

EDITOR'S COMMENT

There is increasing emphasis today on evidence based practices in the field of community based rehabilitation (CBR), so that the field can grow and develop further, and fulfil its promises of bringing about 'real' changes in the lives of people with disabilities. Research and evaluation in CBR will necessarily play a key role in contributing to the body of evidence based practices. However, there is some debate about what type of research - quantitative or qualitative - is more suitable for CBR.

Quantitative research is important when there is need to identify numerical trends of populations, to establish cause-and-effect relationships, to identify major differences between populations, to establish base line data and to make statistical generalisations of findings to other similar populations. It is also useful to know the absolute numbers when there is a need to provision resources cost-effectively.

Qualitative research on the other hand, helps to study amorphous data on contextual and culture specific issues, including people's behaviour, their attitudes, beliefs and perceptions. It is usually less expensive and less time-consuming than quantitative research and more useful when the need of the researcher is to develop capacity in the organisation or plan future interventions. However, qualitative research requires highly skilled researchers with skills to elicit information from a variety of stakeholders, to reduce bias to a minimum and to interpret findings appropriately.

In the earlier years, practitioners in the field of disability followed largely a service delivery approach borrowed from the medical model. Accordingly, research and evaluation tended to be more quantitative in nature, because traditionally the medical model, strong in service delivery, required identifying trend lines to evolve best delivery systems. Today however, the field of disability rehabilitation encompasses broader issues of development, based on a social model and focuses on contextual issues and participation. With this change in perception, qualitative research assumes importance because it can study the differences in behaviour of people and choose appropriate strategies for planning.

The choice of quantitative or qualitative methods in research depends on the questions that the researcher needs to answer. For example, if provisioning of resources is the matter to be decided, then quantitative methods may be more useful. If organisational and project development is what is needed, then a researcher would opt for qualitative methods. Often the two approaches are used together to complement each other.

In a field like CBR, with growing emphasis on social approaches to disability issues, and the need to evolve cost-effective methods, a judicious combination of qualitative and quantitative research may be the need of the hour.

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**PATHFINDERS : TOWARDS FULL PARTICIPATION AND EQUALITY
OF PERSONS WITH DISABILITIES IN THE ESCAP REGION**

Economic and Social Commission for Asia and the Pacific (ESCAP)

This publication provides an avenue for sharing ideas and experiences and for disseminating examples of good practice towards the achievement of full participation and equality of persons with disabilities in the Asian and Pacific region. The case studies presented cover the policy categories of national coordination; legislation; public awareness and accessibility; education; training and employment; prevention of causes of disability; rehabilitation, including community based rehabilitation and health and social development; and self-help organisations. Examples of good practice have been presented from Bangladesh, Cambodia, Hong Kong, China, India, Malaysia, the Philippines, Thailand and Vietnam.

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GUEST EDITORIAL

USING QUALITATIVE RESEARCH METHODS FOR DISABILITY RESEARCH IN MAJORITY WORLD COUNTRIES

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ABSTRACT

This article undertakes to explore the use of qualitative methods in relation to disability research and disability classifications, drawing on medical, social and educational perspectives. It reviews what qualitative research entails, what skills are required to carry it out and why and when it should be used. It gives examples of on-going research in majority world settings and describes what quantitative researchers can learn by engaging in the qualitative paradigm. It concludes by summarising suggestions for a way forward.

INTRODUCTION

Services for people with disabilities throughout the world have evolved as an extension of medical and educational practice. These practices are based on information gathered from a predominantly positivist quantitative approach (1). Positivist approach is one that believes the world operates by the laws of cause and effect. Observation and measurement are the core scientific endeavours, knowledge of anything beyond that which we cannot measure, is impossible. This is an approach where 'proper' scientific research is seen to be based on quantitative methodology, with 'random control trials' as the ultimate 'gold standard' (2) and where Measurement itself gives scientific credibility, which is not awarded to the unmeasured or the immeasurable (1). However in the medical arena Holeman (3), points out that 'the almost sole recognition given to quantitative methods has trained students inadequately, established flawed standards of practice and research, and delayed the development of essential medical knowledge.'

WHAT IS QUALITATIVE RESEARCH?

Qualitative research embraces the view that as far as peoples' perceptions are concerned, there is no one single truth. In other words, different people in different places at different times, interpret things differently. This philosophical viewpoint serves to challenge the validity of socially oriented data that is collected using quantitative methods. It demands an alternative set of methods for exploring peoples' perceptions, one that is contextually and culturally

related. It therefore, seeks to find the answer to questions about the meaning and individual interpretation of life. It is used to answer open questions relating to peoples' attitudes and beliefs, in a given contextual setting. A series of articles in the BMJ provide helpful initial guidance on this topic (4, 5).

Qualitative research also offers the opportunity of closing the gap between the science of discovery and the implementation of such discoveries. It does this by studying things in their natural settings and by providing a vehicle for collecting and analysing information based on the participants' views and the way in which they make sense of the world. This serves to reinstate 'people' at the centre of the research agenda (6). Stone and Priestly (7) argue that this is particularly important in both disability and in majority world research, where research has been based in an oppressive theoretical paradigm, and 'decades of 'scientific' research have perpetrated the marginalisation of disabled people' so that 'research has become part of the problem' (7). Majority world is 'where the vast majority of the world's people live, yet they have access to a fraction of the world's wealth and power' (8). A more emancipatory approach is required to move forward in a positive way and qualitative methods offer potential in this arena.

SUPERIOR OR INFERIOR?

The perception that quantitative research is superior regardless of the research questions asked, is not supported by the literature (9, 10). They argue that qualitative approaches are better for investigating subjective meanings within a culture, understanding attitudes and beliefs and unravelling the dynamic constructs of culture and social traditions. Quantitative methods on the other hand, have their strengths in identifying universalities and making statistical or probabilistic generalisations, or in determining the correlation between two measurable phenomena.

Superiority is therefore dependent on an appropriate relationship between the research questions and the methodology (1, 9). There is also a need for research to be valued for its capacity to alleviate the problems felt by the community and not knowledge for knowledge's sake.

Unfortunately, the misguided perception that quantitative research is a superior method, has impacted on the capacity of researchers to secure funding and this in turn has influenced the frequency or infrequency of its use (11).

EASY OR DIFFICULT?

There is a general misunderstanding that one research method is easier or more difficult than the other (9). But good qualitative research is no easy option. Whilst it may not demand

complex numerical skills, it does require a high level of linguistic competence, good interpersonal communication skills, long-term commitment and in the present research climate, determination. The term 'qualitative research' should therefore, not be confused with the word 'quality research'. It is just as easy to do poor qualitative research, as it is to do poor quantitative research.

COMPLEMENTARY OR COMPETITIVE?

Qualitative research methodologies support the idea that there is a range of different ways of making sense of a given situation. They move away from knowledge for the sake of knowledge, to valuing it for how it can alleviate problems that are felt by communities (6). However, it is only when used together with quantitative research, that it provides the capacity for researchers to uncover a complete picture of the relevant issues, and give a holistic picture. Black (1) and Cresswell (9), therefore, quite rightly argue that the methods are complementary and not competitive.

THE FIVE TRADITIONS

Qualitative research methodology can follow five traditions of research strategies—ethnography, grounded theory, case study, phenomenological research and narrative research. In ethnography, the researcher studies an intact cultural group in a natural setting over a prolonged period of time by collecting, primarily observational data (12). In grounded theory, the researcher attempts to develop a general and abstract theory grounded in the views of the participants. The research process involves collecting interview data and analysing the data, using several methods of coding to develop the theoretical model of the process, action or interaction under investigation. Case studies aim to develop an in-depth analysis of a programme, event, process or individual. Multiple sources of data are used including documents, archival records, interviews and observations, to illustrate the case in depth. Understanding the essence of human experiences about a phenomenon, as described by the participants, is the objective of phenomenological research. It usually involves long interviews of a limited number of participants to develop patterns and relationships of meanings, as experienced and described by the participants of the study. Narrative research, is a form of inquiry in which the researcher studies the lives of individuals, through the collection of life stories usually by interviews. It provides a detailed picture of an individual's life. The choice of particular research strategy depends on the objective of the study and the phenomenon under investigation. For example, researchers might study an individual's experience (phenomenology), or an individual's life (narrative research), explore the process, activity, events and outcome (case study and grounded theory), or explore the behaviours and rituals of a culturally defined group (ethnography).

QUALITATIVE DATA COLLECTION METHODS

Data collection methods for qualitative research largely originate from the field of anthropology, sociology and psychology. Qualitative data can be collected by systematic observations, conducting interviews and focus group discussions, collecting public and private documents and emails and through audiovisual materials like photographs and video-tapes. Each type of data collection method has its own advantages and limitations. The most commonly used data collection methods for qualitative studies, include different types of interviews and focus group discussions to explore the participant's perspective on the research topic. Rifkin and Pridmore (13) provide a useful text for the beginner in these data collection techniques.

QUALITATIVE RESEARCH AND ACTION RESEARCH

Qualitative research can be considered 'Action Research', but this is not inherent within the definition. However, qualitative approaches have many of the key components of action research, such as participation of the stakeholder groups, educative aims, and an iterative rather than linear processes (14). This puts it into a strong position for developing a participatory or emancipatory approach as recommended by disabled researchers and the disability rights movement (15). This does not mean that quantitative studies cannot aspire to Action Research criteria also, but that by the nature of the process, might be more complex and difficult to achieve within the framework of a totally quantitative study.

WHAT QUALITATIVE RESEARCH IS NOT

Ironically it is often easier to say what qualitative research is not. It is not about numbers (its currency is words), it is not a haven for innumerate scientists, but an opportunity for researchers with mature emotional intelligence and advanced linguistic and conceptual skills, to make their contribution to scientific debate and subsequent policy and planning. Qualitative studies do not attempt to predict an outcome, as in many quantitative studies, rather they seek to explore questions to which the answer is not known and predictions cannot be made. Additionally, as qualitative research does not seek to make statistical generalisations, it does not use random sampling. This does not weaken such studies, but allows rich data to be collected on the fullest range of possible views, by purposively selecting people with different backgrounds and experiences. Qualitative research does not follow a linear process. It provides the opportunity to be flexible and iterative, to adjust aims and purposes and collect data in several stages, with the eventual possibility of producing a theoretical frame work which has been grounded in the data. The aim is to represent the widest possible view of the situation, by exploring the different perceptions and meanings, given by the different stakeholders. Additionally, when selection of the participants uses clear inclusion/ exclusion criteria and rigorous interview procedures, sampling to redundancy shows that there is rarely a need for large samples.

WHY USE QUALITATIVE METHODS IN DISABILITY RESEARCH?

Published research in the area of disability in majority world countries is generally scarce (16, 8) and is traditionally and historically dominated by the quantitative approach (17, 3). The research that is documented, focuses on either the prevalence of impairments, biomedical issues or the efficacy of interventions in numerical terms (11). This is problematic for doing disability research on a number of counts.

Firstly, the predominantly quantitative approach to disability research has resulted in a dominance of impairment-related studies and the social aspects of disability have been ignored and under investigated. Over the past decade or so, the introduction of the social and rights model have provided a long overdue challenge to the individual/medical model of disability and has served to reflect the social construct of disability, which had been previously ignored. The International Classification of Functioning and Disability (ICF) (18) gives clarification to the difference between impairment (described as the deviation from normal functional or structural integrity of the tissue, organ or part of the body) and disability. Disability is an umbrella term for impairments, activity limitations and participation restrictions. Disability is characterised as the outcome or result of a complex relationship between an individual's health condition, personal factors and of the external factors that represents the circumstances in which the individual lives. Because of this complex relationship, different environments may have a very different impact on the same individual with a given health condition. ICF has also described the role of participation as involvement in a life situation. This provides a framework where medical, social and rights models can be combined to give a comprehensive/holistic picture of disability. To achieve improvement in disability services and research, there is a need to embrace this 'universal model' (19) and cease the rhetoric of allegiance to one model in particular. Interestingly, a similar parallel exists between the quantitative and qualitative approaches to research. Traditionally the medical model associates with the quantitative approach and as such, struggles to be meaningful when used in situations relating to peoples' perceptions that are complex and dynamic. These are more effectively described qualitatively, but both research methods are required for a complete picture, just as all models are required for a complete understanding of disability.

Secondly, there is a need to utilise qualitative methods to collect information which is culture specific and for researchers to act on the knowledge that the complexities of human behaviour, and the dynamic and cultural nature of such behaviour, may be beyond the scope of quantitative methods (11). Being culturally informed, safeguards the ethical issues relating to validity and allows the people in the community to direct the research so that it reflects their perceptions and needs, and not just those of the researcher. The researcher may have a different agenda such as promotion, or a narrow interest in a specialised and possibly irrelevant topic.

There are also a number of practical problems in using quantitative methods for disability research. For example, the low prevalence rates of different impairment groups, make it extremely difficult to draw any statistical conclusions from a quantitative study and the heterogeneity of these groups further confounds quantitative research designs and makes controlling for variance a logistical nightmare (20, 21).

The capacity of qualitative research to investigate the attitudes and beliefs of the people in the community contributes towards improving the validity (and therefore the value and ethics) of the research. However there is also a need to recognise the limitations of both the quantitative and qualitative approaches and for researchers to be trained to conduct both types of studies with rigour and confidence. Nowhere could this be more appropriate than in the field of disability research in majority world countries.

WHEN TO USE QUALITATIVE RESEARCH METHODS

1. EXCLUSIVELY

When little is known

Disability research in majority world countries is still in its infancy. Many individual countries simply do not have ANY research on particular topics in the disability field (8). Qualitative research methods are known to be appropriate and effective when little or nothing is known about the situation, as they do not require a predictive statement and therefore seek the answers to open questions. (8, 22, 23, 24). In such a situation, predictive, or closed quantitative questions are inevitably based on culturally different norms, imported from other settings. This creates a situation, where, however rigorously the research is conducted, the outcome is likely to be inappropriate in that particular setting, and irrelevant to the problems the local people are facing. In such situations, there is a need to base service development on cultural realities and develop new innovative services, training and policy based on the complex and dynamic actualities. Muecke (6) argues that qualitative research has the capacity to do this and that it has a vital role to play, in putting people and culture back into development by documenting ignored social realities. This makes qualitative research methods a strong initial research option in majority world countries (6).

When target populations are vulnerable

Qualitative methods are also an effective tool when the target group are vulnerable, as is inevitably so, when focusing on people with disabilities. Other common vulnerable groups are women, illiterate groups and people with HIV. An on-going qualitative study in Uganda by the author and colleagues, is looking at the coping strategies of families with disabled

children. Little is known about how families cope with disabled children even though WHO/ILO and UNESCO (25) in their joint position statement recommend that such services should be based on local perceptions of need. The information this study has generated (in press) is providing a valuable basis on which to develop community-based rehabilitation (CBR) initiatives in Uganda and is also improving the validity and relevance of CBR training in the country. Similar procedures are being used by the Bernard van Leer Foundations to investigate practices in Early Childhood care and development (23, 24). Another ongoing study by the authors is looking at the perception and attitudes towards the children with vision related disability in Bangladesh. This study is also exploring the need for service provisions for the children with vision related disability in Bangladesh, as perceived by the children themselves and their families. Use of qualitative research methods provided the opportunity to listen and include the voices of the vulnerable population, in programme planning.

When policy information is required

Quantitative studies have given decades of comparative data that have been used to inform policy and planning of health and education services at all levels, but what this data does not do, is provide information about the variations within the target population and the extremes that are likely to exist. Such studies tend to ignore the socio-cultural context as determinants of health and educational status and the fact that political problems are socially constructed (26). A study by the author and colleagues in Uganda (in press) has looked at the perception of stakeholders towards the implementation of policy relating to disabled people. The results highlight the interactive, iterative relationship between the development of policy and existing practice, and challenge the more linear view of cause and effect, that might have been predicted. This study provides the evidence to support policy development through participation with practitioners. This concept can be utilised in other settings around the world.

2. TOGETHER WITH QUANTITATIVE RESEARCH

Qualitative data can be a prerequisite for good quantitative research in a number of ways. For example, increasing the validity of measuring tools by providing culturally relevant information about the issues that require to be measured. Black (1) says 'It is better to measure what is relevant inaccurately than to measure accurately what is irrelevant', but it is even better to measure accurately what is relevant.

In the initial stages of an on going study by the author and colleagues in Kenya, the local perceptions of the quality of life of disabled children and their families, have been explored in a qualitative study. This information has been used to develop a survey questionnaire, which is presently being used to measure the impact of an intervention utilising women's groups.

Qualitative research can also be used for providing possible explanations for quantitative survey results, which would be otherwise un-explicable. A quantitative study in Kenya, has recently revealed that a large proportion of children with epilepsy, do not avail themselves of medical treatment, even though this treatment is known to have the capacity to improve their condition considerably and is easily available. The reason for this under-utilisation was unknown and so a qualitative study has now examined the reasons for this (27). The Childhood Blindness Project in Bangladesh [CBPB] revealed that the leading cause of blindness in children was congenital/developmental cataract, contributing to 31% of all blindness in children. As cataract blindness in children is completely curable, a qualitative study is currently underway to identify the barriers of uptake of cataract surgery for children in Bangladesh. CBPB also identified about 100 families in which multiple members are affected by unoperated congenital/developmental cataract who never avail themselves for surgery. The qualitative study revealed that the community members perceived familial blindness from cataract as a curse on the family. There was a widespread belief that this type of blindness is incurable which prevented them from going to the eye care facilities for treatment.

What skills are needed by a researcher to carry out qualitative studies?

As qualitative studies rely on collecting data from participants in their natural settings and most of the data are usually non-numeric, unstructured textual data, a high level of linguistic skills are required. Quality and relevance of interview and focus group data largely depends on the linguistic skill of the researcher. Excellent verbal and written communication skill are required to collect qualitative data and to analyse and disseminate the results of qualitative study.

It is also important to appreciate that the ability of formulating open-ended questions and facilitating discussions in a non-directional manner, needs detailed planning, adequate practice and an understanding about the study participants and the environment in which they live. Qualitative research relies heavily on the empathy, commitment and involvement of the researcher. It needs prolonged contact with the community and the people to understand the inner meaning of the qualitative data.

Continuous reflection by the researcher is also required throughout a qualitative study to modify the focus (when required) and to accommodate the initial findings into the subsequent data collection. Involvement with the study participants and with the process or topic under investigation is needed to analyse the qualitative data in a meaningful way. Emotional intelligence and an open mind to learn from the participants are vital in qualitative research, as the whole purpose is to learn the participant's perspective on a given topic.

Qualitative research requires a considerable time by the research team. Quite often, researchers, who are new in the qualitative research, underestimate the amount of time

required to transcribe, translate [if required], transcribe in the second language, and to conduct the data analysis. In the absence of adequate time, good quality data can end up in sloppy analysis and without any meaningful and valid results.

All research requires excellent planning and management skills but in qualitative research changes to the research structure can be made in response to new data at any stage in the process in an iterative way.

Another important skill required by a good qualitative researcher is the ability to listen carefully to better understand other people's views. Qualitative researchers need to learn not to judge people as that can create a communication barrier between researcher and the participants. Facilitating skills are required particularly to conduct focus group discussions.

It is important to consider the skills that are required when recruiting interviewers for a qualitative study and also to provide training in interview techniques and facilitating skills. Most of the skills can be developed and enhanced through active training, regular practice and sharing the experience with other researchers.

WHAT CAN QUANTITATIVE RESEARCHERS LEARN FROM INCORPORATING QUALITATIVE ASPECTS TO THEIR RESEARCH?

There is a growing interest about qualitative research methods among the quantitative researchers. More and more researchers are incorporating qualitative components as part of larger quantitative studies. There are many benefits in doing this. Most of the quantitative research provides very limited opportunity to interact and learn from the study participants on a one to one basis. On the other hand, qualitative research methods can educate the quantitative researchers about the 'people' and their perception, beliefs and practices. They can get a better and broader idea about the lives of the people from whom they are collecting quantitative data. It helps the researchers not only to better understand their data but also to understand the implications of the results and interventions on the people, at a more individual level. Qualitative studies can act as a catalyst for reorientation of the researcher and may lead to more action research to initiate real change in people's lives. It may also illuminate the gap between the 'professional's' view and the participants view on a given topic which may help to interpret the data. By combining quantitative and qualitative methods, researchers will be able to get a holistic view on the research topic.

THE WAY FORWARD

There is a real need for researchers to take a more holistic view in order to make research more ethical by having a closer relationship with the people and their needs. This requires more emphasis on action research with participation of disabled people at all stages of the research. Qualitative research methods can contribute to improving the validity and ethics of

research in general and at the same time offer a method of investigating topics, which are difficult to research using a more quantitative approach. They have much to offer in the area of disability studies worldwide because of the need to examine the effect of the socio-cultural environment and reflect a comprehensive view of disability. Also to examine how this view impacts on service provision, policy and planning. Qualitative research has a particularly valuable role to play in the development of relevant research about disability in majority world countries by virtue of the fact that little is known about this area and that the stakeholders are a very vulnerable group.

Researchers need to acquire qualitative research skills, or employ someone on their research teams to carry out this aspect of the research. There is also a need for people engaged in qualitative research to be prepared to defend their activities against the positivists view and to conduct research in a rigorous fashion with commitment and integrity so that their work can be shared in the public area and take a credible place beside and together with, other research methods.

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DEVELOPMENTAL ARTICLES

THE ASIAN AND PACIFIC DECADE OF DISABLED PERSONS 1993-2002: WHAT HAVE WE LEARNED?

Penny Price, Yutaka Takamine***

ABSTRACT

The Asian and Pacific Decade of Disabled Persons, 1993-2002, was a unique initiative of the Asian and Pacific region - the only region to take such action and focus further specific attention on disability issues following the end of the first UN Decade, 1983-1992. One of the main strengths of the Asian and Pacific Decade was the Agenda for Action, which was the blueprint to guide policy development and implementation by Governments and non-Government organisations, and laid out specific targets in 12 key policy areas. Evaluation of achievements made during the Decade indicated that significant progress had been made in many policy areas, but that progress had been from such a low base, that even areas with good progress could be identified as priority areas requiring further concentrated action. The need for further action was translated into a resolution proclaiming the extension of the Decade for a further ten year period, from 2003-2012. This resolution was adopted by member states of the Asian and Pacific region at the 58th session of the UNESCAP Commission, in May 2002. A new framework to guide action, the Biwako Millennium Framework for Action Towards a Barrier-free and Rights-based Society for Persons with Disabilities in Asia and the Pacific, was adopted in October 2002.

INTRODUCTION

In theory, the rights of person with disabilities, as with the rights of all other persons, have been upheld by the United Nations Declaration of Human Rights, declared in 1948, and all other mandates that have followed. But in practice, this has not been the case and achieving rights for persons with disabilities has been an elusive goal. For decades, persons with disabilities were either neglected, rejected and ignored, or they were placed in institutions where they could be kept carefully segregated from their non-disabled brothers and sisters.

The United Nations International Year of Disabled Persons (IYDP) in 1981, marked the beginning of serious attention to disability issues by the global community. IYDP was followed by the World Programme of Action Concerning Disabled Persons, declared in 1982 (1) and

followed by the United Nations Decade of Disabled Persons 1983-1992. The goals of the Decade were the prevention of the causes of disabilities, rehabilitation and the full participation and equality of persons with disabilities. Careful reviews of the information available on the progress of the United Nations Decade of Disabled Persons, suggested that the major achievement of the Decade had been an increase in world-wide awareness on disability but that this awareness had not translated into action. It was concluded that very specific and well-focused action at all levels was essential, in order to achieve the positive changes that would result in equal opportunities and the full integration of disabled persons in society (2). The Expert Group Meeting to review and Appraise the Achievements of the United Nations Decade of Disabled Persons in the Asian and Pacific Region, organised by UNESCAP in Bangkok, in August 1991, recognised that there was a clear need for a second decade of disabled persons, to consolidate and extend the gains that had been achieved upto this point in time.

The Asian and Pacific region was the first and only region to promote a specific regional initiative in the area of disability, following the end of the first United Nations Decade of Disabled Persons, 1983-1992.

THE ASIAN AND PACIFIC DECADE OF DISABLED PERSONS, 1993-2002

This unique Asian and Pacific initiative was launched at a meeting held in Beijing in December 1992. The Proclamation on the Full Participation and Equality of People with Disabilities in the Asian and Pacific Region, was adopted at this meeting and the Asian and Pacific Decade of Disabled Persons, 1993-2002, was launched. The primary focus and goal of the Decade action was the expansion of opportunities for the full participation of people with disabilities in society and their equality in the development process. It was aimed at encouraging Government Ministries and Departments, NGOs, international organisations, including United Nations agencies and bodies, and committed individuals to take action to achieve these goals. It was hoped that there would be tangible results in villages, towns and cities of the region, with a significant improvement in the quality of the lives of people with disabilities, as a result of the impetus of the Decade.

The lessons learnt from the first United Nations Decade clearly indicated the need for very specific guidelines if the decade was to bring about real change in the lives of people with disabilities, apart from merely focusing on needs and barriers. The Agenda for Action for the Asian and Pacific Decade of Disabled Persons, 1993-2002, adopted by the Economic and Social Commission for Asia and the Pacific (ESCAP), at its forty-ninth Commission session in 1993, attempted to fulfil this requirement. It consisted of 12 major policy categories considered essential to ensure the full participation of people with disabilities, in every aspect of the national development agenda. The policy areas included national coordination, legislation, information,

public awareness, accessibility and communication, education, training and employment, prevention of causes of disability, rehabilitation, assistive devices, self-help organisations and regional cooperation. The Agenda has become an effective tool for Governments in the ESCAP region to guide policy, planning and implementation of programmes concerning people with disabilities. During the evaluation process at the end of the Decade, many Governments cited the Agenda for Action and its very specific guidelines as the key factor responsible for the progress they had made towards achieving the goals and targets of the Decade agenda (3).

The Asian and Pacific region consisted of 61 member and associate member countries and territories, 57 excluding four donor nations from outside the region, at the start of the Decade. At the fifty-ninth Commission session of UNESCAP, Timor Leste was admitted as the sixty-second member. Subregional representation extends to east and north-east Asia, south and south-west Asia, north and central Asia and the Pacific island countries, and includes 13 least developed countries. It is home to two thirds of the world's population, including its poorest people, among whom persons with disabilities are over-represented. With such diversity within the region, it was not unexpected that achievements would be uneven. By the end of 2002, 43 countries had signed the Proclamation on the Full Participation and Equality of People with Disabilities, in the Asian and Pacific Region. Dates of signing ranged from 1992 to 2002, with those who signed more recently, being Governments in Central Asia and the Pacific subregion. This indicates a lower rate of participation and a shorter period of engagement with the Agenda for Action for many countries and territories, in these two subregions. The Governments of Afghanistan and New Caledonia signed the Proclamation in October and December respectively, in 2002.

ACHIEVEMENTS OF THE ASIAN AND PACIFIC DECADE OF DISABLED PERSONS, 1993-2002

The review process was an integral part of implementing the Decade, required by the resolution by means of which the Decade had been proclaimed. Review meetings were held every two years. At the meeting in 1995, 73 specific targets were adopted under the 12 policy areas of the Agenda for Action, and gender dimensions were added. At the third review in 1999, the targets were reviewed and revised and extended from 73 to 107, reflecting changes and new dimensions, since the start of the Decade in 1993. Increased attention to inclusive education and a focus on new technologies were examples. In 2001, a regional survey was undertaken, soliciting information from Governments, on their major achievements towards implementing the Agenda for Action, and asking them to identify priority areas for further action. It was expected that Governments would consult with NGOs in this review process and thus provide a more comprehensive picture of progress made and the current situation of persons with disabilities across the region.

The results of the 2001 survey, and information from a variety of other sources, formed the basis for the reports on national and regional level achievements which were presented for consideration at the High-level Intergovernmental Meeting to Conclude the Asian and Pacific Decade of Disabled Persons, which was held in Otsu, Shiga, Japan, in October 2002 (3). Responses were obtained from 91 per cent of Governments who were signatory to the Proclamation at that time.

Findings

A common outcome across many areas of the Agenda for Action, was a picture of significant progress made, but off such a low base that the same area could also be identified as a priority for further action. Countries which had been engaged with the Decade Agenda from 1993, had progressed in many areas, whereas many Pacific and other more recent signatory countries were just beginning to address the need to develop disability policy and to establish coordination committees.

National Coordination and legislation

National coordination was an area of considerable achievement. In a Decade which spanned the paradigm shift from a charity to a rights based approach to disability issues, the development of national coordination mechanisms is a significant indicator of acceptance, of a multi-sectoral approach to disability as a broad cross-cutting issue. Many countries reported having formed such committees in direct response to the Decade Agenda and more were in the process of formation. Many coordinating committees were still placed within Ministries of Social Welfare, but signs of change were evident with disability included in national development plans in India, Philippines and Thailand. Increasingly, persons with disabilities were represented on these committees and in several countries, regular consultation took place with specially formed consultative committees of people with disabilities. Committees were being formed at grass-roots level. In spite of the evident progress, it was not clear as to what extent these mechanisms were effectively advancing a disability agenda that was reflected in policy planning, implementation, budgetary and evaluation processes, without which any action represents little more than tokenism.

Legislation is the key to enforcing of implementation of programmes and policies. Less than 25 per cent of ESCAP countries have passed comprehensive disability legislation and only 8 have anti-discrimination measures. The right to equality for people with disabilities, is explicitly enshrined in very few Constitutions. A major constraint to achieving equality for people with disabilities, has been the failure of Governments to pass and then strictly enforce legislation, with significant penalties for non-compliance.

Information and public awareness

One of the most critical issues in the region, is the lack of data and accurate information. The Decade was not able to be more accurately represented. Data are not available to verify the claims of many Governments. The problems surrounding disability data are many and of a serious nature. Adequate universally accepted definitions have not been available within the region, data collected have not reflected the full extent of disability, collection procedures have not been transparent and comparison of data is meaningless.

Training workshops were conducted by UNESCAP and the Statistical Institute for Asia and the Pacific (SIAP) to promote strong awareness of the need for the collection of comprehensive, accurate and regularly updated national information on disability, that can be disaggregated according to a variety of variables. These were conducted towards the end of the Decade and it was realised that this will need to be a priority area for action beyond the end of the Decade. Training will need to be undertaken in all the subregions.

During the Decade, nine Governments did establish national data bases, with five more in the process of development. Questions on disability were included in the national census in eight countries, and specific databases, serving particular purposes in a further eleven. Data collection to facilitate the inclusion of children with disabilities in regular education, was reported by Bangladesh and Pakistan as well as Samoa and the Federated States of Micronesia. Sample and household surveys were also conducted in some countries. Several Pacific Island countries have undertaken comprehensive surveys, assisted by and in partnership with the Asia-Pacific branch of Inclusion International and New Zealand Overseas Development Assistance. These have been completed in the Cook Islands and Samoa and are planned for Fiji, Kiribati, Papua New Guinea, and the Solomon Islands. This is in keeping with an increased attention to disability issues in Pacific Island communities. The issue has been addressed by Pacific Island Ministers of Education in December 2002, and is on the agenda of the Leaders Meeting of the Pacific Island Forum Secretariat, scheduled to be held in New Zealand in August 2003.

UNESCAP supported widespread dissemination of information throughout the Decade. This was achieved by many means, but included the development of the Decade home page website in 1997, recently updated and in the process of further modification (<http://www.unescap.org/sps/disability.htm>). It currently includes the use of interactive discussion as part of preliminary preparation for expert group meetings on such topics as the proposed international convention on the protection of the rights and dignity of persons with disabilities. Decade documents and publications were translated into national languages.

Public awareness, one of few success stories in the 1983-2003 UN Decade of Disabled Persons, expanded enormously within the region during the Asian and Pacific Decade. It

ceased to be an annual event held on one day a year only. Many Governments provided financial support for, and participated in such activities. Activities extended from sporting activities to include artistic, and cultural participation. Interesting developments have included a pilot project started by the Government of India to create awareness of disability capabilities in 22 districts. In a potentially far-reaching measure, they have also introduced disability concerns into the national academies for training of administration personnel and civil servants.

Perhaps the most significant measures for creating public awareness were the annual Campaigns of the Asian and Pacific Decade, attended by increasing numbers of persons with disabilities, as the Decade progressed. Campaigns were held in Japan (1993), Philippines, (1994), Indonesia (1995), New Zealand (1996), Republic of Korea (1997), Hong Kong, China (1998), Malaysia (1999), Thailand (2000), Viet Nam (2001) and the final Campaign in Osaka, Japan (2002). The impact on the host country was very great, and resulted in many steps taken by Government as a result, and strengthening of motivation amongst all participants for working towards the goals of the Decade. Some of the side benefits were the strong networks formed (women with disabilities), and life-long friendships made, across all barriers.

Accessibility and communication

Lack of access to the physical environment has been one of the most restrictive barriers faced by persons with disabilities in the region, even more so for people in rural areas or living in slum conditions in urban poverty. This was an obvious area of need and has received a lot of attention. Tangible results have been achieved and momentum gained to continue the necessary work to make the Asian and Pacific environments universally accessible.

UNESCAP has played an active and comprehensive role in promoting non-handicapping environments. Regional guidelines were developed, covering planning and building design, access policy provisions and legislation and the promotion of public awareness to improve access. Pilot projects were carried out to support the implementation of the guidelines at municipal level. They were implemented in Bangkok, Beijing and New Delhi. In each city, a pilot project site of approximately one square kilometre was selected and made accessible. Training workshops were carried out in each of the pilot project cities, with disabled persons as participants, in the final workshop. In Bangkok, a beautiful and fully accessible park is used by thousands, on the banks of the Chao Praya river. Braille blocks abound, five of the sky train stations are accessible, and the underground train system currently approaching completion, will be fully accessible.

Published training guidelines for disabled trainers (4) have been field-tested in India, Thailand and Malaysia. Training on accessible transport was carried out in China in 2000. An innovative event was held in Bali, Indonesia, also in 2000, when the first Asia-Pacific

Conference on Tourism for Persons with Disabilities, was organised by the CBR Training Centre in Solo, Indonesia, in partnership with the Government of Indonesia and UNESCAP. This was a clear indication that disability concerns were penetrating mainstream development in many areas and now included tourism.

A series of regional training of trainer workshops on the promotion of non-handicapping environments for persons with disabilities have taken place in Bangkok in 2000, 2002 and 2003. Teams of architects, urban planners, and disabled persons from 11 countries have attended, building up national level expertise to address the issue of accessible environments. This initiative has resulted in the formation of a regional network of persons with disabilities, architects and urban planners who are actively engaged in training concerned government officials, advocating non-handicapping environments at municipal, provincial and national levels. They exchange information and seek advice from each other by means of internet, with rotating network coordination role. This has been a highly successful outcome of the Decade, with increased expertise as a result of the emphasis on capacity building within the region.

Accessible communication has improved during the Decade, but is clearly not available to the majority of people with disability, particularly those who live in rural areas and urban poverty. In Thailand sign language was declared the national language of deaf people, and sign language interpreters are widely available for hire. In the region, Braille, sign and close captioning are still not widespread.

Access to information and communication technology (ICT), has become an issue for persons with disabilities during the course of the Decade. Computer and ICT literacy are of the utmost importance in transforming lives and enhancing capacity, to gain jobs and livelihoods. The Republic of Korea conducted an interesting research which revealed that persons with disabilities have 75 per cent less opportunity to access the internet, than non-disabled persons. As a result, legislation has been passed to take action to redress this imbalance and enhance the ICT capacity and skills of persons with disabilities. A number of other countries are taking steps to ensure that persons with disabilities are not on the wrong side of the digital divide. In Turkey, free access to computers is provided.

Education, and Training and Employment

The issue of access to education for children with disabilities, is one of the most critical concerns facing the region. Failure to educate young children with disabilities, limits all opportunity for their future development. It reduces their chances of receiving training, employment, engaging in income generation or business development, and of becoming valued members of their families and communities. It greatly increases the likelihood of their lives being lived in poverty.

Data available from a survey conducted by UNESCAP in 1999, suggested that only 2 to 5 per cent of children with disabilities were receiving an education (5). Few countries know how many children with disabilities they have, how many are in school and whether this number is increasing. This situation exists 13 years after the Education for All initiative was launched in Jomtien, in 1990 and reaffirmed in Dakar, in 2000 (6).

By the end of the Decade, there was evidence that education was receiving more attention by Governments in the region. Twenty countries had passed legislation mandating education for all children, although only seven reported that children with disabilities were included specifically in national 'education for all' plans. More emphasis was being placed on data collection on children in education and on the provision of Government funding, for the education of children with disabilities.

Special schools were still the most common form of educational provision, often started by NGOs, and mostly located in urban areas, but inclusive education was becoming much more widespread. Compulsory education in China, mandated in 1993, and significant programmes of integrated education in India have reinforced this trend. An innovative project in Laos PDR, has received a lot of attention and is viewed as a model for neighbouring countries. In 1993, there was only one school in Laos serving 25 children with disabilities. In 2002, there were 65 kindergartens, 142 primary schools, and 9 secondary schools all operating on an inclusive model. By 2005, it is expected that all 141 districts will have at least 3 inclusive education schools. The Laos example is important because it refutes the notion that only wealthy countries can afford to develop an inclusive education system (7).

Early intervention became more widely available, with services planned or in place in 22 countries. Pre-school services were growing and there was some access to post-school or tertiary education for young people with disabilities. Teacher training was still limited, with only 13 countries reporting that they included special training for regular class teachers. Major barriers to the provision of quality education for children with disabilities, includes the lack of early identification and intervention services, negative attitudes and exclusionary practices, inadequate teacher training, particularly training of regular teachers to teach children with diverse abilities. There is a need for restructuring of schools to link them more closely with their communities, to ensure that curriculum is more flexible, specialist support staff and appropriate teaching equipment and devices available. These issues will need to be addressed in the next Decade.

The importance of vocational training for youth with disabilities was beginning to be acknowledged and there was a shift taking place which enabled more young disabled people to participate in integrated training services. In Hong Kong, more than 80 per cent of graduates from skill centres found jobs in open employment. But the over-representation of persons

with disabilities in poverty statistics, suggest there is a long way to go, before youth with disabilities have equal chances of gaining skills and entering employment.

A wide range of strategies for employment promotion were in place, with quota systems ranging from 3 to five per cent. In India this is funded from poverty alleviation programmes. Enforcement was encouraged by means of incentives and fines. Additional strategies included the use of job search agencies, employment placement and support centres, wage subsidies, job coaching, trial employment, and industrial profiling. Positive collaboration was increasing with partnerships between Government and trade unions and between employer networks and federations of employees. There was real concern to increase measures which would result in income generation, self-employment and rural employment. Increasing employment opportunities is one of the key measures needed to reduce the incidence of people with disabilities living in poverty.

PREVENTION OF CAUSES OF DISABILITY, REHABILITATION AND ASSISTIVE DEVICES

Awareness on the importance of prevention of the causes of disability was well-developed during the Decade and 25 countries reported strategies implemented through their health programmes. Early identification and early intervention services for infants with disabilities and their families improved. There was a reduction in infant mortality, and in disability in infants due to preventable causes such as deficiencies in iodine, folic acid and vitamin A. Nutrition education was expanded, as was health and family planning for girls and women with disabilities. Some improvement in reducing disability due to birth injury, was achieved by giving extra training to traditional birth attendants. Immunisation programmes were widely implemented. The training of grass roots workers in preventing causes of disability has led to the establishment of an extensive network of rural district rehabilitation centres.

Community based rehabilitation (CBR), has been extensively developed in countries like India, Bangladesh, China, Indonesia, Malaysia and the Philippines. Other countries which are increasing their CBR coverage include Thailand, Sri Lanka, Solomon Islands and Vietnam to name a few. Some examples of 'urban' CBR were reported, particularly in densely populated Hong Kong. Some concern was expressed that the impetus to develop CBR programmes was diminishing. The Decade has seen a debate about the most appropriate CBR models, and the role of people with disabilities in the management and leadership of CBR programmes.

Although some countries have actively pursued a policy of developing capacity to make low-cost, local assistive devices and aids, others are totally reliant on donor agencies, for support to provide these essential devices. In either case, there is a significant shortfall in availability

and the need within the region, is largely unmet. Priority attention needs to be placed on this issue, at regional and subregional level, to alter the situation for millions of persons with disabilities, who are currently prevented from participating fully in family, community and economic life. As is so often the case, the situation is worse for rural people with disabilities. The development and dissemination of indigenous technology and materials in China and India, and the School of Orthotics established in Cambodia, need to be examined to see if they offer solutions that could be used by other countries in the region.

Self-help Organisations (SHO)

The voice of persons with disabilities has strengthened during the Decade. The paradigm shift from a medical to a social model of disability, has been accompanied by the realisation that people with disabilities have the right to speak for themselves, and should be consulted on all matters which concern them. In addition to the extensive networks of national organisations of the World Blind Union and the World Federation of the Deaf, 22 national cross-disability organisations of people with disability, have been formed in the region, with others in the process of being started. Governments were increasingly seeking consultation with these self-help organisations (SHOs), and providing funds to support their development, indicating that the Government values the role that they play in disability concerns.

The extent to which SHOs operate at extend to the grass roots level is not clear, but in a number of countries, they are playing an important leadership role in community-based services. In some Pacific island countries organisations of families with disabled members have been formed and have been effective in advocating successfully for appropriate education for their children, and on other issues of particular concern, to them and their families. The need for SHOs to adopt issues of children with disabilities in their advocacy platform is apparent. Children with disabilities are unable to advocate for themselves. Parents are frequently not welcome as members of SHOs. This weakness may have contributed to the very slow progress made in the region in achieving the right to education for children with disabilities, in spite of international mandates. Advocacy can be a powerful tool and needs to be used in the interests of all person with disabilities, including children with disabilities.

Regional Cooperation

One of the outstanding achievements of the Asian and Pacific Decade was the strength and collaborative nature of the partnerships formed, harnessing energy from diverse sources, to help make the Decade dream, a reality for people with disabilities in the region. The Central Asian and Pacific subregions became engaged with the Decade later and to a lesser degree, than countries from the other subregions, but by the end of the Decade 15 of 21 Pacific island countries had signed the Decade Proclamation. The Pacific subregion was the first to establish clear priorities for the next Decade. It has developed strong internal networks with organizations of persons with

and without disabilities working closely together toward common goals, extending reach and assisting countries not yet engaged with the Decade agenda.

A coordination mechanism named, the Thematic Working group on Disability-related Concerns (TWGDC) (previously known as the RICAP Committee) had members from Government, United Nations Agencies, international, regional and national NGOs and others with a specific concern about disability issues. This group was the main implementing, monitoring and evaluation partner of UNESCAP throughout the period of the Decade. The annual Campaigns were organised by the Regional and National NGOs (RNN). The distinguishing feature of TWGDC was the strength of the NGO participation. Many Governments contributed significantly by hosting a variety of meetings, workshops and seminars, focusing on policy areas of the Agenda for Action, in addition to the countries which hosted the annual Campaigns referred to, earlier. The Government of Japan, and to a lesser extent the Government of China, provided support and generous contributions which enabled the many and varied activities of the Decade to be carried out so successfully.

THE FUTURE

The progress of this first Asian and Pacific Decade of Disabled Persons, exceeded expectations but the clear message that came out of the detailed evaluation of achievements, was that there is no room for complacency. Progress made was uneven and in most cases from such a low baseline, that it would be surprising indeed, if ten years of attention were sufficient to wipe out the decades of neglect and rejection, which persons with disabilities, have experienced for generations in this region, and indeed around the world.

Significant changes in attitude, in acknowledgement of the rights of persons with disabilities, still have to be translated into continued action, to fully empower persons with disabilities and to ensure that their concerns are reflected fully in national development agenda throughout the region and that progress toward this goal is maintained and sustained. The link between poverty and disability must be addressed - and redressed.

At the fifty-eighth session of the Commission a resolution was adopted by member Governments, proclaiming the extension of the Decade for a further ten year period, from 2003 - 2012. At the Intergovernmental Meeting to Conclude the first Asian and Pacific Decade of Disabled Persons, held in Otsu, Shiga, Japan in October 2002, members adopted the Biwako Millennium Framework for Action Towards an Inclusive, Barrier-free and Rights-based Society for Persons with Disabilities, in Asia and the Pacific (BMF) (8). This is the policy framework that will guide Governments and their partners, in implementing actions to achieve the goals and targets of the second Decade.

The BMF has identified seven priority areas for action, but has nominated these with the understanding that the Agenda for Action of the first Decade will be maintained to guide action

in countries, where progress is at an early stage, as is the case for many Pacific Island and other least developed and developing countries. The seven priority areas of the BMF are: self-help organisations of persons with disabilities and related family and parent associations; women with disabilities; early detection, early intervention and education; training and employment, including self-employment; access to built environments and public transport; access to information and communications and assistive technologies; and poverty alleviation through capacity-building, social security and sustainable livelihood programmes. For each priority area critical issues, targets and action required to achieve the targets, have been identified. Where appropriate, a disability dimension has been included in the Millennium Development Goals, which were designed initially with no reference to persons with disabilities (9).

The framework is concise, the targets clearly defined and the actions for achievement specified. Commitment within the region is strong, collaborative partnerships are established and it is hoped that the next ten years will bring measurable improvements to the quality of the lives of persons with disabilities, thus enriching the lives of all who live in the Asian and Pacific region.

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CATEGORISING CBR SERVICE DELIVERY: THE ROI-ET CLASSIFICATION

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ABSTRACT

This paper presents a descriptive classification framework developed in a training workshop conducted with a community based rehabilitation (CBR) service, in Roi-Et (Northeast Thailand) in June 2002. The "Roi-Et Classification" is based on an adaptation of Bronfenbrenner's Social Ecology model, combined with other frameworks. It seeks to depict for CBR workers and others, the spectrum of strategies that together can comprise CBR practice. It is intended that the Classification and identified strategies will assist in generating discussion about what aspects of CBR intervention should be emphasised within a particular community or service at a particular time. The Roi-Et Classification describes fifteen different elements of CBR service delivery, across two axes or dimensions. One axis identifies four ways in which CBR services are made available (direct provision, assisting, participating and advocating). The other axis identifies five levels of focus of CBR service delivery (individuals, families, communities, formal structures and societal attitudes/beliefs). The Roi-Et Classification is presented in an easy-to-understand, diagrammatic form. While it is anticipated that the Classification will continue to evolve over time, it is hoped that initially, it may contribute to discussion on what comprises (or might comprise) CBR practice, and may also inform CBR conceptualisation, training and evaluation.

INTRODUCTION

A series of workshops and CBR consultancy were conducted by the first author in June 2002, with the Roi-Et Rehabilitation Services for the Rural Blind, which operates under the auspices of the Christian Foundation for the Blind in Thailand, a registered foundation under the patronage of the King of Thailand. In addition to services for the blind, the Roi-Et centre provides CBR services to a variety of people with disabilities within Roi-Et and adjoining provinces. The service has emerged in response to a variety of needs and seeks to be responsive to people with disabilities, families and communities. The success of the Roi-Et CBR service (as with many CBR projects and services) relies largely on the creativity, skills and commitment of staff and managers.

The workshops were developed in recognition that:

- It is beneficial for staff and management to have occasional opportunities for 'taking stock', reviewing their current practice and planning future approaches;
- workers should be able to consider, discuss and critique different models of practice in light of their community experience;
- ideally any service model employed in a CBR service should respond to the needs of people with disabilities, their families and communities in a holistic way.

A fundamental premise of the workshop and the Classification was the recognition that CBR services are usually delivered at a number of levels and in a variety of ways (1). CBR is understood not just as an individual or therapy response to people with disability, but as a social, vocational, economic, educational, justice and development initiative. The Classification proposes that this breadth of practice is mostly healthy and should be further fostered.

THE ROI-ET CLASSIFICATION

The version of the Classification presented here, is adapted from an earlier version that was developed and used in training to assist CBR workers and managers in the town of Roi-Et, North-East Thailand. The name of the town means 'one hundred and one' and was adopted for the classification because it reflects something of the variety of ways CBR can be delivered and understood.

Fundamentally, the Classification identifies many of the disadvantages that people with disabilities face - physical, social, informational, access, financial, attitudinal, and indicates mechanisms by which CBR workers might contribute to responding to those disadvantages - by providing support, services or assistance at appropriate levels in appropriate ways. Table 1 provides an overview of the Classification, which is illustrated by figures 1-15.

THE COLUMNS

The four columns in Table 1 depict different ways in which CBR services are made available. They reflect the fact that there are different ways of delivering rehabilitation and disability services depending on the needs of the individual, the realities within the CBR service, the workers delivering the services, and the context in which services are delivered. It should be emphasised that there is no implied progression or order of importance among these columns.

Table 1: The Roi-Et Classification of CBR service delivery

		How are CBR services made available?			
		'Providing'	'Assisting'	'Participating'	'Advocating'
Focus of CBR service delivery	Individual	Figure 1	Figure 2	Figure 3	Figure 4
	Family (Micro)	Figure 5	Figure 6	Figure 7	Figure 8
	Community (Meso)	Figure 9	Figure 10	Figure 11	Figure 12
	Structures (Exo)			Figure 13	Figure 14
	Attitudes (Macro)				Figure 15

The four ways of delivering CBR services depicted here, are drawn from experience and relevant literature which identifies different methods of service delivery (2,3,4). These categories accommodate the participation and self-development of disabled people and the potential of CBR as a vehicle of change in communities and society, influencing power relations and inequities, as well as the development of rehabilitation policy (5, 6).

Providing

Services described in the first column in Table 1, would include the provision of services, therapy, information, resources, aids, funding, etc. In general, this form of services requires the CBR worker to have particular skills or content knowledge or access to specific desired resources. In some instances, this form of service delivery might be delivered by remote means, such as the Internet.

Assisting

The second column describes service delivery in which recipients of services play an active role. There is less onus on the CBR worker to be a direct resource, but a recognition, that by virtue of their position, they may be able to provide some leverage to people with disabilities to assist them to lessen their disadvantage.

Participating

The third column in Table 1 acknowledges that increasingly, participatory aspects of CBR service delivery are being emphasised. Participatory approaches include those in which the CBR worker works in a participatory manner with service recipients. Ideally, the CBR worker's 'participation' would be facilitated by them being a person with a disability, a family member or a member of the community with whom he or she is working.

Advocating

The fourth column identifies advocacy as a potential part of CBR services. It acknowledges that CBR workers might speak, write, or act on behalf of the interests of a person (or persons) with a disability, or those associated with them. The purpose of this action may be to promote, protect and defend the welfare and justice of individuals or groups.

THE ROWS

The five rows in Table 1, are intended to depict the individual person with a disability and the key contexts that impact on their lives. The five rows are essentially an extension of Bronfenbrenner's Social Ecology Model (7) which were adapted by the first author to include the individual (including biological and psychological) factors (1). This model describes a person's social environment or 'social ecology', which is helpful for understanding social and community variables that impact on the life of a person with a disability. The rows identify key focus points or levels of CBR service delivery.

Individual

The first row, depicting individual level service delivery would include those activities which people mostly associate with rehabilitation. The provision of different types of services to individuals with a disability is a key element in CBR practice.

Family

The second row in Table 1, encompasses services that are focussed on the family of the person with a disability. Depending on the nature of the services being provided, the family is usually fundamental in CBR and plays a key role in assisting the person with a disability. Consequently, the family is also a focus level of CBR service delivery. This level may be seen to roughly correspond with the 'micro-system' in Bronfenbrenner's social ecology model, in which he described immediate person-to-person social relationships, which are key influences in a person's life.

Community

The third row depicts the community level focus of CBR. This might include activities in which the community is the focus for the actions of the CBR worker or service. This corresponds with the 'meso-system' in Bronfenbrenner's typology, which acknowledges the importance of networks, groups and the local community in the life and well-being of the individual.

Structures

The fourth row refers to formal services or structures that might exist through governments or NGOs. This may include the disability service system, educational systems, the health care system, social welfare system, etc. These structures, which Bronfenbrenner described as the 'exo-system', clearly have the potential for significant influence over a person with a disability. These influences may include the direct roles and actions of the respective services, as well as their policies and legislation.

Roles, Attitudes and Beliefs

Finally, the fifth row, which corresponds with the 'macro-system' described by Bronfenbrenner, refers to social customs, attitudes and beliefs. It includes social roles and the way in which society assigns status to individuals, objects or events. It may to some extent, be seen as reflecting and influencing other levels, in that it deals with broad societal beliefs, values and lifestyles. This level refers to potential actions of the CBR worker or service that influence these social roles, attitudes and beliefs.

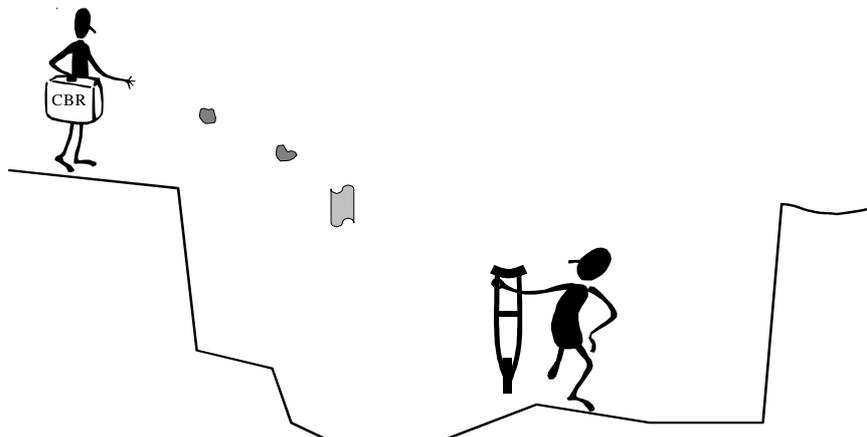
THE FIGURES

The Roi-Et Classification is depicted in diagrammatic form, to promote understanding across languages and cultures. This section describes each figure and details the services or approach that might be provided in it. The person with a disability is portrayed in each of these figures as "in a hole", which is a flawed, but useful way of illustrating the disadvantage or handicap that accompanies disability (e.g. physical, vocational, social, economic, attitudinal or access disadvantage). While we believe that these drawings represent what CBR service delivery does or might include, they are not proposed as the only ways in which CBR might be provided. It is our expectation that the Roi-Et Classification will stimulate debate over what constitutes CBR and that the classification will be further developed and refined over time.

CBR as 'providing' at an individual level

Figure 1, illustrates a CBR worker providing items and services to a disabled person and is what many people traditionally associate with rehabilitation service provision. This would include the provision of direct 'hands-on' therapy, the provision of disability aids or making information available to the individual. Clearly, this type of service responds to a key concern of many people with disabilities and is a centrally important aspect of CBR. Such services are often specifically requested and expected by individuals, families and communities.

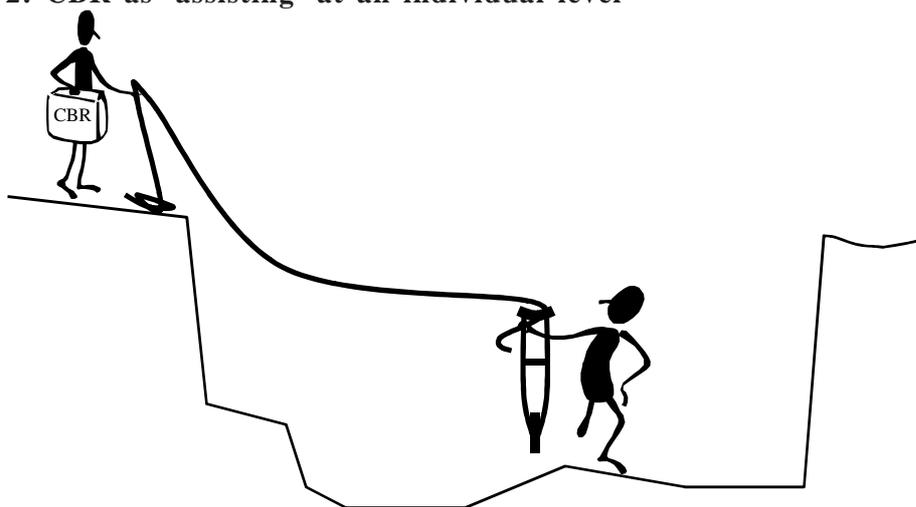
Figure 1: CBR as 'providing' at an individual level



CBR as 'assisting' at an individual level

Figure 2, depicts the CBR worker seeking to assist the person with a disability by 'pulling' them out of their disadvantage. Services that CBR workers provide to assist individuals, but that are not necessarily offered directly to the person with a disability, would fit this illustration. Included in this aspect of CBR might be activities provided by the CBR worker to overcome disadvantage experienced by the person with a disability. Activities that promote individual development might range from encouragement, to the facilitation of work to assist in skills development.

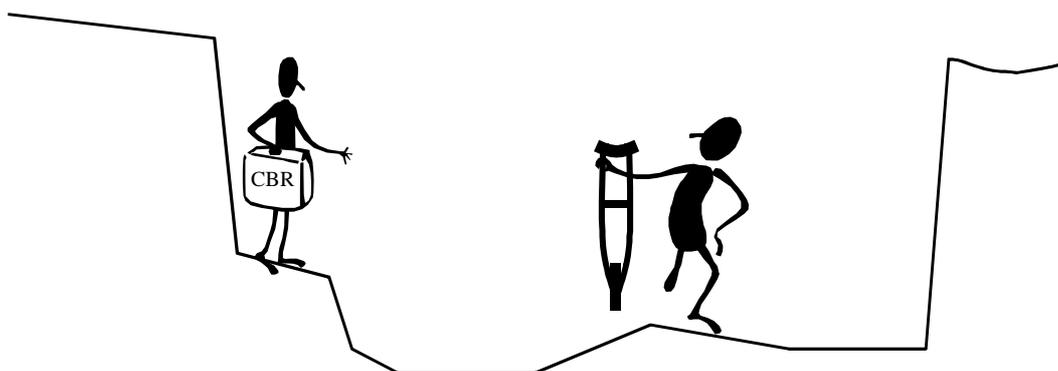
Figure 2: CBR as 'assisting' at an individual level



CBR as 'participating' at an individual level

In the third illustration, the CBR worker reflects a more participatory approach, attempting to deliver services, which require him or her to identify with the person with a disability, in order to work alongside them to address individual disability issues. This aspect of CBR service delivery reflects cooperation between the CBR worker and the person with a disability. It indicates a service response that meets certain needs through a partnership in problem solving. This aspect of CBR service delivery targets those problems that are best addressed by facilitating independence through participatory approaches.

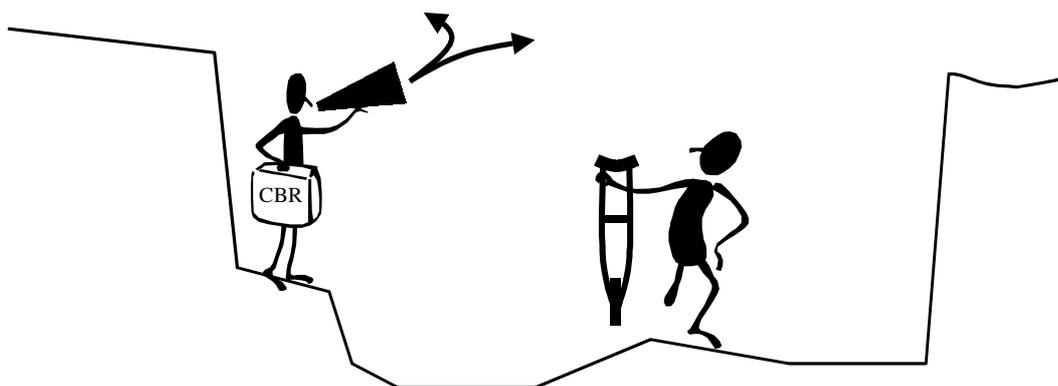
Figure 3: CBR as 'participating' at an individual level



CBR as 'advocating' at an individual level

Figure 4, illustrates advocacy as a mechanism for delivery of services to people with disabilities through CBR. Advocacy can be defined as arguing in favour of, or working for a cause, idea or policy, such as to improve the rights and role of people with disabilities or engaging in activities such as lobbying for access or services. This form of service delivery acknowledges that the social and physical context of the individual substantially influences handicap and rehabilitation outcome. Within this aspect of CBR service delivery, the CBR worker uses his or her position to assist individuals with disabilities. At the individual level, the CBR worker might advocate for, and with the person with a disability, about their role, skills and support needs within their family.

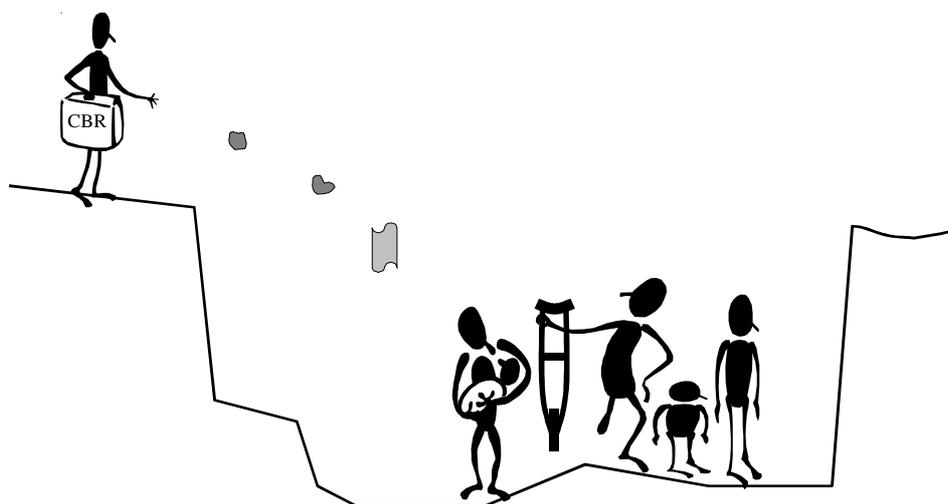
Figure 4: CBR as 'advocating' at an individual level



CBR as 'providing' at a family level

The fifth illustration shows the CBR worker providing direct services to the family. The nature of such services may be much the same as depicted in Figure 1. However in this example, the person with a disability is seen in the context of their family. In addition to therapy, this aspect of service delivery may include the provision of disability aids and modifications in the home.

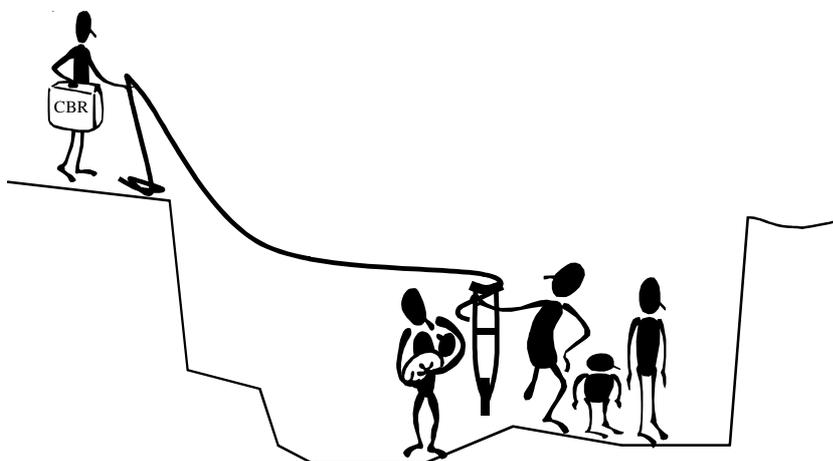
Figure 5: CBR as 'providing' at a family level



CBR as 'assisting' at a family level

In Figure 6, the CBR worker provides assistance at the family level. As with Figure 2, this illustration might include the provision of skills as a way of providing assistance. In this case, skill development would seek to include the whole family. This figure and the next, may be seen to illustrate a major focus of current CBR service delivery, in which skills are transferred to family members (often parents) to assist the family to meet the needs of a person with a disability. In this aspect of CBR service delivery, the family plays a substantial role in service provision.

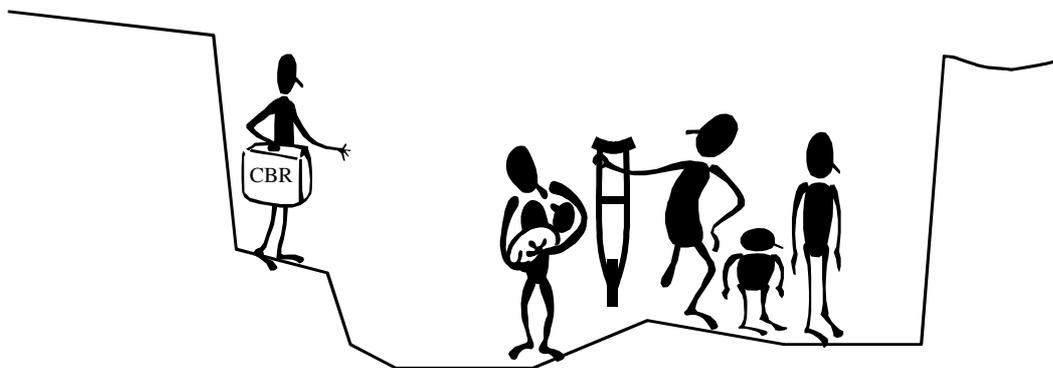
Figure 6: CBR as 'assisting' at a family level



CBR as 'participating' at a family level

Figure 7 depicts the CBR worker as coming alongside the family and participating with them, to address disability issues. As with Figure 3, this aspect of CBR service delivery would be likely to utilise a problem-solving approach and use existing resources to support the family. Strategies within this approach may encourage family solidarity and provide particular support to direct caregivers. Similar to Figure 6, this approach depicts a key strategy within current CBR service delivery, as practised in many settings around the world.

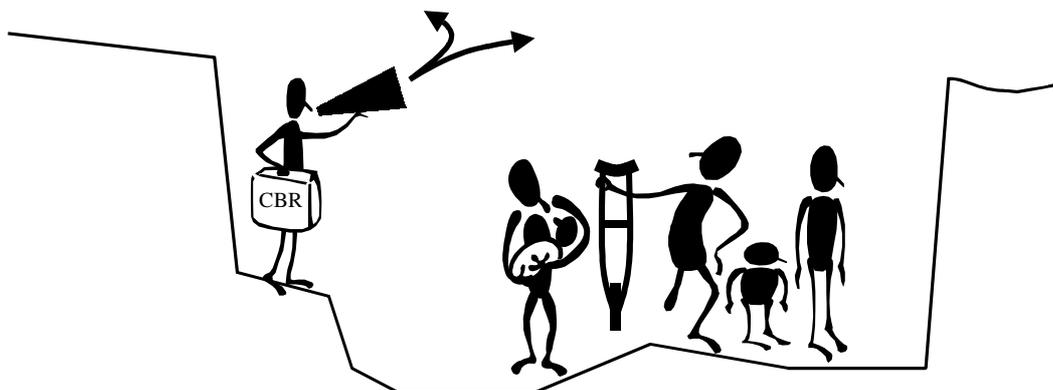
Figure 7: CBR as 'participating' at a family level



CBR as 'advocating' at a family level

The eighth illustration depicts the CBR worker as advocating for the person with a disability and their family. Typically, strategies at this level, seek to address the needs of a particular family by arguing on their behalf, or lobbying for access or services that will benefit the family and the person with a disability. The CBR worker might advocate for and with the family, to the local community or community leaders.

Figure 8: CBR as 'advocating' at a family level



CBR as 'providing' at a community level

As depicted in Figure 9, in some instances, the CBR worker might directly provide services, information, funding or disability programmes to a community, in order to assist people with disabilities in that community.

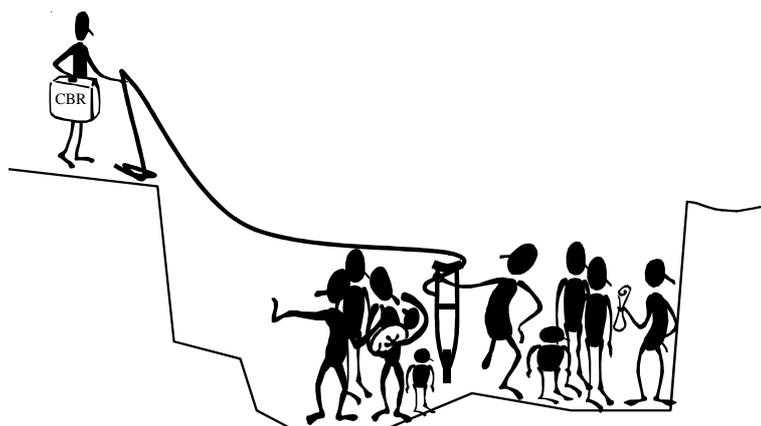
Figure 9: CBR as 'providing' at a community level



CBR as 'assisting' at a community level

Within this aspect of CBR service delivery, the CBR worker may provide assistance (often in the form of skill development or capacity development) to the local community. As depicted in Figure 10, activities such as Participatory Rural Appraisal (PRA) conducted by an 'outsider', may be seen as falling into this aspect of CBR service delivery.

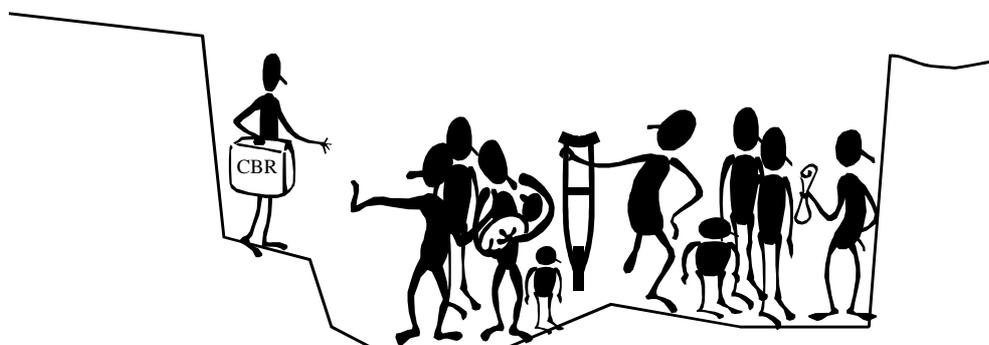
Figure 10: CBR as 'assisting' at a community level



CBR as 'participating' at a community level

As depicted in Figure 11, another aspect of CBR service delivery might include working alongside and being involved in community decision making and problem solving with the local community, around disability issues. This illustration may be seen to depict community development type approaches and may include PRA conducted from within the local community. In such an example as in the previous illustration, the CBR worker might foster and support community initiated activities or efforts, such as self-help groups. A goal of this approach, might be to build greater community solidarity on disability issues.

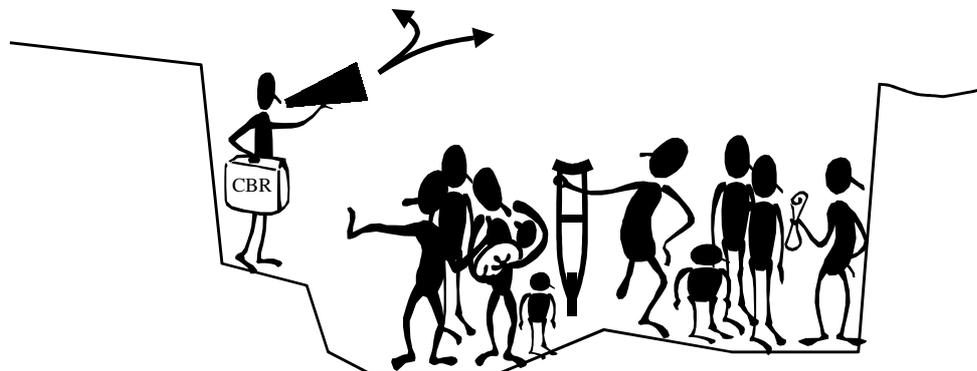
Figure 11: CBR as 'participating' at a community level



CBR as 'advocating' at a community level

Figure 12 also, portrays advocacy, though this time advocating for a community. Such advocacy may involve activities such as community organising, in order to achieve better support or services for people with disabilities within a particular community.

Figure 12: CBR as 'advocating' at a community level



CBR as 'participating' at a structural level

In Figure 13, the level of community, social and organisational structures is introduced as a target for CBR service delivery. In this illustration, structures are depicted as people in charge of budget, health and other formal services and systems. The CBR worker works with the community to influence the formal structures that impact on people with disabilities. An aspect of CBR service delivery in this example, might include working with family or community members to influence the local school to promote integration of children with disabilities. The goal of such activities might be to bring about changes in key service delivery systems such as the health, welfare or education systems.

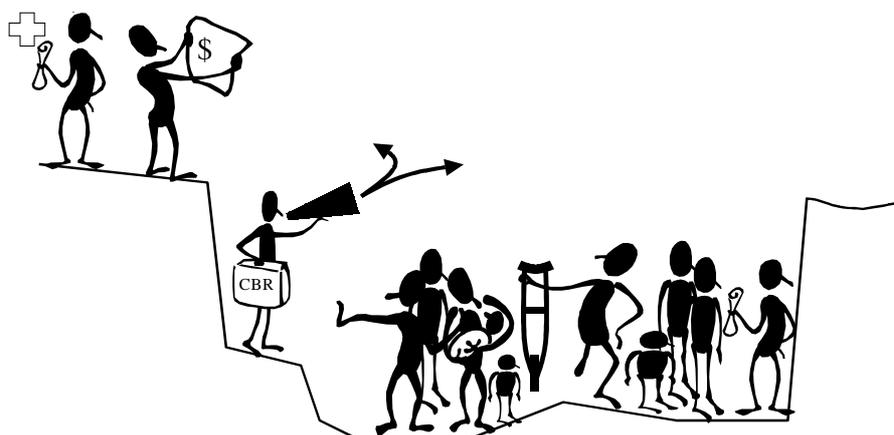
Figure 13: CBR as 'participating' at a structural level



CBR as 'advocating' at a structural level

The aspect of CBR illustrated in the fourteenth figure, is advocacy (conducted with people with disabilities, families and community members). The advocacy of the CBR worker in this illustration is primarily directed toward the formal structures described earlier. Advocating at this level within the structures, usually benefits people with disabilities in general, rather than one individual or a family.

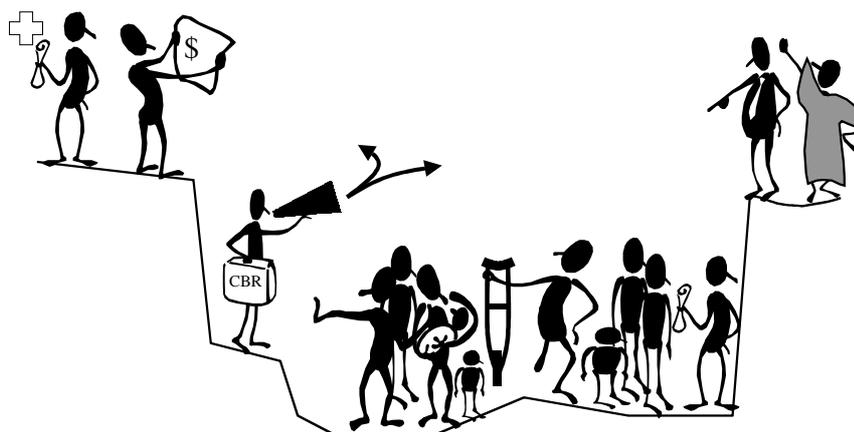
Figure 14: CBR as 'advocating' at a structural level



CBR as 'advocating' at a beliefs, attitudes and roles level

Figure 15 illustrates the CBR worker advocating and seeking to bring about change in social attitudes, roles and social beliefs relevant to disability. Beliefs, attitudes and roles are depicted by religious and social leaders who may influence these factors. This aspect of CBR service delivery, recognises that societal attitudes and beliefs about disability can have substantial positive or negative influence in areas such as social integration, vocational opportunities and access for people with disabilities. The focus for change in this level of service delivery is clearly very broad and includes the whole society, but may, in the first instance be addressed to the media, and social and religious leadership. Seeking to influence government or NGO policy by advocating for, and with people with disabilities, would also fall within this example.

Figure 15: CBR as 'advocating' at a beliefs attitudes and roles level



As noted earlier, the Roi-Et Classification should not be interpreted as a progression with some approaches being superior to others. The current version of the Classification is intended as a description of existing and potential ways of delivering CBR. CBR ideally comprises many aspects or strategies - including medical or therapy, educational, vocational and social responses. Which aspect is emphasised at a particular point in time, within a particular setting, will depend on any number of factors which may include:

- the identified and expressed needs and goals of the person with a disability,
- their functioning, activities and participation,
- their family context,
- their community context,
- the particular issues at hand,
- the physical, cultural, social and economic realities of the broader community and society,
- the nature of service systems and structures within the country,
- the skills and resources of the CBR worker and
- the capacity and structure of the organisation.

The Roi-Et Classification seeks to depict something of this diversity of potential responses to these and other factors.

THE ROI-ET CLASSIFICATION AND OTHER FRAMEWORKS

CBR is a dynamic and complex entity. As such, attempts to classify it will always be inadequate in some respects. Despite this, the authors (and others) see substantial value in attempting to describe, clarify or classify CBR service delivery. There have been a number of very helpful frameworks presented over the years, that continue to inform and guide CBR. The Roi-Et Classification may contribute to the existing discussion and thought, in this important area. To this end, we have also identified some preliminary points of comparison with some important frameworks that have recently been published.

Turmusani and colleagues (5) published a very helpful listing of common interpretations of CBR service delivery in a recent article discussing ethical issues in CBR. They described the following six types of CBR service delivery, which may be seen to have distinct parallels with the Roi-Et Classification.

- The provision of rehabilitation through home based programmes. In the Roi-Et Classification such activities are described as 'providing' and 'assisting' at the individual and micro levels (figures 1,2,5,6).

- Working with communities. In the Roi-Et Classification aspects of working with communities are elaborated in the third row in Table 1 (figures 9,10,11,12).
- Integrating people with disabilities in poverty eradication campaigns. This is not specifically described in the Roi-Et Classification. While such activities may be classified under the columns of 'participating' and 'advocating' (i.e. figures 3,4,7,8,11,12,13,14,15), the lack of specific identification of poverty eradication may highlight an area in which the Roi-Et Classification requires further development.
- Income generating activities. As with the previous point, these activities may come broadly under the columns of 'participating' and 'advocating' (figures 3,4,7,8,11,12,13,14,15), and they may indicate scope for refinement of the Classification.
- Provision of services by people with disabilities. In the Roi-Et Classification, little distinction is made between who provides the services. It would be expected that service delivery by people with disabilities, would be more in line with services described under the 'participating' approach (figures 3,7,11,13). (Though people with disabilities might provide services in a participatory or non-participatory manner depending on their approach, the nature of the issues, and a host of other variables).
- Human rights focus. In the Roi-Et Classification, this form of CBR service delivery is mostly consistent with that described under the 'advocating' column (figures 4, 8, 12,14,15).

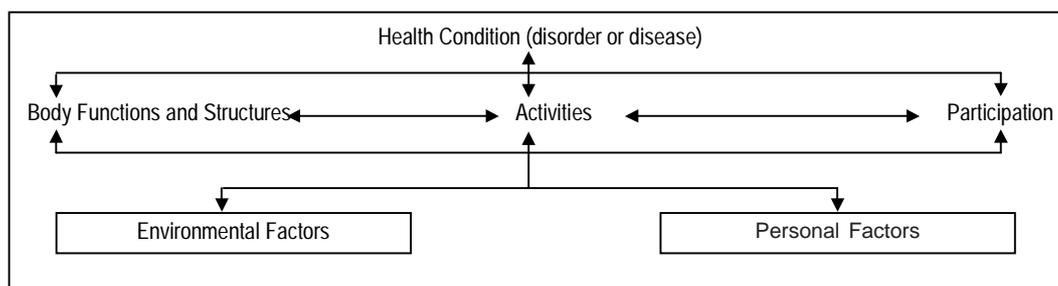
In a very different but innovative classification system developed for evaluation purposes by Huib Cornielje and colleagues, (8, 9) four dimensions were proposed. While the intent of this classification system differs from that in which the current system was developed, some overlap may be noted between them.

- The first dimension classifies three types of service activity (restoring physical function, social and economic rehabilitation, rights perspective). These three types of service activity may be loosely classified under the columns (Table 1) of 'providing' and 'assisting' (restoring physical function), 'participating' (social and economic rehabilitation) and 'advocating' (rights perspective).
- Their second dimension classifies the degree of involvement of people with disabilities in the management of the enterprise (minimal, limited or full). This is an important organisational issue, which is not expressly dealt with, in the Roi-Et Classification. The focus of the Roi-Et Classification is primarily service delivery rather than management structures (though it might be expected that participatory service delivery might arise from participatory management structures).
- The third dimension in Cornielje's framework classifies the focus of the service (individuals, family, community). This dimension may be seen to equate directly with the first three rows of the Roi-Et Classification (Table 1).

- Their fourth dimension classifies the variety of strategies and integration of a CBR service within a service network. To some extent, this dimension may be seen as evaluating whether the CBR service demonstrates something of the range of strategies described in the Roi-Et Classification.

A significant recent development pertaining to any conceptualisation of disability, rehabilitation or service provision, is the recent release by the World Health Organisation, of the International Classification of Functioning, Disability and Health (ICF) (10). The ICF proposes an interactive model of disability, where a person's body functions and body structures interact with activities, participation and environmental and personal factors to affect, either positively (facilitating) or negatively (inhibiting), all aspects of a person's condition, function, participation and lifestyle (Figure 16).

Figure 16 Structure of the ICF



One of the defining aspects of the ICF is that it seeks to emphasise the influence of environmental factors over a person's functioning and disability. (Interestingly this may be seen to highlight one of the strengths of CBR over other models of rehabilitation service delivery, in its acknowledgement of the importance of environmental factors, such as family issues, community issues, local access issues, etc.).

With reference to the ICF, it may be noted that in the Roi-Et Classification:

- The first column ('providing') mostly pertains to the sorts of interventions that can influence 'body functions' and 'structures'.
- The 'assisting' column may be seen to relate to the ICF category of 'activities,' in which people with disabilities engage.
- The third and fourth columns ('participating' and 'advocating') would appear to relate to 'participation' in the ICF model.

- The 'assisting', 'participating' and 'advocating' columns in the Roi-Et Classification, categorise activities that address 'environmental' issues documented in the ICF.

CONCLUSION

As noted previously, the Roi-Et Classification is not presented as a hierarchy in which some forms of service delivery are preferable to others. It is suggested that each aspect has a place in the assortment of strategies that together comprise the universe of CBR service delivery.

The Roi-Et Classification describes different ways of delivering services and different contexts in, and through which CBR might be delivered. The Classification has interesting parallels with previously published frameworks, providing a greater level of detail in classifying many of the complexities of CBR service delivery. While it is anticipated that the Classification will continue to be developed and refined over time, it may assist those involved and associated with CBR to: (a) broaden the ways in which they think about CBR; (b) identify skills and resources needed to work towards desired outcomes for people with disabilities; (c) identify skills and resources needed to work in particular settings; (d) structure a CBR curriculum or training programme; or (e) divide relevant tasks between workers, people with disabilities, managers, self help groups, communities and others.

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MANAGEMENT OF CHILDREN'S HEALTH IN THE AUSTRALIAN COMMUNITY

Carol O' Donnell*

ABSTRACT

Health risks for Australian youth are discussed in order to make suggestions for their control. Health statistics are examined and a historical description of key developments in Australian family and indigenous policy is provided. While the physical health of youth has improved, there is growing concern about their mental health. This problem can be understood partly as a result of past treatment of deviation from the expected conduct norms of the dominant community, and partly as the consequence of comparative deprivation. Services should be broadly and flexibly coordinated on a regional and community basis to promote health, education and development, including prevention of child abuse and neglect. Key stakeholders should work in partnerships with government and non-government service providers, to deliver health and related services, using a quality management approach to meeting community needs with regionally pooled funding. Self-governance based on relevant international conventions is vital to the process.

INTRODUCTION

HEALTH OF AUSTRALIAN YOUTH

Health is relative. Approximately 600 million of the world's two billion children under eighteen live in absolute poverty. In the poorest countries, children under fifteen are 40% of the population. Poverty is therefore disproportionately absorbed by children (1). Of the fourteen million children under the age of fifteen who had lost their parents to AIDS by 2001, around 90% were in sub-Saharan Africa (2). In 2002, a meeting of the World Summit on Sustainable Development pointed out that one in five children in the poorest parts of the world, will not live beyond their fifth birthday because of environment related diseases. It adopted the goal of reducing this mortality rate by two thirds, by 2015, through addressing household water quality and availability, hygiene and sanitation, air pollution, disease vectors, and injuries.

In Australia, despite community concern about childhood obesity, statistics suggest the physical health of children is excellent. However, mental health should now be a major focus (3, 4, 5). Most Australian women have access to effective fertility control. The birth rate has fallen to 1.7. Despite substantial continuous decline, drowning and motor vehicle accidents remain

the leading causes of death for children under fourteen. Injury, including poisoning, is the third most common reason for hospitalisation, after respiratory and perinatal conditions. Asthma is a leading contributor to childhood illness. Some states require all children to be immunised before commencing school. This prevents diphtheria, tetanus, whooping cough, poliomyelitis, measles, mumps and rubella. The dental health of children is excellent, due to fluoride in the water.

Mortality rates for those aged 14 to 24 are lower than for all age groups, except younger children. Death has been declining, mainly due to reduction in motor vehicle related deaths. Teenage fertility fell sharply between 1971 and 1997, and there have been reductions in new HIV diagnoses. However, mental health disorders, including drug dependence, are a major concern. Two thirds of teenage deaths are attributed to injury. Alcohol dependence and motor vehicle accidents are the greatest problems. Over the period 1979-98, the suicide rate rose by 40%. The death rate from drug dependence among young people in 1998, was almost 5 times the 1979 rate. There are more than three male deaths for every female death and higher male death rates for accidents and suicide, account for most of the difference. On the other hand, rates of depressive disorders are three times higher for young females, and the female hospitalisation rate for attempted suicide is greater for females at all ages, despite the much higher suicide rate for males. The 20% of males in the lowest socio-economic group are 1.7 times more likely to die and 1.4 times more likely to be hospitalised, than the 20% of males in the highest socio-economic group. Socio-economic differences in death and hospitalisation are less pronounced for females.

The relationship between poverty, unemployment and poor health is clear. According to the Australian Institute of Health and Welfare, the risk factors for poor health, particularly in the pre-school years, include difficult temperament, harsh parenting, abuse or neglect; parental mental illness or substance abuse; family conflict, low socio-economic status, and poor links with the community. Social and economic disadvantages such as poor education, unemployment and social issues such as lack of connectedness, have also been shown to have negative effects on the health of youth. However, the profile of health risks in Australia must also be understood in the historical context of the changing expectations of the dominant community. For example, in the 1960s, only white males were allowed to drink in public bars. Acceptance of their heavy alcohol consumption meant its causes and effects were unlikely to be conceptualised as health problems. On the other hand, levels of motor accident death declined sharply, when heavy penalties for drink driving were eventually introduced (6).

COMPARATIVE HEALTH OF INDIGENOUS AUSTRALIANS

In 1998, the first national health promotion goals for cancer, cardiovascular disease, injury and mental health were established in Australia. A national programme aimed at improving

Aboriginal health, was set up. Fostering participation of communities and individuals in decision making at all levels of health service, planning and delivery is also a major national goal (7). In 2001, 410,003 people or 2.2% of the Australian population reported being of Aboriginal and/or Torres Strait Islander origin, up 16% since the 1996 Census (8). About one in four indigenous people live outside urban areas, compared with one in seven other Australians (9). The life expectancy of an indigenous man is 56 years and 63 years for a woman, compared respectively with 76 and 82 in the total population. Indigenous people appear to be about 70% more likely to be disabled or handicapped, than the population as a whole. Lack of essential services, including housing, clean water, electricity, sanitation, health care and education, are factors which combine with unemployment, poor nutrition and drug abuse to explain comparatively poor health.

Improvements in indigenous life expectancy over the past two decades have primarily resulted from reductions in infant mortality and infectious and parasitic diseases. However, indigenous infant mortality rates continue to be more than three times the rate for all Australians in some areas. The 1986 Australian census showed that in the 15-19 years age group, indigenous fertility was almost five times that of non-indigenous people and twice as high for the 20-24 age group. Although indigenous fertility rates have halved in the last decade, in 2001, more than 20% of indigenous births were to women aged less than twenty, compared with 4.2% of those to non-indigenous women. Currently, forty percent of Aboriginal and Torres Strait Islander people are under the age of fifteen. The indigenous advocates Dodson and Jonas respectively note that the age structure in indigenous communities is typical of an underdeveloped country, and that this has enormous consequences (10).

Australian domestic violence research shows a link between alcohol and violence. It also suggests the presence of dependent children in a relationship, increases the likelihood of violence continuing (11). Men are more than twice as likely as women to have substance use disorders and 22% of males aged 18-24 appear affected (12). Alcohol disorders are about three times as common as other drug disorders. Women are more likely than men to experience anxiety disorders, and 11% of young women aged 18-24 report mood disorders. This is more than three times the rate for men of this age. Unemployed people generally have a high rate of substance use and anxiety disorders. Death rates for Aboriginal and Torres Strait Islander youth are almost three times higher for males and twice as high for females as for their non-indigenous counterparts. In 1996-97, almost half of all women admitted to hospital for reported domestic violence were indigenous. Twenty percent of victims and 22% of offenders in intimate partner murders were indigenous. Aboriginal and Torres Strait Islander children make up 28% of all children in the Australian care and protection system.

HISTORICAL CONTEXT OF AUSTRALIAN FAMILY POLICY

The current situation of Australian youth must be understood in historical context. During the 1960s, the advent of an effective contraceptive pill coincided with the general trend towards greater levels of Australian female participation in education and work. In 1972, the Whitlam Labor government introduced a wide range of social policy initiatives primarily as a result of growing community demand for the equal treatment of women, migrants and Aborigines. (indigenous people did not get the vote until 1967). Equal pay cases were initiated. Pearson points out that before this, many Aborigines had a low-paid but vital place in the Northern Australian cattle industry. Later there was increasing dependence on welfare handouts (13).

In 1975, no-fault divorce legislation was introduced. A supporting mother's benefit (retitled the supporting parent's benefit in 1977, and the sole parent pension in 1989) was established, making it possible for a woman to care for a child outside marriage. Prior to this, 'illegitimacy' was a source of great shame. In the general community, an unmarried pregnant woman was expected to marry immediately, or hide and have the baby adopted at birth. Nobody spoke about it (14). In 1972, safe abortions became available after a NSW court found that abortion was legal if a qualified doctor said it was necessary to preserve the woman's mental or physical health. The Medibank system of taxpayer funded universal health care provision, was first introduced in 1973, but dismantled when the Labor government lost office. Labor reintroduced a similar Medicare system in 1984. It performs comparatively well (15). In 1988, a Commonwealth child support scheme was introduced which aims to ensure that parents not living with their children contribute to their upkeep. The Family Law Act was amended to ensure that the courts ordered more adequate levels of maintenance. A child support agency was established to enforce regular and timely child support payments through the taxation system.

The Commonwealth Child Care Act was passed by the Liberal coalition government on the eve of the 1972 election, which brought the Labor government to power. The latter greatly increased funds available for child care (16). It reversed the previous policy by primarily funding long day care centres suitable for use by women in the paid work force. Earlier, the lion's share of funding had gone to sessional pre-schools, through a submission-based funding model. (Housewives from comparatively privileged backgrounds usually made submissions most effectively). Economic support was increased for family day care schemes, where women who are looking after their own pre-school children at home, take on the care of extra children for a fee, with back-up support from local councils.

Other childrens' services may be grouped under substitute care or child protection. The latter services are designed to combat child abuse and neglect. Their origin is comparatively

recent. State welfare departments and other church or welfare organisations have played a role in substitute care and adoption, since the earliest days of white colonisation, whenever children were abandoned or taken from parents. However, the first article on abused children appeared in the Australian medical literature only in 1966. This was path-breaking public evidence, that parents and the community were failing to care for children adequately. Later, the Commonwealth Labor government established the Royal Commission on Human Relationships, which addressed formerly taboo topics such as domestic violence, rape, child abuse, and sexuality. This led to government support for refuges and counselling for women and young people. Formerly, the church and charitable groups had been the sole service providers.

Requirements for medical practitioners to report physical and sexual abuse were introduced in NSW in 1977. Most States have introduced systems for compulsory reporting. Family court staff are required to report all suspected cases under the Family Law Act. Under the NSW Children (Care and Protection) Act of 1987, teaching staff are also required to report suspected cases of abuse. Specialist sexual assault services were set up. Members of the community may also report suspected child abuse to the Department of Community Services (17).

These historical changes contributed to the fact that today many people never marry and around 70% of marriages are preceded by cohabitation. Divorce, single parenthood and blended families are common. A peak of 9798 adoptions occurred in 1971-72, but this had dropped to just over 500 by 2000/01, due almost totally, to decline in local adoptions. Just over half of all adoptions in 2001, were inter-country adoptions. Of Australia's 4.6 million children under eighteen, 1.1 million live with only one of their natural parents, usually because of marriage or a relationship breakdown. Around 88% of children with a parent living elsewhere live with their mother, and 42% of one-parent or step and blended families receive cash child support from the other parent (18).

The stated aim of contemporary family policy is to provide parents with a choice about how to combine paid work with responsibility for care of children. Women are entitled to a year of unpaid maternity leave, and some workers have paid maternity leave. A government funded requirement for twelve weeks paid maternity leave, is now being debated. Currently, day care centres with educational programmes for children under school age are run by government and the non-government sectors, with government subsidy. Pre-schools provide educational programmes and operate on a sessional basis. Local councils usually regulate family day care and provide back-up support to carers. Outside school hours programmes provide for primary schoolers. Occasional care services for preschool children exist, as well as playgroups which meet under parental or carer

supervision. Mobile services for child care and playgroups may provide toy and book libraries as well as parental support to families in rural and remote areas. A regional planning approach rather than a submissions model of funding is necessary, if services are to meet the needs of the comparatively large populations of children in more disadvantaged communities.

HISTORICAL SITUATION OF INDIGENOUS WOMEN AND CHILDREN

The situation of indigenous children has been different from the norm. Through 'protection' acts at the end of the 19th century, state governments could declare them wards of the state and control every aspect of their lives. Manne writes that in 1899 the Chief Protector of Aborigines in Western Australia produced the following typical report:

“The intercourse between the races is leading to a considerable increase of half-castes. Many of them find their way into the missions, but a far greater number are probably reared in native camps, without any sort of education, except a vicious one. Each half-caste so brought up is a menace to the moral safety of the community” (19).

The aim was to transfer 'half-caste' children from Aboriginal camps to Christian missions. The preferred minimum age of removal was six. Many in the white community favoured state-run institutions over Christian missions for separated 'half-caste' children. The missionaries allowed 'half-castes' to marry 'full-bloods'. The government view was that eventually traditional Aboriginal society would die out, and everyone should become white through intermarriage. Removed 'half-caste' children were educated and prepared for work in European society, mainly as manual labourers if they were boys, and as cheap domestic servants, (for which there was insatiable demand) if they were girls. The increasing application of assimilationist policies from the 1940s to the 1960s saw greater numbers of indigenous children removed from their families for alleged neglect, poor school attendance or medical treatment. In 1997, the Human Rights and Equal Opportunity Commission found that between one in ten and one in three indigenous people, had been forcibly removed from their families during the period 1910 to 1970 (20). These people are popularly known as 'the Stolen Generations'.

In the historical context of herding formerly nomadic people onto reserves and taking their children, one can clearly see why contemporary indigenous people feel so strongly about their right to manage their own affairs. Horrific as this practice was, the forced mass removal of indigenous children must be understood in the context that any unmarried pregnant woman was a social outcast who would be pressed to marry, or relinquish the child. On the other hand, social scrutiny of any apparently harmful relations inside marriage was avoided.

THE CONVENTION ON THE RIGHTS OF THE CHILD

In 1989, the United Nations (UN) General Assembly unanimously endorsed the Convention on the Rights of the Child (CROC) and Australia ratified it in 1990. The Convention affirms the rights of children to special protection and to opportunities and facilities for healthy, normal development. It extends the concept of human rights to a healthy standard of living, without discrimination on the basis of race, colour, sex, religion, political, ethnic, social or other status. Article Three states the best interests of children shall be the primary consideration in matters which centrally affect them. Article Twelve states that children shall have the right to be heard and to express their own views, which shall be given due weight, in accordance with their age and maturity. The Australian term 'Stolen Generations' tends, on the other hand, to suggest that children are property.

In 1991, the National Child Protection Council was established to gain a national approach to child abuse prevention. It consists of a Commonwealth government representative, one from each State/Territory and five expert community members. It provides general and cross-portfolio advice to the government through Ministers for Community Services. Each State and Territory has its own branch of the National Child Protection Agency. Primary prevention programmes target the whole community. Secondary prevention targets populations deemed to be at risk. Tertiary prevention, refers to interventions to help those who have already been abused.

In 1994, NSW Health committed recurrent funding to each of the seventeen area health service management structures, for the enhancement of physical abuse, emotional abuse and neglect services. Coordinators were appointed to assist development of service models in regional areas, and to implement strategies to improve the coordination, quality and scope of services. In 1995, a National Child and Youth Health Policy was established to improve health, enable equity of access to comprehensive services and to improve their quality. Across Australia in 1993/94, State and Territory welfare departments received close to 75,000 reports of child abuse and neglect - an increase of 25% over the previous year. The numbers kept on rising. Most reports come from friends and neighbours, followed by parents, guardians, school personnel and police.

Investigations may be carried out by the Department of Community Services, or another agency, such as a hospital, police, or both. The responsible officer determines an assessment outcome. Substantiated cases are assigned to one of four categories - physical, emotional, sexual abuse, or neglect. A child who is the subject of a substantiated case of abuse or neglect, may be placed under a 'care and protection order', or placed in substitute care, or both (21). In 1994 there were 12,750 Australian children under care and protection orders. Children may be placed in foster care, with another parent or relative, in residential care or

in a corrective establishment. The Department of Community Services currently provides a large proportion of residential care and it is also provided by the voluntary sector. Kinship care, through child placement with relatives or other family members accounts for around 40% of total placements. Standards have been developed for substitute care services, and a code of conduct for group homes and refuges has been written. However, the Department is currently a planner, funder, monitor, purchaser, broker, provider, and programme and policy developer in regard to children's care needs (22). Its regulatory and service management functions require clearer definition to ensure accountability. Many other groups and individuals should also be made more clearly accountable for ensuring delivery of caring, reliable support which meets the needs of children and families.

THE CONTEMPORARY CHILD HEALTH DIRECTION

More highly educated women are also more likely to do paid work and to have fewer children. This increases social inequality. Employment and apprenticeship in manufacturing has declined and the proportion of Australians on unemployment, disability or supporting parent pensions has grown. Currently, around 2.6 million Australians are on income support payments - one in five people of workforce age, compared with one in seven ten years earlier. Around 900,000 Australian children are in households with no adult in paid work and of these 500,000 are in lone parent families (23). Centrelink offices run by the Commonwealth Department of Social Security provide pensions, and non-government sector organisations across Australia have been contracted to provide Job Network offices to assist job placement. The Commonwealth has now introduced 'mutual obligation' policy. There is general agreement that the community should support and assist those who cannot support themselves, and that individuals should contribute what they can to the community. There is debate about how this ideal should be delivered.

In 2000, the NSW Health Council initiated area health service plans containing population profiles, including socio-economic status and information about needs of the aged (24). A coordinated planning approach to meet the needs of children is required. The concept of community based rehabilitation (CBR) promoted by the International Labour Organisation, the United National Educational Scientific and Cultural Organization and the WHO states that 'community' may mean a group of people with common interests who interact with each other on a regular basis. Alternatively, it may mean a geographical, social or government administrative unit (25). This provides a micro and a macro perspective to assist planning and programme management, which can also be broadly based around the area health service, local government or other appropriate regional boundaries relevant for achieving identified community goals.

Community partnerships with government and non-government organisations are needed. The regional framework should coordinate local, state government and non-government health, child protection, education and recreation related activities with broader community development aims. Local governments have already made agreements with Aboriginal communities in NSW about infrastructure needs and maintenance, as well as the provision of other council services (26). Affordable, flexible and diverse children's services need to be coordinated with this and other relevant health plans (27, 28) to provide a comprehensive network of community support, especially for families with special needs. Three tiers of government are involved in funding, regulating and providing child care services. Since 1994, a condition of continued funding has been to register services with the National Childcare Accreditation Council, and provide self-assessment of the quality of care, measured by 52 criteria. This assessment is validated by external peer review appointed by the Council. Services are expected to give preference to children in families where both parents (or a sole parent) is in the labour force or studying; children who have a disability or whose parents have a disability; children at risk of abuse or neglect; children of parents at home with more than one child under school age; and sole parents.

After some damning inquiries, the NSW Premier has committed an extra \$1 billion over five years, to address child abuse and neglect (29). A general requirement for out of home care plans, developed in consultation with the child and relevant others should be implemented for every child at risk, whether the care is in family, group or institutional settings. Funds may be necessary for one-on-one care for the most troubled. The NSW departments of health and school education recently collaborated with the Catholic Education Commission and the Association of Independent Schools on a manual of steps, for schools to plan their interface with homes and communities (30). Technical and further education institutions and universities should provide planning, mentoring, research, education, monitoring and assessment services related to community projects. For example, Green and Brown describe a project which has four strands. The first aims to give young people something to do; the second aims to increase communication between the generations; the third covers all aspects of living arrangements; the fourth seeks harm minimisation (31).

Kendig and Duckett propose that all Commonwealth and State funds for aged care services, be pooled into a single regionally managed fund (32). A major advantage would be that care could be better tailored to local circumstances. They recommend housing and aged care be funded separately, with streams for accommodation on one hand, and for living costs and care needs on the other. Care provision based on identified personal needs should apply the current resident classification system for the elderly, irrespective of whether services are provided in residential care, or the home. Community managed implementation of national standards should assist development of a more coordinated, data driven, consultative, flexible

and effective approach to improving services for the elderly. A similarly coordinated approach to provision of child and family support, appears appropriate.

COORDINATED COMMUNITY MANAGEMENT

Pearson recently claimed that some indigenous communities are being destroyed by 'passive welfare' and a related substance abuse epidemic. He argued there should be no more unconditional support in indigenous communities for substance abusers, enforcement of social order and mandatory treatment. The Aboriginal and Torres Strait Islander Commission (ATSIC) is the primary Commonwealth authority responsible for assisting self management by Aboriginal communities and providing assistance to meet related community development aims. It oversees an Australian network of thirty-five elected Regional Councils. In 2002, Geoff Clark, Chairman of ATSIC, pointed out that, of an overall figure of \$2.3 billion of Commonwealth funding for services to Aborigines and Torres Strait Islanders, the ATSIC budget was \$1.1 billion.

Two large programmes account for more than half of the Commission's expenditure. They are the Community Development Employment Projects (CDEP) programme and the Community Housing and Infrastructure Programme (CHIP). The former outlaid \$450 million in 2001-02 and the latter \$240 million. Additional ATSIC expenditure of between \$30 million and \$60 million per annum, focuses on native title and land rights, legal aid related prevention and diversion, commercial development and a self-funding home loans scheme. Smaller ATSIC programmes support indigenous broadcasting and other media, language maintenance, arts, crafts and other cultural activities, heritage and environmental protection, sport, recreation and family reunion services for the 'Stolen Generations'. Budget expenditure is not entirely at the discretion of elected representatives. The Federal Government asks the Commission to guarantee minimum levels of expenditure on about two thirds of its budget. A recent Commonwealth review of ATSIC aims to improve transparency and management accountability through clearer separation of policy and administrative responsibilities.

The apparent success of CDEP, which is more than 'work for the dole' suggests the programme requires expansion and coordination with programmes such as the NSW Aboriginal Family Health Strategy and other relevant indigenous and non-indigenous programmes. Indigenous participants voluntarily forego entitlements to income support payments in return for increased training and work opportunities. CDEPs are used as a stepping stone into more meaningful employment. The first CDEP started as a pilot project in 1976, to provide work opportunities for indigenous people in remote areas. More than 36,000 people currently work in urban, rural and remote locations on a diverse range of projects and enterprises such as freight transport, fencing, waste control, horticulture, aquaculture, broadcasting, tourism, education and aged care. Broader coordination between CDEP projects and appropriate theoretical

and practical education and employment is vital for individuals who wish to climb a particular career ladder, as well as provide effective community service.

Plans to support children and families should be established in a community development context. A recent Cape York Justice Study appears to offer an approach for indigenous community development, which has broader relevance. It recommends that each Aboriginal community develop simple action plans. A coordination unit established in the Queensland Premier's Department may help with planning, prioritisation and costing. The report says curbing alcohol and substance abuse, and breaches of the law, especially violent offences, should be priorities. Agencies assisting communities to implement their plans would be accountable to their respective Ministers and would make periodic progress reports to the coordination unit, which should also have the ability to divert funds between agencies. No advisory group or other expedient should be interposed between the coordination unit and the communities.

QUALITY MANAGEMENT

Behrendt comments that indigenous people raise an important question for anyone concerned about Australian democracy (33). Her query is that if policies, institutions and procedures do not work for a small, socioeconomically disadvantaged minority, how good are they? She argues that indigenous experience provides a vital measure of legal norms and institutions. The use of this experience as a measure of the effectiveness of rights protection, will necessitate investigation and understanding of those unique experiences, histories, narratives and identities, bringing them to the centre of discussions over rights and democracy. This is in the general interests of Australian, international and indigenous development.

Local people may have intimate knowledge of the needs of their particular communities, but relevant UN Conventions reflect the agreed values and principles of an ideal international, multicultural and democratic society. The application of these guiding principles at the local level promotes consistent, equitable treatment and more effective comparison of outcomes everywhere. This should serve to promote cultural diversity and individual choice, while reducing any oppressive features which may be related to traditional decision making in any society. In the absence of a universal, multicultural and democratic approach to social regulation, diversity of beliefs and decision making practices may lead to increased social differentiation but also to increased social intolerance, moral confusion and related conflict.

Transparency is necessary for management accountability. Popper stated that all social administration should be conducted as experimentation and combine discovery and implementation in one process (34). Action research, like health promotion, risk management and programme or project management, proceeds in a spiral of steps, composed of a cycle

of consultative planning, action, and fact finding about the results of the action. In this process, people should use an evidence based approach, not slavishly apply received standards regardless of apparent needs in a particular situation. Risk management requirements of State occupational health and safety acts, and those for professional independence are consistent with this. Decision makers should deviate from the relevant approved practice, if the evidence is that another is likely to be better in a specific situation. The deviation from normally expected good practice and its justification should then be recorded. Documentation of the decisions and outcomes of individual judgments should be aggregated and studied. This comparative research leads to increasingly informed evaluation of practice in all settings, to continuously improve outcomes (35).

The Human Rights and Equal Opportunity Commission, ideally has a role in community based service delivery related to implementation of UN Conventions and other standards. The Commission was established in 1986, to administer federal laws on human rights and discrimination. Its main responsibilities relate to public awareness and education, complaints, human rights compliance, policy and legislative development. Among its responsibilities, the Commission oversees implementation of the Convention on the Rights of the Child, the Racial Discrimination Act (1975), the Sex Discrimination Act (1984) and the Disability Discrimination Act (1992).

The UN statement on CBR stresses that improving the capacity and skills for facilitating community involvement is very important and must be closely coordinated to ensure optimum use of scarce resources. Systems should be developed, at the community level and between government and non-government organisations that reach out to each other and also more broadly to employers and other communities. The National Committee on Human Rights Education (Inc.) is an independent association established with the support of government, business and community groups dedicated to promoting and extending human rights education. The Federal Government sees the Committee as the national focal point for the UN Decade of Human Rights Education (1995-2004). The committee requires support from schools, employers, technical and further education colleges and universities.

CONCLUSION

The physical health of Australian youth is excellent but there is growing concern about their mental health. Alcohol dependence and motor vehicle accidents remain leading causes of death and injury. Suicide levels have risen and so has the death rate from drug dependence. The statistics must be understood in historical context. Since the 1970s, Australia has experienced the demise of many traditional expectations about family and working life, including a reduction in suppression of information about deviations from expectations of the dominant church and community. Problems in self-perception, self-acceptance, and relationship

to others can be understood as the logical consequence of comparative childhood deprivation. This is a particular issue for the health of indigenous Australians. Regional services should be broadly coordinated and designed to promote community health, education and development, including the prevention of child abuse and neglect. Community representatives should work in partnerships with government and non-government sectors to deliver health and related services using a regionally pooled funding approach and quality management which aims to meet consultatively identified community needs. Education for community self-governance in the light of the requirements of relevant international conventions is vital to the process.

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ORIGINAL ARTICLES

**QUALITY OF LIFE FOLLOWING SPINAL CORD INJURY FOR 20-40
YEAR OLD MALES LIVING IN SRI LANKA**

Paul Chappell, Sheila Wirz*

ABSTRACT

This study aimed to find out the quality of life achieved by 20-40 year old males living in Sri Lanka who have either received rehabilitation or have not following spinal cord injury.

The study used both quantitative and qualitative methods to answer the research question. Data was collected by using a questionnaire within semi-structured interviews with 20 SCI males, who were living independently throughout Sri Lanka. As one of the researchers has a SCI, it allowed for a closer relationship to develop with the sample, bringing a richer experience to the research project.

The findings indicate that those who received rehabilitation, had a statistically lower incidence of health complications following discharge. Although no statistically significant results were found in terms of psychosocial and economical well being, the qualitative data revealed those who received rehabilitation had a more positive and realistic outlook on life.

Although the quality of life for those who received rehabilitation is somewhat better, the study highlighted that other extrinsic factors such as, individual self-esteem and lack of community support, could affect the quality of life achieved by those with spinal cord injury in Sri Lanka.

INTRODUCTION

Having a spinal cord injury (SCI) can be a devastating and at times life-threatening event. According to the WHO (1), between 20-40 people per million of population will acquire a spinal injury each year. In contrast however, information gathered in Sri Lanka found a minimum of 66.7 per million of population incur a SCI, which is 67% higher than the WHO estimates (2).

As a result of SCI, important changes occur within an individual's physical and psychosocial relationship with their environment (3). Some of these changes involve the loss of motor and sensory function, inability to control bladder or bowel function and vitiated sexual functioning.

In respect to these changes, they are likely to have profound effects on an individual's social role and interpersonal relationships within their community.

In Sri Lanka individuals are usually transferred to one of the 506 general hospitals in the country for initial treatment and then discharged without any rehabilitation. Figures from the only spinal injuries unit in Sri Lanka (Ragama Rehabilitation Hospital, in fact reveal that only 5% of the national total of spinal injury cases in the whole of the country receives rehabilitation (2).

THEORETICAL CONCEPTS OF QUALITY OF LIFE

The concept, quality of life has been widely studied from both a research and theoretical perspective since shortly after the First World War. Luria (4) in a historical review, reports of studies conducted by neurologists, who examined cortical function and well being of soldiers during the First World War. Over the past two decades however, it has increasingly become a key outcome measure for many health care systems in the Western world e.g. QALYS and DALYS (5, 6). Tam (7) believes this is a result of the growing recognition that individual well being is just as important in treatment as are cure and sustainment of life.

As a theoretical concept, quality of life is a complex and dynamic phenomenon that has no simple, single definition (see Table 1). The reason for this complexity is that much confusion abounds over what is actually meant by the term, 'quality of life.'

Table1: Examples of definitions of quality of life from the literature

AUTHOR	DEFINITION
Young and Longman (8)	'Satisfaction of needs in the physical, psychological and social structural realms'
Goodison and Singleton (9)	'The fulfillment of life plans'
Dijkers (10)	'The sum total of desirable possessions, statuses and traits such as a good job and good health'
Tam (7)	'Individual well being'
Duggan and Dijkers (11)	'A reaction to the (lack of) congruence between aspirations and accomplishments as perceived by the person involved'

Earlier work on quality of life was very much focused on social and objective external factors such as education, income and housing (12,13,14). However, researchers have suggested that qualitative measures would provide a more direct indicator of individual quality of life (11).

Qualitative measures refer to an individual's subjective understanding of quality of life and include indicators such as 'happiness', 'life satisfaction' and 'well being'. These indicators depend predominantly on the direct experience of an individual's life and how they perceive it and need to be measured qualitatively. Day and Jankey (14) cite that the above indicators have been found to account for over 50% of the variance in quality of life for people with disabilities. In analysing this statement, quality of life is perceived to be more of a psychological experience that may not necessarily correspond to external indicators.

Interestingly a study conducted by Fuhrer et al (15) found that there was no significant correlation between life satisfaction and extent of paralysis. However, life satisfaction appeared to be associated with issues of social integration, mobility and locus of control.

From this study it appears that in relation to SCI both objective and qualitative elements of a person's life need to be addressed in the assessment of quality of life. As appositely stated by Tartar et al (16), quality of life is 'a multi-faceted construct that encompasses the individual's behavioural and cognitive capacities, emotional well being and abilities requiring the performance of domestic, vocational and social roles' (12). Quality of life is therefore a dynamic concept that not only incorporates physical, psychological and social domains, but individual perceptions and values of their role function.

THE DISABILITY PARADOX

Bowling (17) defines quality of life as "a concept representing individual responses to the physical, mental and social effects of illness on daily living, which influences the extent to which personal satisfaction with life circumstances can be achieved". The widespread view of a good quality of life is usually based on the idea of good health and experiencing personal well being and life satisfaction e.g. independence, fitness, status and respect.

In accepting the above notion, it could be argued that people with disabilities are therefore incapable of experiencing a good quality of life. For example, in the milieu of a biomedical model of disability, Kasonde-Ng'andu (18) points out that one of the underlying values is that disability is perceived to be a 'sickness', 'personal tragedy' and 'object of charity'. From these perceptions, further assumptions are made by both health professionals and society in general about people with disabilities in the majority world. For instance they are assumed to be limited in function and role performance (19) and as a result are often underprivileged and ostracised from local communities.

Empirical evidence however, suggests a paradoxical relationship occurring. For example, in relation to individuals with SCI, Devivo and Richards (20) found that individuals reintegrating back into the community reported high levels of quality of life. Siosteen et al (21) who studied 56 individuals with SCI in Sweden, also found that involvement in social activity

correlated well with levels of mental well being and quality of life, outweighing levels of physical dysfunction.

On reflection of this evidence, it can be seen that there are other psychosocial factors that may contribute to a spinally injured individual's quality of life, besides functional capacity. Clayton and Chubon (22) for example, found in a sample of 100 persons with spinal injury, that education was associated with perceived life quality. Not only does education increase access to work and economic resources, according to Albrecht and Devlieger (19), it also increases a sense of control over life of a person with disabilities and creates opportunities for social relationships to emerge.

Correspondingly, social support and community acceptance can also influence the inherent balance and well being of individuals with spinal cord injury. Although social support is known to act as a buffer against anxiety and depression amongst the spinal injury population (23), it has also been found to be a significant variable in the adjustment to disability. In a study on the long-term adjustment to disability amongst 100 middle-aged individuals with spinal injury, Schulz and Decker (24) found that those who were satisfied with their social contacts and who felt in control, reported increased levels of personal satisfaction.

QUALITY OF LIFE AND REHABILITATION

As a result of the changing social and political emphasis on disability, the evolving field of spinal injury rehabilitation does not only now focus upon functional outcomes, but also incorporates the emergent themes of independent living and psychological well being. As highlighted by Inman (25), the aims of spinal cord injury rehabilitation include 'optimising physical function, facilitating social independence, minimising medical complications, enhancing emotional adaptation and promoting reintegration into the community'. In view of this, it can be said that enhancing quality of life is the ultimate goal of spinal injury rehabilitation practice.

In addition, it is thought that through incorporating the theme of independent living into SCI rehabilitation, it will inevitably make individuals more aware of the social barriers that may limit their quality of life. This was made evident in a cohort study conducted by Smith (26), which compared the efficacy of specialist and non-specialist management of SCI amongst a sample of 800 people. The results found in relation to life satisfaction compared with individuals receiving non-specialist rehabilitation, a large proportion of those receiving spinal injury rehabilitation reported access to be a major limitation within society. Such a difference raises the point, that the expectations of those who have more access to information through specialist rehabilitation, are higher than those who do not know they have such social opportunities available.

Smith's (26) study also highlights other benefits of receiving specialised rehabilitation following SCI, compared to non-specialist centres. For example, in terms of health there was a significantly lower incidence of complications such as urinary tract infections, chest infections and pressure sores amongst the spinal injury rehabilitation cohort. Furthermore, the study indicated positive social outcomes for the spinal injury rehabilitation cohort, in relation to levels of paid employment, participation in leisure activities and satisfaction with sex.

Despite this being the only study that compares the outcomes of those who have had specialised spinal injury rehabilitation to those who have not, it provides substantial statistical evidence that individuals who have access to spinal injury rehabilitation, have improved health, psychological and social outcomes.

In acknowledgement of the long-term benefits of spinal injury rehabilitation and the small numbers of individuals that receive rehabilitation in Sri Lanka, this study was conducted to see if there is a difference in the quality of life achieved by those who had rehabilitation as compared to those who did not.

RESEARCH AIM

To determine the quality of life achieved by 20-40 year old males living in Sri Lanka, who have either received rehabilitation or have not, after spinal cord injury.

RESEARCH OBJECTIVES

- To identify the information individuals with a spinal cord injury receive during rehabilitation in Sri Lanka.
- To identify the quality of life achieved by those individuals with a spinal cord injury, who have received rehabilitation in Sri Lanka.
- To identify the quality of life achieved by those individuals with a spinal cord injury, who have not had rehabilitation in Sri Lanka.
- To compare the quality of life achieved by those individuals with a spinal cord injury, who have had rehabilitation as compared to those who have not in Sri Lanka.

RESEARCH METHOD

Research into quality of life for individuals with SCI in Sri Lanka or Southeast Asia is limited, therefore, a combined method, which draws upon both quantitative and qualitative paradigms, was used. Through using a combined method it meant that both the objective and qualitative assessment of individual quality of life, would be incorporated within the study.

The research measures used within the study included a semi-structured questionnaire within a semi-structured interview schedule. The questionnaire was made up of both, open and

closed questions and was broken down into seven main sections. However, this was only done for analysis purpose and not for the interviewee.

Within the first two sections of the questionnaire, closed questions were used to collect demographic details of the study population i.e. age, marital status, family set up and level of education. Sections 3 and 4 concentrated on details of individual's injury such as level of injury and issues relating to spinal cord injury rehabilitation and education. The last four sections used both, a mixture of open and closed questions to determine individual physical, emotional and social well being.

In order to check the validity and suitability of the question format in the questionnaire and interview schedule, key informants' comments were sought on early drafts of the research measures used. The key informants used within the study, included the president and vice-chairman of the Spinal Injury Association in Sri Lanka (SIASL), who are both spinally injured and 2 expatriates working for an INGO, who have experience of working with SCI individuals in Sri Lanka.

The data collated from the closed questions in the questionnaire, were analysed through using both EPI Info and SPSS. In order to identify any significant relationships between the quality of life achieved by those participants who had received rehabilitation compared to those who had not, chi-square was used. Likewise, the data collected from the open questions and interview transcripts were analysed by examining key issues, concepts and themes. By doing so, it allowed for a thematic framework to be developed. To enhance the reliability of the key themes identified, a couple of interview transcripts were given to a Sinhalese speaker to analyse.

After contacting SIASL, written consent was gained from them to contact individuals with SCI, in both Colombo and Ragama. Likewise, verbal consent was also gained from the CBR projects in Tangalle and Kandy. All 4 regions made sure they contacted individuals with SCI from a variety of settings. Time was also spent familiarising 3 translators with the structure of the questionnaire and interview schedule. Each interview took on average 45 minutes to complete and were both audio-taped and later fully transcribed. At the end of each interview, the interviewee was given the opportunity to ask any questions and time was also spent with the translator to crosscheck the data gathered.

The study population consisted of 20 participants. The participants were taken from a list of those registered as having a spinal injury, from the main hospital in Colombo and those known to the SIASL and CBR projects in Tangalle and Kandy. The subject criterion entailed that all participants were male, between the ages of 20-40, with a spinal cord injury and are currently living independently in the community, following initial hospital treatment.

In terms of ethical considerations, ethical approval was gained from the ethics committee at CICH. To protect individual rights, verbal or written consent was gained from each participant after it was explained that at no time would any personal information be disclosed to any other person or organisation. Furthermore, as the study was dealing with a potentially sensitive issue, the address and telephone number of the SIASL who offer a counselling service, was left with each participant.

RESULTS

Demographic Characteristics of Study Population

Table 2: Age Range Of Study Population (N=20)

AGE IN YEARS	FREQUENCY (N)
20-2	4
25-29	4
30-34	2
35-40	10
Total	20
Missing	

The study population consisted of 20 participants, 11 of whom had received spinal injury rehabilitation and 9 who had not. The ages ranged between 20-40 years with the majority being between the ages of 35-40 (see Table 2). A greater number of the participants were married and lived in a nuclear family structure.

Nature of injury and disability

Within the study 90% of the participants were paraplegic with a median of 2.00. The time since injury ranged between 1 to over 10 years, with the majority of participants being injured between 1-4 years (see Table 3).

Table 3: Age range of study population (N=20)

AGE IN YEARS	FREQUENCY (N)
20-2	4
25-29	4
30-34	2
35-40	10
Total	20
Missing	

Table 4: Cause of injury (N=20)

The most frequent cause of injury amongst the study population was due to road traffic accidents (RTA), followed closely by falls from trees (see Table 4).

CAUSE OF INJURY	FREQUENCY (N)
RTA	7
Fall/Tree	5
Assault	3
Sports	2
Occupational	1
Other	2
Total	20
Missing	

Rehabilitation and activities of daily living

The majority of those who had received rehabilitation were given education about managing their urine ($X^2 p=0.653$). Likewise, they were also given education on bowel management ($X^2 p=0.02^*$).

Furthermore, the majority of those who had received rehabilitation had been given information about preventing pressure sores ($X^2 p=0.02^*$, see Table 5). Interestingly, out of the participants who had received rehabilitation and information about pressure sores, none of them had a sore within the last year ($X^2 p=0.001^{**}$, see Table 6).

Table 5: Given information about pressure sore prevention (N=20, $X^2 p=0.02^*$)

	Pressure Sore Information		
	Yes	No	Total
Received Rehabilitation	10	1	11
Yes			
No	3	6	9
Total	13	7	20

Table 6: Pressure sores within last year (N=20, $X^2 p=0.001^{}$)**

	Pressure Sores in Last Year		
	Yes	No	Total
Received Rehabilitation	10	1	11
Yes			
No	3	6	9
Total	13	7	20

Table 7: Received information on sexual function and fertility (N=20, X² p=0.02*)

In terms of sexual function and fertility, none of the participants who had no rehabilitation were given information (X² p=0.02*, see Table 7). Likewise, none of them had received information on coping, after injury (X² p=0.001**, see Table 8).

Information on Sexual Function			
	Yes	No	Total
Received Rehabilitation	6	5	11
Yes			
No	-	9	9
Total	6	14	20

Table 8: Received information on coping after injury (N=20, X² p=0.001)**

Information on Coping			
	Yes	No	Total
Received Rehabilitation	8	3	11
Yes			
No	-	9	9
Total	8	12	20

PHYSICAL, SOCIAL AND EMOTIONAL WELL BEING

The majority of those who had both received and not received rehabilitation, reported that their health as compared to when first injured, was good (X² p=0.543). However, in relation to life control compared to before their injury, more of those who received rehabilitation reported it to be good, or no different (X² p=0.415).

Although both groups reported no difference in family relationships compared to before injury, the majority of those who received rehabilitation reported that their social life with friends compared to before injury was good or no different. However most of those who had no rehabilitation though it was now worse (X² p=0.257). Furthermore, in terms of involvement in community activities both groups reported it to be worse now as compared to before they were injured (X² p=0.790).

INCOME GENERATION

Before their injury, the majority of the study population was employed and mostly doing manual work. However, one of the participants was a full time university student. In terms

of employment after injury, although more individuals who received rehabilitation were employed, compared to the non-rehabilitation group, the majority of the sample were still not involved in employment ($X^2 p=0.194$, see Table 9).

Table 9: Employment after injury (N=20, $X^2 p=0.194$)

	Employers after injury		
	Yes	No	Total
Received Rehabilitation	4	7	11
Yes			
No	1	8	9
Total	5	15	20

Interestingly however, the majority of those who had received rehabilitation and were not employed had plans for future income generation activities ($X^2 p=0.147$).

DISCUSSION

Rehabilitation Issues

The results revealed that the majority of those who had received rehabilitation had been given adequate information about managing urine, bowels and pressure sores. However, although some of those who have had no rehabilitation received limited information on urine management and pressure sores, it would appear that the information they received, was inadequate. This for example, is made evident by the fact that all those who received information during rehabilitation about pressure sores, reported having no sores within the last year.

Similar results were also found in a study conducted by Smith (26) who studied 800 individuals who had either been through a spinal injury unit or a non-specialised unit in the UK. It was found that those who had been through the spinal injury unit (702), reported a statistically significant lower incidence of pressure sores in the last year, than those who attended a non-specialised unit. This suggests, that the training given in specialised spinal injury rehabilitation is both longer and more comprehensive.

It was also clear from the results, that none of the non-rehabilitation sample had received information on sexual function, fertility or coping following injury. This may indicate a lack of knowledge, or inabilities in interpersonal skills that the Sri Lankan medical staff may have in dealing with such specialised issues.

For instance, in relation to information on coping, King and Kennedy (3) found in a case control study with 38 spinally injured individuals, that those who followed coping effectiveness training during rehabilitation, reported significant psychological adjustment to their injury six weeks after discharge. This shows that although changes have occurred in the individual's understanding of their injury, they will have also gained the coping skills necessary, to continue living consequential lives. For example, in the current study in terms of income generation, those who had received information on coping during rehabilitation were either employed, or had realistic plans for future income generating activities. However, in critical analysis of this notion it is also possible that other confounding variables that were not accounted for, such as, personality and religious beliefs, may also affect individual coping skills following injury.

PHYSICAL, SOCIAL AND EMOTIONAL WELL BEING

Compared to the previous section, no statistically significant findings were found in the quantitative data relating to individual well being. Although this may be linked to the small sample used, it may also be due to the fact that unlike the previous section, which used tighter parameters in gathering information, this section had a wider choice of answers that could be selected. However, in combining the quantitative data with the qualitative themes that emerged, some interesting similarities were found.

For instance, within the quantitative data, it appears that the majority of those who received rehabilitation reported their relationship with friends to be good or no different. However, a majority of the non-rehabilitation sample reported it to be worse. This apparent discrepancy is supported by the qualitative results. For example, many of those who had no rehabilitation frequently reported that their friends did not visit, which they perceived was related to their disability.

According to Whiteneck et al (27), losing friends after injury can produce greater social isolation, than isolation from lack of access to other environmental resources. Therefore, it is put forward that interdependence as found amongst those who received rehabilitation, is a more relevant construct than independence, especially in terms of promoting adjustment and community reintegration for individuals with SCI.

According to the quantitative data, involvement in community activities amongst the study population was worse for both, those who had received rehabilitation and those who had not. These findings coincide with Stambrook et al (28) who believe that individuals with SCI are often perceived as being less socially engaging and less active socially. One of the reasons for this analogy, is that these individuals face many social barriers when reintegrating into the community, such as, transport difficulties and inaccessible buildings. In analysing the qualitative data numerous themes emerged, which reiterate this point.

For instance, although the majority of those who received rehabilitation reported positive societal attitudes towards them, those who had no rehabilitation, perceived societal attitudes to be quite negative, believing that no one was interested in helping them now. Given Sri Lanka's current civil unrest, it was also interesting to note that none of the individuals who were injured in military service mentioned whether this had a positive or negative effect on societal attitudes. Craig et al (29) point out, that demands of others who lack understanding of SCI or who interact unnaturally i.e. avoidance of people with disabilities may not only increase levels of depression, but maladjustment to living in the local community for spinally injured individuals. From this it is suggested, that the longer misunderstanding towards individuals with SCI abound, the less likely they are, to participate in community activities.

However, in critical analysis of this it is thought that there are other variables, such as self-esteem, which may actually bias the individual's perception or opinion of the community around them. For example, findings from Craig et al's (29) study of 41 spinally injured individuals, found that in comparison to an able-bodied control group, spinal injury affected individual self-esteem, which lead to feelings of helplessness and fatalism.

INCOME GENERATION

In terms of employment, it was not surprising to find that more individuals who had received rehabilitation were now employed, in comparison to those who had no rehabilitation. However, the actual overall numbers of those employed was low. Furthermore, those who had received rehabilitation and were not employed, all had realistic plans for future income generating activities.

These findings coincide with other studies that looked at the quality of life of long-term spinally injured individuals. For example, Harrison and Kuric (30) found in their study of 62 individuals with a spinal injury, that only 8% were employed following injury, compared with 39% prior to injury. This suggests that there are other variables that affect the number of people taking up employment following injury, such as, access to places of work, employers attitudes and more importantly, the individual's belief in their abilities.

What does the future hold?

As regards 'the future', the study population were asked as to what they could see themselves doing in 5 years from now. Through analysing the interview transcripts, a table was constructed with all the themes and the frequency with which each theme was reported and were recorded e.g. frequent, not frequent or nothing (Table 10).

Table 10: Summary of what sample propose to do in 5 years

Theme	Examples of Quotations	Rehab	No rehab]
Business Plans	'Maybe go ahead and start some business activities' R09, p.4 'Engage in business activities.' R10, p.4' To go into the food business.' N03, p.4	F	NF
Independence	'To rebuild my life more and more towards independence' R08, p.5 'I want to be making as independent as possible' R15, p.4	F	NF
To Walk	'I want to get up' N02, p.4 'My only hope is that I will be able to walk' N08, p.5 'My only plan is to go to the USA or UK for the stem cell implant operation' R12, p.5	NF	F
No Plans	<i>'I don't have any plans' N06, p.4</i> <i>'I've never really thought of 5 years ahead, I only think of tomorrow'</i> N09, p.4	NF	F
Educate Children	'To educate my children' R10, p.4	NF	N
Marriage	'To marry, if all goes well marriage' R13, p.5	NF	N
Improve Health	'I would like to be in better health condition' R13, p.5	NF	N

Key: F= Frequent; NF= Not Frequent; N= Nothing

From analysing the table it can clearly be seen that overall those who have received rehabilitation appear to have more realistic goals and ambitions compared to those who had no rehabilitation. This suggests that the wealth of information received during rehabilitation

encourages the individual to think about their future once discharged from the spinal unit. Although the rehabilitation group as a whole were more realistic as regards the future, whether or not these goals and ambitions are achievable will ultimately depend upon themselves and the social structure of their community.

STUDY LIMITATIONS

A limitation identified within the study was working through translators. Although overall they were good, some of the translators at times had a tendency to summarise the participant's response in their own words, thus introducing bias to the results. This could have been overcome by having local Sinhalese spinally injured individuals carry out the interviews, which would have allowed a closer and more natural relationship to develop between researcher and subjects allowing for a greater insight into quality of life following spinal cord injury in Sri Lanka.

Furthermore, as the researcher has a SCI and came from overseas, there was a potential for researcher bias being introduced to the findings. This is mainly due to the fact that coming from a country where facilities for those with SCI are markedly better than in Sri Lanka, the researcher may have entered the study with their own expectations of how things should be.

CONCLUSION

Despite the small sample and the drawbacks identified in this study, this research provides valuable insight into the quality of life for individuals following SCI living in Sri Lanka. More importantly it has highlighted the overall benefits of having specialised spinal injury rehabilitation in terms of health, physical function and psychosocial integration. However, it is important to remember that there are other confounding variables other than receiving rehabilitation, such as self-esteem and low social support that can affect individual well being and life satisfaction. For example, it could be put forward that although an individual has received rehabilitation, they may have a low self-esteem, which causes them to view their life situation negatively.

In respect of this, to fully reap the benefits of rehabilitation, more support needs to be given to individuals once they are discharged from hospital in terms of both reintegrating into the community and in the achievement of their goals and ambitions, thus helping to improve their overall life satisfaction.

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LIFE AFTER INJURY

A rehabilitation manual for the injured and their helpers

Authors: Liz Hobbs, Susan McDonough, Ann O'Callaghan

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**AN INTER-COUNTRY STUDY OF EXPECTATIONS
ROLES, ATTITUDES AND BEHAVIOURS OF
COMMUNITY-BASED REHABILITATION VOLUNTEERS**

Manoj Sharma, Sunil Deepak***

ABSTRACT

World Health Organisation (WHO) recommends community-based rehabilitation (CBR) as the chosen approach for meeting the needs of persons with disabilities (PWD), in developing countries. A key element in the implementation of this approach is the CBR worker at community level, a role often played by community volunteers. Often, CBR projects involving volunteers face the problem of high turn over of volunteers. However, the profile of the community volunteer has not been studied enough. Therefore, this study gathered information from CBR volunteers in Eritrea, Egypt, India, Mongolia, Papua New Guinea, Pakistan, and Vietnam (n=176) regarding their expectations, roles, attitudes and behaviours pertaining to CBR work. The survey revealed that majority of CBR volunteers volunteered their time as a personal decision (63%) and were not personally disabled (84%). It was found that satisfaction from CBR work was directly related to self-efficacy or behaviour specific confidence in their ability to perform CBR-related tasks, while inverse and significant relationships were found with barriers and outcome expectations. Thus, for retaining volunteers, CBR projects need to provide educational activities that build self-efficacy of volunteers to fulfil CBR-related tasks and reduce barriers.

INTRODUCTION

In 1976, World Health Organisation (WHO) estimated that 90% of persons with disabilities were totally neglected in developing countries and introduced the community-based rehabilitation (CBR) strategy as part of its goal to accomplish "Health for All by the year 2000" (1). Whilst the year 2000 has gone by, yet the needs of persons with disabilities (PWD) remain largely unmet in developing nations, even though there has been a large increase in the number of countries, which have decided to adopt the CBR approach. However, often such projects remain limited to "pilot" areas and in spite of national policies for implementing CBR, a lack of resources hinder their actual implementation (2).

The Joint Position Paper of United Nations agencies defines the main objectives of CBR, "to ensure that people with disabilities are empowered to maximise their physical and mental

abilities, have access to regular services and opportunities and become active, contributing members of their communities and their societies. Thus, CBR promotes the human rights of people with disabilities through changes within the community. CBR aims to include people who have disabilities from all types of impairments, including difficulty hearing, speaking, moving, learning or behaving. CBR also includes all age groups: children, youth, adults and older people" (3).

The five basic principles of CBR strategy include (4)

- Active participation of disabled persons, their families and communities in all aspects of CBR with utilization of available resources in the community.
- Transfer of knowledge about disabilities and skills in rehabilitation, to people with disabilities, families and communities.
- Community involvement in planning, decision making, and evaluation.
- Utilisation and strengthening of referral services that are able to perform skilled assessments with increasing sophistication, at district, provincial, and national levels and make rehabilitation plans, participate in training, and supervision.
- Utilisation of a co-ordinated, multisectoral approach.

In performing all the above activities, the lynchpin is the CBR worker at community level, a role often played by community volunteers. It is the community CBR worker who provides information to disabled people and their families, e.g. advice about basic functional rehabilitation activities, construction of simple assistive devices to improve independence in daily activities, use of sign language, or use of a walking cane by a person who is blind. The community CBR worker also acts as an advocate for people with disabilities, by making contacts with schools, training centres, work places and organisations, to promote accessibility and inclusion of community members with disabilities (3).

Despite being an important element in the delivery of services, the CBR volunteer still remains least studied and largely misunderstood by national CBR managers, planners, trainers and donors. In industrialised countries volunteers are usually people who have a good job or business and in their free time of their free will, devote their time, money and energy on an issue that interests them. However, this is not the case with CBR volunteers working in developing countries where this term covers a wide spectrum of identities and roles (5). Therefore, the purpose of this study was to explicate the expectations, roles, attitudes, and behaviours of community-based rehabilitation volunteers from a subsection of CBR projects across a section of developing nations.

METHODOLOGY

The eight countries chosen for this study were Eritrea, Egypt, India, Mongolia, Papua New Guinea, Pakistan, and Vietnam. These countries were chosen because the CBR projects established there had been in existence for over five years, utilising the services of volunteers. The eight projects varied greatly in terms of management, coverage and multisectoral nature of activities. Thus, Eritrea, Mongolia and Vietnam represented projects covering large areas and managed by Governments (in Eritrea by Ministry of Labour and Human Development, in the other two, by Ministries of Health). On the other hand, Egypt, India, Papua New Guinea and Pakistan covered more limited geographical areas and were managed by non-governmental organisations. While the projects in India and Papua New Guinea operated only in rural areas, the remaining projects covered both rural and urban areas.

Volunteers for this study were defined as those people who were: (a) local residents; (b) involved in some aspect of community-based rehabilitation work, which meant working for persons with disability in a geographically defined area; (c) not employed as regular employees of the organisation; and (d) provided services or time to the organisation for which either they were not paid by the organisation/ government as part of their regular duty, or were paid a token amount which was lower than the locally prevalent wages, or, what could be considered less than what was commensurate with their qualifications, experience or expertise. Current volunteers were defined as those who met all the criteria and former volunteers were defined as those individuals, who had met these criteria at any time within the past three years. A sixty item questionnaire was validated by three international experts, in a two round process. The attitudes chosen in the questionnaire were based on the constructs of Social Cognitive Theory (6, 7). The final instrument had 14 questions pertaining to demographics, 15 questions pertaining to outcome expectations (anticipated benefits of volunteering), 15 questions on outcome expectancies (value placed on anticipated benefits of volunteering), 10 questions about self-efficacy (behaviour specific confidence) in performing CBR-related tasks, 5 questions on barriers encountered in performing CBR work, and 1 question on overall satisfaction. Data collection was facilitated by country programme managers. Fixed quota cluster sampling was utilised. One main project in each country was identified as the cluster. Cluster projects that had less than 25 current and former volunteers, were asked to get information from all the volunteers who consented to answer the questions. Cluster projects that had more than 25 current and former volunteers, were asked to put all the names in a hat or a basket and pick out names of 25 volunteers and elicit information from them (random selection within the cluster).

Permission to carry out this survey was provided by Associazione Italiana Amici di Raoul Follereau (AIFO) and while the programme manager collected the information from the volunteers individual identity was kept confidential. The questionnaire was developed in the

English language and translation in local language/dialect was done by the programme managers, if needed. A total of 176 questionnaires were completed and returned. The projects from Eritrea, Egypt, Mongolia, Pakistan, and Vietnam returned all 25 questionnaires. The project from Papua New Guinea returned 16 and the project from India returned 10.

All data were analysed using SPSS (Statistical Package for Social Sciences), Version 10.0. (8). For modelling predictors of satisfaction, stepwise multiple regression was used. The apriori criteria of probability of F to enter the predictor, in the model was chosen as less than and equal to 0.05, and for removing the predictor as greater than and equal to 0.10. The predictors used were age, decision to become a volunteer, disability status, education, gender, hours per week, in-kind incentives, length of time as volunteer, marital status, monetary compensation, profession, religion, total outcome expectations score, total self-efficacy score, and total barriers score.

RESULTS

As indicated earlier a total of 176 completed questionnaires were returned. The age of the respondent CBR volunteers ranged from 16 years to 68 years with a mean age of 34.9 years (sd. = 12.8).

Table 1: Summary of demographic characteristics of CBR workers working in eight countries (n=176) depicting description of frequencies and percentages

Variable	Subgroups	n	Frequency	Percentage
Gender	Males	171	78	45.6
	Females		93	54.4
Education	None	170	5	2.9
	Primary School or less (up to 5 years of schooling)		18	10.6
	Middle school or less (between 6-8 years of schooling)		32	18.8
	High school or less (between 9-12 years of schooling)		53	31.2
	Professional training (12+ years of schooling)		26	15.3
	College or University education (12+ years of schooling)		36	21.2

Variable	Subgroups	n	Frequency	Percentage
Marital status	Single, never married	174	56	32.2
	Single, divorced or separated		4	2.3
	Single, widowed		8	4.6
	Married		106	60.9
Religion	Muslim	172	64	37.2
	Christian		39	22.7
	Hindu		19	11.0
	Buddhist		16	9.3
	Atheist		31	18.1
	Others		3	1.7
	Profession		Unemployed	174
	Retired	8	4.6	
	Student	13	7.5	
	Home maker (housewife)	50	28.7	
	Health worker	22	12.6	
	Teacher	14	8.0	
	Others	51	29.4	
Status as CBR worker	Current and regular	171	99	
	Current but irregular		28	16.4
	Former		44	25.7

Table 1 depicts other demographic characteristics including gender, education, marital status, religion, profession, and current status as CBR worker. From Table 1 it is noted that women were almost ten percent more than males in this sample. Almost seventy-four (74) percent of the respondents had an education less than high school and a majority (60.9%) were married. CBR volunteers belonged to all major religions in the world in this sample. Only 9 percent of the respondents from the CBR volunteers reported themselves to be unemployed. Almost fifty-eight (58) percent of the sample comprised of current and regular CBR workers and a fourth (25.7%) were former with the remaining (16.4%) were current but irregular.

Table 2: Summary of disability status of CBR workers working in eight countries (n=176) depicting description of frequencies and percentages

Variable	Subgroups	n	Frequency	Percentage
Disability status	None	166	139	83.7
	Visual disability		3	1.8
	Hearing and speech disability		2	1.2
	Mobility-related disability		17	10.3
	Other disabilities (incl. multiple disabilities)		5	3.0
Type of disability in family member	None	137	78	56.9
	Visual disability		5	3.7
	Hearing and speech disability		11	8.0
	Mobility-related disability		19	13.9
	Other disabilities (incl. multiple disabilities)		24	17.5
Relationship of worker with PWD in family	Not applicable	136	79	58.1
	Spouse		8	5.9
	Child (son or daughter)		14	10.3
	Sibling (brother or sister)		16	11.8
	Other		19	13.9

Table 2 depicts the distribution of disability status in the CBR volunteer and his/her family. A clear majority (83.7%) of the volunteers were found not to be disabled and more than half (57%) did not have a family member who was disabled. Among the disabilities reported, mobility-related disability was the most common among both categories of volunteers (10.3%) and their family members (13.9%).

Table 3: Summary of distribution of compensation profiles of CBR workers working in eight countries (n=176) depicting description of frequencies and percentages

Variable	Subgroups	n	Frequency	Percentage
Monetary Compensation	None	135	75	55.6
	Stipend		35	25.9
	Other forms (incl. salary, honorarium)		25	18.5

Variable	Subgroups	n	Frequency	Percentage
Reimbursement	None	135	25	18.5
	Travel and/or meals		85	63.0
	Others		25	18.5
In-kind incentives	Community recognition	110	25	22.7
	Periodic awards		10	9.1
	Multiple incentives		75	68.2

Table 3 depicts the distribution of compensation profiles of CBR workers in the eight countries. It is evident that the majority reported receiving no compensation (56%). It is also interesting to note that almost one fourth (25%) of the sample did not answer this question. Reimbursement for travel and meals was found to be quite a common practice across all the projects, with less than a fifth (18.5%) reporting that they did not receive reimbursement of any kind.

Table 4: Summary of volunteering experience (n=176)

Variable	Subgroups	n	Frequency	Percentage
Decision to become a volunteer	Personal decision	170	111	65.3
	Family decision		4	2.4
	Community decision		52	30.6
	Other		3	1.7
Profile of CBR related activities performed	None	169	1	0.6
	One type		8	4.7
	Multiple		160	94.7
Profile of other than CBR-related activities	No other activity	163	46	28.2
	Health-related		28	17.2
	Family planning-related		1	0.6
	Youth-issues related		3	1.8
	Religion-related		2	1.2
	Political work-related		5	3.1
	Agriculture-related		7	4.3
	Other		3	1.8
	Multiple activities from above categories		68	41.8

Variable	Subgroups	n	Frequency	Percentage
Reasons for quitting in former volunteers	Permanent job	43	6	14.0
	Lack of time		11	25.6
	Moved away		4	9.3
	Too much work load		0	0.0
	Further study		4	9.3
	Marriage		2	4.6
	Personal		2	4.6
	Other		6	14.0
	Multiple reasons		8	18.6

Table 4 summarises dimensions of the volunteering experience. It is evident from Table 4 that a majority of volunteers (65%) indicated that personal decision led them toward volunteering. However, being traditional community-oriented societies, community decision also played a role in the case of at least 30 percent of the CBR volunteers. An overwhelming majority (94%) was involved in multiple CBR-related tasks. Further, more than two-thirds (72%) were involved in one or more tasks besides CBR work. Among the volunteers who quit volunteering, lack of time (25%) was reported as the most common reason.

Table 5: Summary of means and standard deviations of attitudinal variables of CBR workers (n=176)

Variable	Number of responses	Possible range	Observed range	Mean	Standard Deviation
Total score of expectations from volunteering	136	0-225	41-197	118.26	33.97
Self-efficacy in Volunteering	167	0-40	0-39	23.75	8.40
Perception of barriers in volunteering	169	0-20	0-19	8.60	4.23
Overall satisfaction from volunteering	169	0-4	0-4	2.95	1.00

Table 5 depicts the means and standard deviations of the Social Cognitive Theory based attitudes related to volunteering. These are, expectations, self-efficacy, perception of barriers, and overall satisfaction.

Table 6: Final regression model for overall satisfaction scores for barriers, self-efficacy (SE) and outcome expectations (OE) as predictors

Source	df	SS	MS	F	p-value	Adjusted R Squared
Regression (Barriers, OE, SE)	3	12.383	4.128	9.895	0.001	0.39
Residual	39	16.268	0.417			
Total	42	28.651				

Table 7: Parameter estimates from final regression model

Parameter	Coefficient	Std. error	t-statistic	p-value
Intercept	3.423	0.425	8.051	0.0001
Barriers score	-0.382	0.022	-3.119	0.003
Self-efficacy score	0.619	0.017	4.000	0.0001
Outcome expectations score	-0.395	0.004	-2.539	0.01

Tables 6 and 7 depict the results from regression modelling. From all the predictors, only outcome expectations score, self-efficacy score, and barriers score were found to be significant predictors and retained in the model. Thirty nine percent of the variance in satisfaction was predicted by these three variables.

DISCUSSION

The present study is among the few studies that have been undertaken to understand the profile of CBR volunteers. The purpose of this study was to paint a detailed profile of community-based rehabilitation volunteers from a subsection of CBR project across a section of developing nations, primarily aiming to understand the predictors of satisfaction. In deriving satisfaction from CBR-related work, from all the possible predictors three predictors stood out as statistically significant. The advantage of these predictors is that these are educationally modifiable. The first of these predictors was self-efficacy or behaviour specific confidence

in one's ability to perform CBR-related tasks. The relationship between this variable and satisfaction, was found to be significant ($p < 0.0001$) and direct, meaning that higher the self-efficacy score higher would be the satisfaction. Self-efficacy can be modified educationally by having credible role models, having observational and participatory learning activities, breaking down the task into smaller steps and practising these small steps (9).

The other two predictors were found to have significant but inverse relationships with satisfaction. These were barriers ($p < 0.003$) and outcome expectations ($p < 0.01$). Projects can work at reducing barriers that confront volunteering. Some of these barriers related to insufficiency of time and resources, are amenable to managerial solutions; while some of the barriers pertaining to limitations with regard to knowledge and skills, can be easily modified by educational means through programs geared toward capacity building. This way the lesser the perceived barriers become, greater will be the satisfaction and retention of CBR volunteers. Recruiting volunteers who are "less ambitious" will also lead to outcome expectations being less. In community-based rehabilitation work results may often come very slowly and more so for the volunteer. If a person who volunteers, has high ambitions exhibited by higher outcome expectancy scores, the likelihood of his or her being satisfied will be less.

The study also clarified some misperceptions regarding the identity of the CBR volunteer. It is generally believed that volunteers in traditional, agrarian societies of the developing world are appointed by community leaders. However, this study found that this is not the case and a majority of volunteers indicated personal decision (65%) as the key factor for volunteering. Another finding was that majority (84%) of volunteers were not disabled. The data in this sample, shows that in these projects only a limited number of persons with disabilities or their family members, were involved as volunteers, which may depend upon the kind of volunteer recruitment strategies used by these projects. Disabled persons, even with limited formal education, often make excellent rehabilitation workers and community health workers (10). It has also been proposed, that parents of disabled children make more motivated and committed CBR volunteers and have less problems of turnover (11). Further, this study asked for relationship of the worker as spouse, child and sibling but not as a parent, which was clubbed under the category of "other." Future researchers need to rectify this measurement error.

It was also interesting to note that only a small proportion of CBR volunteers were unemployed (9%) and only a small proportion were exclusively working for CBR (26%). Reasons for quitting mostly related to time (26%), securing a job (14%) or moving away (9%). It is also interesting to note that a minority of volunteers were paid some token form of financial remuneration. Financial compensation to volunteers has implications for sustainability and continuity of CBR programmes. Hence, it would have been interesting to also analyse the sources of funding for this compensation and the participation of communities in this area. However, this information was not collected in this study, but future researchers can probably do so.

RECOMMENDATIONS

The project sample included in this study represents different countries, geographical coverage, rural/urban settings, and governmental/non-governmental settings. At the same time, all the projects are supported by the same international partner namely, Associazione Italiana Amici di Raoul Follereau (AIFO). This could have influenced similar strategies in terms of volunteer selection, training and management. Despite some limitations pertaining to sample selection, measurement error, and data collection, the findings of this survey lend themselves to several useful programmatic, policy and funding implications. Firstly, each programme can build capacity of their volunteers by careful recruitment, and design tailored educational programmes. These educational programmes must be conducted on a regular basis and must build capacity of the volunteers in performing CBR-related tasks by enhancing self-efficacy. Secondly, programmes must aim at reducing barriers of time and resources, by implementing effectual managerial changes. Thirdly, it would be important to ensure mechanisms for acknowledging the role of volunteers and reimbursement of expenses. Finally, adequate training programmes for volunteers must receive priority attention. A more in-depth educational needs assessment can be a future research study as well.

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BRIEF REPORTS

**INCLUSIVE EDUCATION IN THE 21ST CENTURY: CHALLENGES
AND OPPORTUNITIES FOR NIGERIA**

Ayo Garuba *

ABSTRACT

The readiness for acceptance of inclusion varies across countries and continents of the world. While countries within the advanced economies have gone beyond categorical provisions to full inclusion, Nigeria and most countries of Africa, are still grappling with the problem of making provisions for children with special needs especially those with handicaps, even on mainstreaming basis.

This paper attempts to highlight and examine the concept of inclusion and the prospects it holds, for special education practice in Nigeria in the 21st century. In addition, the paper discusses the challenges of inclusion in Nigeria, while reflecting upon the ground reality in the country.

INTRODUCTION

Today, if there is any concept that has gained currency in the world of special needs education, it is inclusion. A run down of major publications in the field, will reveal the volume of intellectual energy that has been (and is being) dissipated in the examination of this emerging concept. Inclusion is generating thoughts and attention world wide as a new approach in the provision of services for learners with special needs. International organisations particularly UNESCO, now see inclusive schooling as an effective approach in the education of this class of learners.

The Salamanca Declaration of 1994, provided the needed international and theoretical frames for inclusive education. In the report, the point made was that "the task of the future is to identify ways in which the school, as part of the social environment can create better learning opportunities for all children and by this means, address the challenge that the most pervasive source of learning difficulties is the school system itself (1).

The report further described inclusion "the most effective means of combating discriminatory attitude, of creating welcoming communities, building an inclusive society

and achieving education for all; moreover they provide an effective education for the majority of children" (1).

CONCEPTUAL EXPLORATION

Inclusion refers to the "full-time placement of children with mild, moderate and severe disabilities in regular classrooms" (2). The inclusion movement believes that children with special needs should be placed in the regular school classroom which they would have otherwise attended, if they had been normal children. In other words, each child belongs to the regular classroom and therefore, there should be no condition imposed, to exclude him/her from that environment.

Inclusion is a step further in mainstreaming, as it presents a means "by which a school attempts to respond to all pupils as individuals, by reconsidering and structuring its curricular organisation and provision, and allocating resources to enhance equality of opportunity. Through this process, the school builds its capacity to accept all pupils from the local community who wish to attend, and in doing so, reduces the need to exclude pupils" (3). Thus, the high point of inclusion lies in its emphasis on restructuring of the entire school programmes and practices. Here, the content, the process and the environment of the mainstream programme are restructured "in order to accommodate a much wider range of ability" (4).

For Lons Florain, "inclusion of all pupils in the mainstream schools is part of an international agenda which calls for the full inclusion of all pupils with disabilities, into all aspects of life" (5).

Inclusion is based on the assumption that:

- The original place of the child with special needs is in the regular classroom. Therefore, no condition should be allowed to remove him/her from that environment.
- All children have the right to learn and play together. Inclusion is thus a fundamental human right. For instance, the Nigerian constitution makes a provision for suitable education for all children (6).
- Denying opportunity to children to learn under the same roof with other children, is devaluing and discriminatory.
- Exclusion is inhuman and indefensible.

SPECIAL EDUCATION PROVISION IN NIGERIA

Two eras have been identified in the development of provision for persons with special needs in Nigeria (7). The first is the humanitarian/missionary era (1945-1970) during which, provision

of services was dominated by private voluntary organisations (PVOs) and private individuals. During this era, religious bodies (mostly Christian) were the driving force behind establishing and maintenance of services and programmes for children and adults with handicaps. During this era, the attitude of the Government was somehow lackadaisical, in matters concerning persons with disabilities.

The second was the social service era which saw the development of service. The country witnessed a significant contribution from the government, in terms of commitment as well as inputs and there was a relegation of the PVOs and private individuals to the background. This era which commenced immediately after the civil war that ravaged the country for three years, also saw the commencement of the system of Universal Primary Education (UPE) and the eventual take over of all schools (including special schools) established by PVOs and individuals (8). There was also the commencement of training programmes for special teachers. The following institutions were either established or commenced programmes in special education:

1. University of Ibadan started the Diploma in special education in 1974 and a Bachelor's programme in 1976 (9).
2. University of Jos started the Bachelor's programme in special education in 1977 and Master's in 1978.
3. The Federal Advanced Teachers College, Special (FATC), was established by the federal government in 1977. The college, now known as Federal College of Education, Special remains the only college of special education in the whole of black Africa.

It was also during the social service era that in 1977, the National Policy on Education (NPE) was released. The release of this policy was a significant turning point in Nigeria's special education programme.

The aims of special education as stated in the policy are as follows:

- (a) to give a concrete meaning to the idea of equalising educational opportunities for all children; their physical, mental and emotional disabilities notwithstanding;
- (b) to provide adequate education for all handicapped children and adults, in order that they may play their roles fully in contributing to the development of the nation;
- (c) to provide opportunities for exceptionally gifted children to develop their skills at their own pace, in the interest of the nation's economic and technological development (10).

In addition, the policy also contains the following provisions that are beneficial to persons with special needs.

- integration of children with handicap into the mainstream of regular schools;
- provision of special education for children;
- setting up of a committee to coordinate special education activities, conducted by the Federal Ministry of Education (FME) in collaboration with the Ministries of Health, Social Welfare and Labour;
- provision of special education services for the gifted and talented children;
- conduct of census of persons with handicap (7).

The social service era also marked the emergence of legislation that are meant to address the problems of children and adults with handicap. It was the Plateau state government that first enacted a law called 'Plateau state handicapped law' which was introduced in 1981. Among other provisions, the law stipulates that the education of children with handicap is compulsory and provides for the rehabilitation needs of adults with handicaps. The law was however, restricted to Plateau State which was just one among the then nineteen states in the country (Nigeria has thirty six states). It was in 1993, that the Federal Government enacted the first and only legislation on the handicapped. The 'Nigerians with Disability Decree' was enacted to " provide a clear and comprehensive legal protection and security for Nigerians with disability, as well as establish a standard for enhancement of the rights and privileges, guaranteed under this decree and other laws applicable to the disabled in the Federal Republic of Nigeria" (11).

IMPLEMENTATION OF SPECIAL EDUCATION PROVISIONS

At the level of policy provisions, it can be said that special education has fared better. It is however a different ball game when it comes to the implementation of the policy declarations. Very little success has been seen in the actualisation of the programmes that are part of the nation's education policy. This is even acknowledged in the National Blueprint on education of the Handicapped published by the FME. According to the blueprint " success made so far in the delivery of special education in Nigeria, although minimal in terms of anticipated impact, largely due to inadequate funds" (12).

As stated in the NPE and the blueprint, a census of the handicapped was taken in 1991. However, though the census was not really targeted at the persons with handicap, since it was only during the general census that two columns were focused on this category of people, it was still a movement in the right direction. The other strategy mapped out in the implementation blueprint, stating that the Federal and State ministries of education should conduct a census of the handicapped, is yet to be done.

In addition to the significant progress made in the implementation of policy provisions, especially those dealing with training of personnel in special education, the federal government established an academy for the gifted and talented children. Although it is pointed out, that in practice, some of the children who are admitted in the academy are not necessarily there because they meet the screening criteria, but through the influence of higher ups in society (7); the fact still remains that the establishment of the academy is in keeping with the provision of the education policy and an attempt at touching the lives of children with special needs.

Apart from these provisions, other aspects of the policy particularly those dealing with administration, integration, provision and management of facilities and identification of children with special needs, for the purpose of enrolment for services, exists mostly on paper.

This situation has led to low enrolment of children with special needs in schools and other service outlets. For instance, enrolment of school age children with handicaps, stands at 0.42% (13), while that of their normal school going counterparts is around 67.05% (14).

INCLUSIVE EDUCATION IN NIGERIA

It is a matter of fact, that no concrete step has been taken with regard to inclusive education in Nigeria. Even at policy level, integration remains the focus of planning special education programmes. However, professional associations concerned with the education of people with special needs, have been addressing the issue of inclusive education in the country. For instance, inclusive education was one of the major issues examined at the 12th Annual National Conference of the National Council for Exceptional Children held at Minna, Niger State, in August, 2002. In the keynote address presented at the conference, Tim Obani (one of the pioneers in special education in the country), argued, "The old special education system with its restrictive practices cannot successfully address these problems [of special needs children]. The answer lies in inclusion or inclusive schooling, in changing and recognising the entire school system to accept all children and cater to their varied 'special' or 'ordinary' learning needs and difficulties" (15).

As alluded to earlier, the education of people with special needs has received wide attention at policy level, even though it is otherwise, at the level of implementation. The following problems have been identified with special education in Nigeria.

- Inadequate plans for the identification of handicapped children,
- Lack of adequate guidance services for the parents and the nature and extent of special education facilities available for their children,
- Most special schools are located in urban centres,

- Begging, which is fast assuming the status of an occupation among adult persons with disabilities, as well as other adults who have children with disabilities (7).

There is also the usual problem of attitude towards persons with handicap, which in most cases is far from being favourable. For instance, the writer was a witness to an ugly incident where parents threatened to (and some actually did) withdraw their children from school, because of the presence of a child with epilepsy. The local culture is a great influence on perception of disability and the resulting attitude towards it. Parents and other family members may be ashamed of exposing their children with disabilities, as these children might 'tarnish their image', especially in African societies where the common way of explaining phenomena are unscientific. In addition, there is a poor awareness about special education and about the fact that some children with disability can also have an education.

Beyond this, the all-pervading problem of illiteracy and its management is more important and therefore, which is more often than not, it takes priority over special needs education. For instance, most intervention programmes carried out by International Agencies and International non Governmental Organisations are in the area of literacy and non Formal Education. Even the recently launched Universal Basic Education (UBE) programme of the Federal Government, laid more emphasis on basic education, especially regular primary education and literacy education. Where attention is focused on special needs education, it is mostly in the area of basic education for the nomadic groups and the girl-child. Little or no special consideration is given to the education of children with disabilities.

The question now, is that how realistic is the adoption of inclusion as a strategy, in an environment where special education has to contend with the earlier highlighted problems and several others, that have not been highlighted here.

Given the nature of the environment of special education in the country, one will have to exercise caution in the attempt to implement inclusion, especially full inclusion. Even in the United States, from where the concept originates, many special educators like Kaufman and Hallan (16) and Zigmond (17), are still sceptical about its practicability.

One has reservations on whether the general educational system designed and implemented in its present form, has the adequate ability to cater for the special learning needs of exceptional children in Nigeria today.

PROMOTING INCLUSION IN NIGERIA

Inclusion as a strategy meant to include the excluded or marginalised groups in educational programmes including schooling, holds a lot of prospects for Nigeria.

1. Inclusion enhances the attainment of the objectives of EFA. Education cannot be for all until it is received by all (7). A system that excludes some people, cannot be for all and

should therefore give way to one that is accommodating of all. It has been argued, "A system that serves only a minority of children while denying attention to a majority of others that equally need special assistance ... need not prosper in the 21st century (15).

2. Inclusion promotes a sense of cooperation and the feeling of togetherness in the learner.
3. It promotes favourable competition among school children of different abilities, endowments and backgrounds.
4. In addition to its direct benefit on learners with special needs, inclusion allows for the resources of special education teachers to be tapped to the fullest, since they could be used as regular school teachers. It should be noted here, that special education teachers have the unique ability to teach in both the special and regular schools. Inclusion thus presents an avenue for full utilisation of the resources of all the members of the community.
5. Inclusive education provides a means of building a cooperative school community, where all are accommodated and able to participate.
6. Inclusive schooling is cost effective, as all the learners are accommodated in the same environment using virtually the same facilities. Unnecessary duplications of cost that are associated with segregated arrangements, are avoided in inclusion.

The following points can facilitate inclusion in the Nigerian setting.

1. Adequate planning which must be proactive (4) and realistic and take into consideration the peculiar and undeveloped nature of special education in Nigeria.
2. Campaigns to enlighten all the stakeholders in the education of children with special needs. This should be done in addition to aggressive awareness campaigns to reach out to parents of normal children who need to be receptive of special needs children.
3. More exposure of regular teachers to the nature and demands of special needs. Although the education policy provides for a compulsory component of Elements of Special Education for all teacher education students, there are still some teacher education institutions (especially in the universities) which are yet to implement this important policy provision. In addition to getting these institutions to implement the projects, more course units on special education should be made compulsory for all teachers-to-be, especially those going to teach at primary and secondary school levels.
4. Adults with disabilities living on the streets, need to be rehabilitated and gainfully engaged.
5. The Government needs to mobilise people to form more NGOs, to pursue the cause of people with special needs.

6. Professionals and other stakeholders should work towards getting the National Assembly to legislate the creation of a special fund for the education of children with special needs.
7. Though the education policy makes provision for a special education commission, this is still to be implemented. The Government should step up action towards this end.
8. Lastly, there is the need to get the machinery going towards the process of monitoring, in order to ensure effective implementation of inclusive schooling for children with special needs.

CONCLUSION

Presently in Nigeria, inclusion still remains in the realm of theory and far from practice. Special needs education in Nigeria is still grappling with problems of policy implementation, an environment that is not conducive for practice and a lackadaisical attitude of the people and government. Implementing inclusion in such an environment may be unrealistic and counterproductive.

In addition, the complexity and diversity of the country requires more intensive mobilisation of resources and information dissemination before inclusion can be institutionalised. With a nation still given to unscientific modes of explaining natural phenomena and human conditions, where illiteracy still exists in significant proportion, adoption of the inclusive school system, may end up not in the best interests of the concerned individuals.

Inclusion should not and must not be considered in the absolute. The Salamanca report said as much in the following statement, “we call upon governments and urge them to adopt as a matter of law or policy, the principle of inclusive education, enrolling all children in regular schools, unless there are compelling reasons for doing otherwise” (1). As far as Nigeria is concerned, presently there are enough compelling reasons to treat implementation of inclusive education with caution. There have to be restraints, lest one ends up assisting the special needs children and they finally learn nothing. Instead, it is suggested that there be a phased implementation of inclusion. This will mean gradual implementation, commencing with the first phase which is to identify and remove all the potential and actual obstacles to the implementation of inclusive schooling. The next phase would be to establish the required infrastructure and then get on to the final phase which is the actual implementation.

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PUBLICATIONS FROM SAVE THE CHILDREN

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**A STUDY ON CERTAIN FACTORS INFLUENCING
LANGUAGE PERFORMANCE OF
HEARING IMPAIRED STUDENTS**

Philomena Joseph *

ABSTRACT

This is a study on certain factors which had positive impact on the language performance of the hearing impaired students. Language handicap is the biggest hurdle in the education of the hearing impaired. Research reveals that hearing impaired persons commit more syntactic errors as compared to semantic errors. Though language acquisition is innate for human beings, it needs a proper environment to develop. Hence, the investigator formulated a grammatical assessment tool and compared the performance of three hundred upper primary class hearing impaired students with certain variables like the use of a hearing aid, type of management of the school, size of the class and residential vs non-residential set-up. The results showed that regular use of a hearing aid, private schools (both aided and unaided), size of the class (up to ten students) and a non-residential set-up had a positive impact on the performance of students. This study will help planners, administrators, academicians and teachers to formulate appropriate policies and teaching strategies in improving the academic performance of the hearing impaired; as language proficiency is the basis of better performance in other subjects and all round development in school.

INTRODUCTION

Man is a social being, who wants to converse and make contact. A hearing child masters language automatically by picking up from the talking environment around him. But in the case of a hearing impaired child, he/she should be 'taught' language. Children who are deprived of hearing, are cut off from the world of sound and language. According to Quigley and Paul (1) language handicap is the biggest hurdle in the education of the hearing impaired. Therefore, teaching language and acquisition of language skills are the central themes of any educational programme for the hearing impaired.

NEED FOR THE STUDY

From the experience of the investigator as a classroom teacher and teacher educator for the hearing impaired, it is observed that in spontaneous written language, hearing impaired children commit many syntactic errors. It is almost similar to telegraphic language i.e., with omission

of prepositions, conjunctions, case and tense markers etc. They are unable to write complex and compound sentences. Hence, the investigator felt the need to develop an assessment tool and to assess the written language skills of the hearing impaired children of Upper Primary Level, in the Malayalam language of southern India. So far, such studies have not been conducted for the hearing impaired in the Malayalam language.

The poor language performance of the hearing impaired is supported by the previous studies of Heider (2), Kretschmer and Kretschmer (3), Quigley, Power and Steinkamp (4) and Power and Wilgus (5). Though language learning is innate in human beings, it is not so, in the case of the hearing impaired. They should be given the right environment to compensate for their hearing loss.

OBJECTIVES OF THE STUDY

1. To develop a tool to assess the written language performance covering the grammar aspect in Malayalam for hearing impaired children of upper primary (Std V, VI and VII) level.
2. To compare the performance of students using a hearing aid regularly and those who use it occasionally.
3. To compare the performance of students in private unaided, private aided and government schools for the hearing impaired.
4. To compare the performance of hearing impaired students in schools with class sizes up to ten and above.
5. To compare the performance of students in a residential and non-residential set-up.

HYPOTHESES FORMULATED

1. There is no significant difference between the test scores of students who are using a hearing aid regularly and occasionally.
2. There is no significant difference between the test scores of hearing impaired students in private unaided, private aided and Government schools.
3. There is no significant difference between the test scores of the students whose class size is up to ten and above.
4. There is no significant difference between the test scores of residential and non-residential students.

METHODOLOGY

Development of the Tool

In the initial stage of the study, the investigator collected spontaneous written language samples in Malayalam, from two hundred hearing impaired students studying in V, VI and VII classes, from eight schools of the hearing impaired, in the State of Kerala. The investigator collected 6000 sentences and assessed them thoroughly to identify the main grammatical errors, categorised and compiled them under ten major headings based on the most frequently repeated errors. Keeping in mind the major syntactic errors, an assessment tool was made, dividing them into ten subtests. Each subtest had ten questions and each question had four multiple choices. The students had to mark the letter of the correct answer from them. The following were the ten subtests: (1) Copula (2) Pronouns (3) Tenses (4) Derived Forms of Verbs (5) Case Markers (6) Negatives (7) Question Forms (8) Compound Sentences (9) Complex Sentences (10) Word Order.

After the pilot study, an item analysis was carried out to find out the facility value and discrimination index. As the items were objective type, objectivity was established. Internal consistency was also calculated by Spearman Brown Prophecy Formula (split half method). Hence reliability and validity were established.

Sample

As the study aimed to assess the written language performance covering the grammatical aspect of the Malayalam language for the upper primary (Std. V, VI and VII) hearing impaired students, the investigator selected three hundred samples from all over Kerala. They were above average, average and below average, in academic achievements as per the assessment of the class teachers. They were between the ages of ten to seventeen years and as per the school records were normal in all respects except for the hearing loss and were perlingually deaf. They had hearing loss from severe (61 to 90 dB) to profound and above (91 dB above). Thus the sample was purposive and was selected on simple random procedure.

The test was conducted; answer sheets were scored and subjected to statistical analysis. The necessary information like use of hearing aid, (regular/occasional), size of the class (up to ten and above ten), type of management (Government/Private Aided and Unaided), residential/non residential etc. were collected from the respective school records. Mean Values, Standard Deviation, 't' values, 'F' values and L.S.D. were calculated.

RESULTS AND DISCUSSIONS

Hypothesis - 1

"There is no significant difference between the test scores of students who use hearing aids regularly and those using it occasionally."

The 't' value computed between the regular and occasional users of hearing aid according to the test scores, is given in the following table

Table 1: Comparison of Test Scores According to the Use of Hearing Aid

Sl. No.	Category	N	Mean	SD	't' value
1.	Regular	168	53.6607	17.9510	5.3970**
2.	Occasional	132	43.9697	11.4665	
	Overall	300	49.3967	16.1494	

Significant at 0.01 level.

The mean value of the test scores of students using the hearing aid regularly was 53.6607 and the mean value of students using the hearing aid occasionally, was 43.9697. The difference between the two mean values was 9.6810 and it was found significant at a 0.01 level. When the mean values were observed, the students using the hearing aid regularly, scored better than the students who used it occasionally. Hence the hypothesis formulated was rejected.

With the regular use of a hearing aid, the hearing impaired child got auditory feed back constantly and it might have resulted in the better performance of those students, when compared to the occasional users of a hearing aid. So use of hearing aids should be encouraged in schools for the hearing impaired, as much as possible. This finding was in agreement with the studies of Hart and Risely (6) and Luterman (7).

Hypothesis - 2

"There is no significant difference between the test scores of the students of Government, private aided and private unaided schools".

The F value computed to see the interaction effect of the students' performance under the different types of management according to the test scores, is given in the following table.

Table 2: Comparison of Test Scores According to Management of Schools (One Way ANOVA)

Sl. No.	Management	N	Mean	SD	F value
1.	Government	89	37.0225	7.3716	50.9580**
2.	Private aided	133	53.3835	16.1267	
3.	Private unaided	78	56.7179	15.6860	
	Over all	300	49.3967	16.1494	

Significant at 0.01 level.

The mean value of the students from the Government school was 37.0225, Private aided schools was 53.3835 and Private unaided schools was 56.7179. There was a significant difference among the mean scores according to management of the schools. This was confirmed by the calculated 'F' value 50.9580. The LSD (Least Significant Difference) test showed the following comparisons.

Table 3: LSD Test for Multiple Comparison

Sl. No.	Pair	Mean difference	Sig-Level
1.	Private unaided vs Government	19.6950	0.0000
2.	Private aided vs Government	16.3610	0.0000
3.	Private unaided vs Private aided	3.3450	0.0960

It was seen that the difference between the mean scores of students belonging to Private Unaided vs Government, was 19.6950, that between Private aided vs Government was 16.3610, and that between Private unaided vs Private aided was 3.3450. Hence the difference between the scores of students belonging to Private and Government schools was found to be significant, while there was no significant difference between the students of Aided and Unaided Private schools. Hence the hypothesis was rejected.

The reason for poor performance in government schools might be that, there was no proper supervision and administration as in the case of other types of schools. In private aided and unaided schools, proper supervision and follow-up activities might have been strictly followed, both, for the staff and the students. In the Government sector, in the schools as well as in the hostels, lack of enough teachers and personnel would have added to a lack of attention in the

teaching and management of these students.

Hypothesis - 3

"There is no significant difference between the test scores of the students where class size was up-to ten and above ten".

The `t' value calculated between the class size upto ten and above ten according to the test scores, is shown in the following table.

Table 4: Comparison of Test Scores According to Class Size

Sl. No.	Size	N	Mean	SD	`t' value
1.	Up to ten	211	54.6161	16.0092	9.9260**
2.	Above ten	89	37.0225	7.3716	
	Overall	300	49.3967	16.1494	

Significant at 0.01 level.

The mean value of the test scores of students where the class size was up to ten was 54.6161 and the mean value of the test scores of students where class size above ten was 37.0225. The difference between these two mean values was 17.5936, found significant at 0.01 level. When the main values were observed, the students who belonged to class size up-to ten scored better than the students where the class size was above ten. Hence the hypothesis formulated initially, was rejected.

For optimum results, hearing impaired children need personal attention. The lesser the number of students, the better their performance, as the teacher can pay individual attention to the students. This is probably the reason for better performance of the students where the class size was up to ten. The study by Hart and Risely (6) supported the findings of this study.

Hypothesis - 4

"There is no significant difference between the test scores of residential and non-residential students".

The `t' value calculated between the residential and non-residential hearing impaired students according to test scores, is shown below.

Table 5: Comparison of Test Scores According to Type of School

Sl. No.	Type	N	Mean	SD	't' value
1.	Residential	240	48.5333	16.3267	1.8590**
2.	Non-residential	60	52.8500	15.0579	
Overall	300	49.3967	16.1494		

Not significant.

The mean value of the test scores of students belonging to the non-residential school was 52.8500 and residential schools were 48.5333. The non-residential students could perform better than residential students. But the difference of 4.3170 was not significant. Hence the hypothesis formulated was not rejected.

The reason might be that at home these students got more attention and care from their parents, in their studies and development of language skills. The parents made sure of the optimum use of residual hearing, by regular use of a hearing aid. At home, students were surrounded by a comfortable talking environment, which probably had a positive impact on the performance in the test, as compared to residential students.

IMPLICATIONS OF THE STUDY

Language handicap is the biggest hurdle in the education of the hearing impaired. If one were to analyse, it can be seen that for any learning to take place, language is the first prerequisite. As hearing impaired children lack language skills for their better educational performance, a better learning environment must be taken care of.

As the study has revealed, variables like regular use of hearing aids, type of management of the school, size of the class, residential/non-residential set up etc. have a vital role to play in the language performance of the hearing impaired. So, while formulating educational policies for hearing impaired children, regular use of hearing aid, private management (aided and unaided), class size (up to ten), non residential set up etc. should be emphasised by the educational planners and administrators.

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LEARNING DISABILITIES IN INDIA

WILLING THE MIND TO LEARN

Editors: Pratibha Karanth, Joe Rozario

This volume brings together professionals from diverse fields who share their experiences of tackling the problem of learning disabilities (LD) in the Indian context. The issues covered include: The neurological, psychiatric and neuro psychological aspects of LD problems of language and reading in the bilingual and multi-lingual situation in India, issues of identification and assessment and speech and hearing issues.

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**REGIONAL SPINAL INJURY NETWORK -
INITIAL EXPERIENCE (2001-2002)**

Maggie Muldoon*, Stephen Muldoon

ABSTRACT

At the International Conference on Spinal Cord Lesion Management held in Bangladesh, in November 2001, participants representing organisations from various countries in the region, discussed the formation of a network, to promote advances made in spinal cord injury management within the region, through the facilitation of mutual learning.

The network has been operating for one year. This paper discusses the information and experience which has been gathered to date, and covers the aims, objectives, activities and name of network, activities undertaken by network member organisations and how the objectives of the Network can be furthered.

Information was collected through a questionnaire and continuous communication during the year. Based on the results, there were suggestions on formally launching the regional network, developing clear goals, objectives and an action plan, naming the network and use and effectiveness of the newsletter.

The information gathered, provides a framework for the network to remain appropriate, effective and receptive to members, and for the sustainable development of this initiative.

INTRODUCTION

During the International Conference on Spinal Cord Lesion (SCL) Management, held in Bangladesh in November 2001, a Regional Networking Meeting was convened so that participants representing various organisations from different countries in the region, could discuss how to continue to build upon the links made during the Conference.

As a result of the meeting, a Regional Spinal Injury Network was established. The Network consists of a group of organisations in the Asian region, who have come together to share and mutually learn all aspects of spinal cord injury management, from initial treatment of the patient to reintegration/rehabilitation of the person.

BACKGROUND

The Conference hosted by the Centre for the Rehabilitation of the Paralysed (CRP) in Bangladesh, provided a platform for organisations in the region working in the field of spinal cord injury management, to share knowledge, experiences and views on how to develop services in this area. At the Regional Networking Meeting, participants shared their views on what had been learnt from that conference. Comments included:

"We are learning what is happening at a local level."

"There is now a platform to develop our own way."

"We have a lot to learn from each other."

"We have seen quality services at low cost, improve the lives of disabled people, such as the wheelchair production."

"We can share technology."

"Bangladesh could be made a model centre for spinal injury management and rehabilitation"

All those present at the Conference expressed the opinion that there was now a forum for organisations in the region to voice their opinion on SCL management, appropriate to the local situation. It was felt that such a forum could lead to improved services for people with spinal cord injury.

However, there was a fear that the interest and enthusiasm generated by the conference would diminish when the participants returned to their own workplaces and got busy with their day-to-day work. As a result, it was decided that a regional network should be formed, which would promote and facilitate mutual learning in the field of spinal cord injury management, in the region.

The suggested objectives of such a network were :

- To facilitate the exchange of ideas, technology and staff, in order to further develop treatment and rehabilitation services;
- To establish a database of organisations;
- To use telemedicine as a means of exchanging ideas, as well as for referrals;
- To develop a website relating to the network.

For the objectives to be realised, the following course of action was suggested:

- CRP would take the initiative to co-ordinate efforts.
- A letter would be sent to IMSOP (now ISCoS) to request their support in forming a network/society.
- Members would concentrate on setting up the network and see how it developed.
- Organisations would begin networking and creating links with each other.
- Members would seek the opinion of disabled people to see what they wanted.
- Member organisations would use their own resources and be willing to exchange ideas.
- A basic document would be drafted which would form the basis of different ideas and suggestions.

The network has since been running on an informal basis. CRP has been responsible for co-ordinating efforts and has been assisted by John Grooms Overseas, through the publication and distribution of a regular newsletter.

METHODOLOGY

The information presented in this paper represents feedback from a questionnaire which was sent to members of the network and through observations of the authors as editors of the Regional Network Newsletter.

Questionnaires were sent by email to 31 members comprising 21 member organisations in 11 countries.

RESULTS

9 members representing 6 member organisations in 5 countries within the network, returned the questionnaires. The results have been subdivided in order of :

- Membership
- Network
- Newsletter

MEMBERSHIP

There are currently 27 member organisations in 9 countries within the region. Initially, in November 2001, there were 20 member organisations representing 8 regional countries. The 9 countries in the region include Bangladesh, Bhutan, Cambodia, India, Indonesia, Laos, Nepal, Sri Lanka and Thailand. In addition, Ireland and the UK are also represented.

Over half the respondents had introduced new members. The new members include Handicap International, Laos; Leonard Cheshire International, Bangalore; Aspire, UK; Individual practitioner, Nepal; and Ragama Rehabilitation Hospital, Sri Lanka.

The respondents suggested other organisations that should become members including Green Pastures Hospital, Pokhara, Nepal; Spinal Lesion/injury Centre, Ho Chi Ming city, Vietnam (2003 onwards); and the National Rehabilitation Centre, Laos.

The other countries which the respondents felt should be encouraged to join the network include Malaysia, Pakistan, Singapore and China. Respondents also felt that new members would be able to join the network at the ISSICON 2002 Delhi Conference.

It was suggested that a standard application form for new members should be devised and the possibility of a membership subscription be discussed.

MAIN ACTIVITIES OF RESPONDENTS

The majority of respondents work in the management and rehabilitation of people who have sustained a spinal cord injury. Other activities undertaken by member organisations include community based rehabilitation; health education; advocacy, awareness raising and prevention programmes; development of disabled peoples' organisations; rural development; training of health care staff; research; capacity building and network initiatives; occupational health and safety; and the control of unexploded ordinance.

THE NETWORK

The question as to whether the regional network should be formally launched was raised, and received a positive response from all respondents excepting one. One respondent was unsure, but suggested that further discussion take place at the regional meeting during the ISSICON 2002. Suggestions on how best to proceed towards formally launching a regional network included:

- The development of clear objectives and an action plan.
- The drafting and approval of a constitution.
- The selection of a committee with specific responsibilities designated to members.

The development of strategies to enable realisation of the objectives.

To ensure the continued success of the network, more than half the respondents suggested that the annual conference and regional meeting should continue, as also the newsletter.

Only one respondent had had previous experience in developing a constitution for such a network. It was suggested that a constitution belonging to similar international societies could be adopted or used as a model.

Suggestions for names of the network included:

- Asia Pacific Spinal Cord Society (APSCS)
- Asian Spinal Cord Society (ASCoS)
- Spinal Cord Society of Asia (SCSA)
- Asia Regional Spinal Cord Network (ARSCoN)
- Spinal Asian Society (SAS)

Goals

A common goal expressed by all respondents, was that the network should be a forum for the exchange of ideas, knowledge, information and support, relating to spinal cord injury management. The network should also promote good practices and work, to develop human resources, leading ultimately to improved services for people recovering from spinal cord injury.

Objectives

Numerous objectives were suggested which included:

- Experience sharing of knowledge, technology, information and resources, leading to improved treatment and rehabilitation facilities for people with spinal cord injury in the region.
- To become a recognised body, promoting models of good practice.
- To facilitate/arrange conferences, seminars, workshops and short training courses.
- To arrange exchange visits of staff and students between member organisations.
- The promotion of regional cooperation, in line with the UN Standard Rules.
- To develop a mutual strategy for prevention of spinal cord injuries in the region.
- To ensure financial support for the promotion of activities.
- To communicate through the newsletter.
- To improve scientific knowledge of practitioners through the development of a research centre.

Mutual Learning

Examples of how mutual learning has taken place through the regional network included:

- The replication of equipment featured in the Newsletter.
- Information on the work that the current and new members are doing.
- Scope to develop practice through case studies.
- Knowledge of what was going on in the region and elsewhere, e.g. details regarding forthcoming workshops, seminars and conferences.
- The organisation and hosting of the second conference in Delhi in 2002.
- Demonstration of how limited resources can be used to the maximum, in the care of patients with spinal cord injury.
- Knowledge and ideas gained from attending the conference in Bangladesh were helpful in the setting up of a new cervical cord injury unit.

Many respondents had made contact with other organisations in the network and continue to be in correspondence. The reasons for making contact included requests for technical advice; sharing of experiences; training related issues and staff and student exchanges.

Other comments/suggestions

There should be a regional network link-up with international bodies working in a similar field.

Initiatives should remain low cost and appropriate.

The management of spinal cord injury involves many disciplines and this should be reflected in the membership of the network and contents of the Newsletter.

The Network should be organised more actively.

Members should continue to meet at least once a year and the infrastructure/support should be available to enable members to attend the relevant training.

Members were appreciative of the initiative and thankful for all those involved in network coordination and development.

THE NEWSLETTER

The majority of respondents felt that the newsletter should be published bi-monthly. All but one respondent had received all copies of the newsletter. A new member had received only the last issue published.

On an average, 6 people in each organisation read the newsletter. At CRP in Bangladesh, the newsletter is posted on a general notice board and is available to all staff involved in the rehabilitation process.

Over half the respondents have been able to use some of the information in the newsletter. Two respondents have not used the information and one respondent does not use the information herself, but passes it this on to others with an interest in this area.

Some examples of how the newsletter can be utilised include:

- Expand depth of knowledge.
- Expand regional network.
- Insight into the work and approach of other organisations in the network.
- Awareness on forthcoming seminars, workshops and conferences.
- Contact addresses.
- Technical information.

In order to encourage members to send items for inclusion it was suggested that:

- Reminders be sent to members on a regular basis.
- Member organisations should submit organisation profiles on a rotational basis.
- Close contact be maintained with key resource people.
- Scientific papers written by members should be forwarded in the hope that it would evolve into a scientific publication.
- Incentives or remuneration be provided.

Members have also been active in passing the newsletter on to other organisations and individuals from different countries including Brussels, Zimbabwe, Japan, South Korea and South Africa.

Respondents felt that it would be particularly useful for the newsletter to include:

- Profiles of member organisations.
- Job Announcements.
- Valid information related to spinal cord lesion management.
- Models of good practice.
- Scientific discussions (regionally appropriate).
- Information on advances and newer methods in the management of spinal cord injury patients.
- Information regarding the start-up of new projects related to spinal cord injury.
- Useful links and website addresses.
- Perspectives of persons living with a spinal cord injury.
- A section for Letter to the Editor.
- Donors Contact Address.

In addition, current features such as Feedback Section, Feature of the Month and Calendar of Events should continue. Other methods of circulation of the newsletter should also be considered.

DISCUSSION

It has been a year since the members of the network met to discuss how to promote and facilitate mutual learning in the field of spinal cord injury management. Therefore, it is now time for useful reflection upon the progress made so far and to consider how this initiative can be further developed in the future.

There is evidence to suggest that the networking initiative has been beneficial to members. Members are becoming more aware of what the other is doing and of different management techniques, appropriate in the Asian context. Respondents have found the network to be supportive whilst they were developing new centres or wards specifically for the management of spinal cord injury.

There has been evidence that the network is growing and will continue to do so. The majority of members work in the field of spinal cord injury management, rehabilitation and integration. Some organisations are newly formed while others have been established for

many years. The network provides good opportunities for newly developing centres to learn appropriate systems of management from more developed centres and for all centres to keep abreast of new initiatives and developments. As well as management, rehabilitation and integration, member organisations undertake many other activities which are a valuable learning resource in their own right.

The database of members has been updated as a result of information received, but can be further updated when all questionnaires are returned. The database can then be used by all members, so that they are fully aware of each others' activities and what each organisation can potentially offer, in supporting the development of services in other organisations.

As most respondents feel that the regional network should be formally launched, this can be done following a systematic approach which would include:

1. Drawing up and approving a constitution and selection of a designated committee, with specific roles assigned to committee members.
2. Developing clear goals, objectives and a related action plan.
3. Developing strategies to ensure sustainability of the network and its activities.

Constitution/Committee

This regional meeting during the ISSCON 2002 conference in Delhi should provide a good opportunity to enable members to draft a constitution and select committee members. This draft can then be circulated to all members for further comments. A deadline would need to be set and the constitution completed by that date.

As most members have limited or no knowledge of drafting a constitution it is suggested that members use existing contacts with similar organisations to gain support in developing a constitution. The network should have a clear identity and name. The results provide some suggestions. It is also important that a standard application form for new members (individual and organisations) be devised.

Goals/objectives/action plan

The overall mission and goals of the network should relate to the development of services for people recovering from spinal cord injury, through the exchange of knowledge, ideas, information and human resources. This would reflect the spirit in which the network was established. It would also relate to the promotion of regional cooperation in keeping with the UN Standard Rules for the equalisation of opportunities for disabled people.

The results provide numerous suggestions as to what should be the central objectives of the network and are grouped under three heads:

1. Training and development

- The organisation of an annual conference and meeting.
- Short training courses for the network conducted by members themselves.
- Exchange of staff between member organisations.
- Attendance and active participation in conferences, workshops, seminars, etc.

2. Regional Network Newsletter

- Publication and distribution of a newsletter

3. Development of research activities

- Within member organisations
- Multi-centre projects between member organisations
- Developing links with internationally recognised institutes
- Development of prevention campaigns/initiatives appropriate to the region.
- Development of a database of incidence and prevalence of spinal cord injury in the region.

Action Plan

When the overall goal/mission and objectives of the network are agreed upon, it will be necessary to draw up an action plan to ensure that the objectives are realised and the overall goal achievable.

The action plan will be most realistic, beneficial and relevant if member organisations themselves identify a) what support they can provide, b) what support they require in relation to the stated objectives. The success of the action plan will therefore depend on the initiative, enthusiasm and motivation of the different member organisations.

Newsletter

The publication of a regular newsletter has been identified as a central objective of the network. To date, 5 newsletters have been produced and circulated among members. It is envisaged that the newsletter will continue to be produced and circulated bimonthly.

The newsletter has helped to expand knowledge, share information and keep all members informed about important events and developments. The newsletter can grow and develop, only if members continue to contribute material regularly. The results section outlined several useful suggestions on how to encourage increased participation, but ultimately, the newsletter and its growth is very much in the hands of members.

Over half the respondents have introduced new members, or shared the newsletter and networking initiatives with other organisations and individuals within the region and internationally. This is encouraging and should be continued. The more people know about the network, the greater the opportunity for mutual benefits. This study has also helped to identify new items for inclusion, which would be particularly relevant to members. These suggestions will be used to redesign and improve the newsletter.

It is hoped that the newsletter will specifically include:

- A regular case study.
- An organisational profile of member organisations.
- Information regarding advances in the treatment, rehabilitation and integration of spinal cord injury management.
- A feedback section (which can also be used to monitor effectiveness).
- Perspectives from disabled people.

The editor also needs to consider other means of circulation apart from email, since not all the members have internet access.

Sustainability of network

The network, to date, has been operating informally with no designated budget. This has proven that such initiatives can be achieved at low cost. However, if all the objectives are to be realised, then funding will be required. There will be costs relating to exchange of staff and students between organisations; training of members; publication and distribution of the newsletter; the organisation of an annual conference; and costs relating to undertaking joint research programmes.

There are numerous possibilities which can be explored to garner funds through :

- Member subscriptions.
- Member organisations including the regional network costs into their yearly budgets.

- Support from educational institutions working in partnership with the network.
- A funding proposal developed by the network members.

As funds are generated, they also require to be managed effectively and efficiently. Therefore, it is important that the logistics involved in this, be discussed by members at the annual meeting.

CONCLUSION

Although the number of respondents who completed the questionnaire was not as many as anticipated, the responses provided the authors with some very useful information, which has been used to develop a framework for the future direction and sustainable development of the regional network.

For the network to continue to develop, it is now necessary to have a clear constitution and strategy including goals, mission and objectives. Financial implications to member organisations will also need to be considered. Once the members are agreed upon the agenda, further work can then be undertaken by members collectively, to ensure that services in the region for those suffering from spinal cord lesion continue to develop and remain effective and appropriate.

Formulation of the action plan will depend, both, upon the strengths that member organisations can offer and the identified needs of members. The design of such an action plan will ultimately benefit all, as it will result in mutual learning.

The network has already developed a mechanism to ensure that members share and gain relevant information in the form of the newsletter. This has proved beneficial and can continue to develop in the future.

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Since the paper was written, the network is now called the Asian Spinal Cord Network (ASCoN). Other countries which have joined ASCoN include Afghanistan and Pakistan.

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1. Twible RL. **Final Fieldwork Placements of Australian Occupational Therapy Students in CBR Projects in India.** ACTIONAID Disability News 1996; 7(2): 68-72.
2. Pandey RS, Advani L. **Perspectives in Disability and Rehabilitation.** New Delhi: Vikas Publishing House Private Ltd., 1995.
3. Thomas M, Thomas MJ. **Evaluation Based Planning for Rehabilitation Programmes in India.** In: O'Toole B, McConkey R, eds. *Innovations in Developing Countries for People with Disabilities.* Chorley, UK, Lisieux Hall Publications, 1995: 243-254.

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