement this process are given below:

- Each District Hospital should run a programme and the Audiologist should function as programme co-ordinator.
- All children born in the district should be screened at birth, or, within a month's time. Primary health centres and community health centres should make arrangements for referral.
- New-borns who fail on screening, should be given a diagnostic test and proper interventions within 3 months.
- Those who have high-risk for hearing loss should be followed up at intervals of 6 months even if they are cleared at the screening.

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## ACKNOWLEDGEMENT

I would like to express my thanks to Dr R. Rangasayee, Director, AYJNIHH, Mumbai, for his constant support and encouragement in all my endeavours. I would also like to express my gratitude to Dr Ujjawal Bhattacharya, ISI, Kolkatta, for his kind support, suggestions and feedback on article. I express my gratitude towards my parents and my wife Dr. Sameera Ansari for their patience and best wishes.

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## UNPAID CBR WORK FORCE: BETWEEN INCENTIVES AND EXPLOITATION

Gitta Brinkmann\*

### ABSTRACT

*The notion of 'unpaid CBR work force', the so-called 'volunteers' in CBR, can create several problems because of the financial situation of most of the 'volunteers' who are dependent on paid work. This article illustrates the shortcomings of the WHO Community-Based Rehabilitation (CBR) model with regard to the 'unpaid CBR work force'.*

### INTRODUCTION

Community-Based Rehabilitation (CBR) is a popular instrument for rehabilitation of people with disabilities in the 'majority world' (this term is used here instead of 'third world' and other similar terms). According to this concept developed by WHO and widely implemented since the 1980s, people with disabilities remain in their personal living environment instead of being rehabilitated in institutions. Local members of each community (a social group that is dynamic and heterogeneous) are selected to work as 'community workers'. They are then trained within a short time to teach family members on how to provide assistance to their relatives with disabilities. Helander (1) describes the role of 'community workers'. After assessing people with disabilities in the community, a rehabilitation programme is developed for them. This is followed by instructions to family members of disabled people, the 'family trainers'. 'Family trainers' carry out rehabilitative measures with their family members who have disabilities on a regular basis. They receive information on how to support their relatives with disabilities on their own. Among numerous supportive measures learned during this phase, some include learning of sign language and the use of cane by visually impaired persons for walking. Helander also goes on to promote further supportive measures for community workers that are not illustrated in detail here.

WHO views family trainers and community workers as 'volunteers' who make up the largest part of the unpaid CBR work force. In one of the CBR programmes in Afghanistan there were 2000 unpaid CBR workers while it had only 400 paid workers (2). According to the author, Helander's use of the term 'volunteers' can be misleading. For this group of workers this article uses the term 'unpaid CBR work force' instead. Deepak and Sharma note that many community workers involve in CBR in the hope of eventually receiving a salary (3). This is not surprising if one considers the poverty in the majority world. To speak of a substantially large voluntary work force in a CBR is therefore entirely unrealistic. The term

'unpaid CBR work force' referring to 'volunteers', comprises of a large spectrum of different identities and roles. They include those who work for CBR without receiving a salary and those who receive compensation that may range from being able to access a credit or earn a small salary. The UN organisations provide only vague statements regarding payment of unpaid CBR work force. In the 'Joint Position Paper' (4) the issue of payment of community workers is left open: 'Community CBR workers may be employed within the sector that provides the framework for CBR. They can also be volunteers working in co-operation with other community workers who are employed'.

How do people volunteer to work in CBR although they do not receive any payment? Helander (5) seems to be aware that the results of a CBR programme depend largely on the motivation of the unpaid CBR work force. To reach this end he fashioned the idea of providing incentives. Such incentives include participation in an official ceremony, receipt of uniforms, food, livestock, land or a written statement from an important person that help him in his career prospects, award of an official document such as a diploma or participation in seminars and so on (1). At first glance, it does not seem possible that these incentives can influence the participants to such an extent that they would be willing to commit themselves as unpaid CBR work force for numerous hours every week. However, reports show that they are quite effective in practice and that participation of volunteers as unpaid CBR work force is partly influenced by these incentives (6).

Although incentives achieve their goal partly, it is still a questionable method to use. A discussion of incentives described in the 'Joint Position Paper' will illustrate this point (4). Annual competitions for the best community worker or the distribution of uniforms are two of the incentives suggested in this report. They are expected to help ensure participation of CBR workers. It is debatable however if unpaid CBR work force will be able to gain adequate recognition and respect through these measures. Dealing with them in this manner suggests that they are taken lightly. Even though incentives and their effects are culturally dependent and can result in different outcomes in different cultures, they also appear to be a method of exploitation of the unpaid CBR work force. The strenuous work of CBR workers is compensated in a dubious manner, and in most cases they do not even receive a salary. This happens because of the assumption that CBR can not be implemented without 'volunteers', a form of cheap unpaid work force (7).

Despite the fact that incentives may have a motivating effect for the unpaid CBR work force to participate in CBR, their effect seems to be limited. In practice there are difficulties such as finding willing community workers, high dropout rates and lack of motivation among unpaid CBR work force (3). Further overriding difficulties could also exist beyond these problems. Many community workers are expected to participate in additional programmes. In Krefting and Lysacks's study (6) carried out in Indonesia, 80% of the unpaid CBR force

was involved in other programmes. Consequently, they had limited amount of time and energy to invest in the CBR programme. Many community workers who work full-time in the hope of receiving a salary could view the unpaid work for CBR as a form of exploitation (8). It is not surprising that many of them may eventually leave the programme because they are unable to fulfil their expectations of receiving a payment. Poverty seems to be the major obstacle for unpaid work in CBR programmes. Willingness to engage in unpaid work is less with reduced salary (9). Thomas and Thomas (10) believe that most people cannot afford to work without pay in the 'majority world'. Before community workers can afford to work for CBR, other acute needs, such as the ability to feed one's own family must be fulfilled. Due to their participation in CBR, they are unable to work for a salary. The importance of this issue becomes magnified when participants are well below the poverty level.

At least one of the disadvantages mentioned here also affects family trainers. By assisting family members who have disabilities through CBR programmes, family trainers are hindered from earning a living. Poverty in the majority world poses an existential problem for them. The amount of time demanded from family trainers for assisting their disabled relatives can be quite high, depending upon the degree of assistance required for the person with disabilities. Beyond the issue of time, the family will also have to obtain money for medication and for transport to consult specialists or healers who do not live within the community (11). The widely stated reduction of rehabilitation costs with the 'creation' of CBR merely transfers the costs to the family (10). CBR is much more expensive than generally assumed when one considers the time and money required by the family (12).

The disadvantages resulting from utilising the unpaid work force may also effect people with disabilities themselves. If, for example, community workers are unmotivated because they do not receive a salary, the quality of their work will eventually reduce. Family trainers, who assist their family members with disabilities conscientiously, will possibly reduce the time they devote to their relatives if they can not guarantee basic support of all family members. Their priorities thus change from assisting their relatives to having to earn a living for their families.

It is possible that financial situation of people in the majority world, including the family trainers and community workers, will become worse in the future. The World Bank (WB) and the International Monetary Fund (IMF) call for many countries of the majority world to implement structural adjustment programmes. This causes countries to open their markets, abandon specific controls and reduce public expenditure (3). The neo-liberal politics of development could lead to increased social conflict and to a further marginalisation of the poor (11, 13).

How will the WHO deal with this problem? The unpaid work force in CBR is barely mentioned in the plans of WHO or UN. Helander only hints at difficulties of implementation of CBR: 'The availability of volunteers is influenced by many factors. Economic factors include the

amount of time free from work and household duties, and competing possibilities for remunerated occupations' (1). Although he recognises the correlation between unpaid work and the financial situation of the unpaid CBR work force, he makes some sweeping generalisations in some of his remarks. He speaks, for example, of 'giving up early' in reference to the dropout of unpaid CBR workers from programmes (1). In another passage, he makes the following generalisation: 'In some parts of Asia, it is easy to recruit non-salaried volunteers for community work – I have come across good examples in India, Indonesia, Myanmar, Phillipines, Sri Lanka, Thailand and Vietnam. In Africa, the tendency is to seek financial or other compensation' (1). Deepak and Sharma (3) report many contrary experiences about unpaid work force from different continents. They give examples of CBR programmes that used unpaid labour successfully, although this seems to be more of an exception (10).

This article does not question the entire concept of CBR. However, the author holds that WHO or UN have failed to consider a major aspect related to unpaid workers in CBR in their conceptualisation of CBR. Due to additional commitment of time to CBR and resulting financial consequences for the CBR workers, unpaid CBR work can lead to many problems for people with disabilities and their families. Hence one has to rethink on the issue of unpaid labour force in CBR. Such rethinking should have the active participation of people from the majority world. The deficiencies of CBR that stem from a eurocentric perspective – which possibly influenced the concept of unpaid workers in CBR- can only be overcome this way.

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## ACKNOWLEDGEMENT

The author thanks Jennifer Davy for translating the text from German to English.

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**Produced by:** Shree Ramana Maharishi Academy for the Blind, 3<sup>rd</sup> Cross, 3<sup>rd</sup> Phase, J.P. Nagar,  
Bangalore - 560 078, India. Tel : 91-80-6581076, Fax : 91-80-6588045 Email: srmab@vsnl.com  
website: [www.welcome.to/srmab](http://www.welcome.to/srmab)

**Printed at:** National Printing Press, 580, K.R. Garden, Koramangala, Bangalore - 560 095, India.  
Tel : 91-80-5710658 Email: nppbangalore@vsnl.com

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