EDITOR'S COMMENT

The Millennium Development Goals (MDG) are a little more than half way through their term. The disability sector has been critical of these goals, which do not explicitly address issues specific to people with disabilities. In defense, one has heard the oft repeated statement that concerns of people with disabilities are supposedly inherent and implicit in the MDGs.

The recent mid-term review of the MDGs in different parts of the world has however, highlighted the fact that sufficient attention has not been paid in the MDGs to some disadvantaged groups, including people with disabilities. This review has brought out the need to include people with disabilities in the MDG targets.

It is evident that for each of the 8 goals, there is a clear rationale to include issues specific to people with disabilities. For MDG 1 on eradication of poverty and hunger, there is sufficient evidence to show that people with disabilities in developing countries constitute a significant proportion of the population that lives in poverty. For MDG 2 on universal primary education, evidence has highlighted the exclusion of children with disabilities. In relation to MDG 3 on gender equality and women's empowerment, it has been documented that disabled women and disabled girls are particularly vulnerable to abuse. For MDG 5 on child mortality, studies have shown that mortality rates are higher for disabled children even in countries with a low under-five mortality rate. MDG 6 is about maternal health, and it well accepted that improved maternal health can significantly reduce incidence of some impairments that can cause disability. For MDG 6 on HIV/AIDS, malaria and other diseases, again there is evidence to indicate that people with disabilities may be particularly vulnerable to sexual abuse, besides having limited access to information and other support systems. MDG 7 is about environmental sustainability: a poor environment can perpetuate conditions that lead to ill health and impairments, and environmental barriers are a major reason for exclusion of people with disabilities. The last goal talks about global partnership for development. This has implications for inclusion of disability issues in all mainstream development processes.

It is clear that for the remaining term of the MDGs, the specific concerns of people with disabilities in relation to each goal need to be explicitly stated and taken into consideration in

the implementation process. The process of achieving this is already initiated. Efforts are underway to develop supplementary targets and indicators to the MDGS, which would include the concerns of people with disabilities in the remaining term of these goals. This is a very welcome move and needs to be supported by all countries that are implementing the goals. Only with this can the aim of mainstreaming disability issues into the development process, be realised.

The APDRJ team wishes all the readers a Happy New Year!

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GUEST EDITORIAL

BEST PRACTICES IN THE SOCIO-ECONOMIC REHABILITATION OF PERSONS AFFECTED BY LEPROSY AND OTHER MARGINALISED PEOPLE IN THEIR COMMUNITIES: FINDINGS FROM NINE EVALUATIONS IN BANGLADESH, INDIA AND AFRICA

Johan P. Velema*

ABSTRACT

This paper presents an overview of findings from the formal evaluation of 9 socio-economic rehabilitation programmes (SER), in 4 countries in Africa, in Bangladesh and in India from 2002-2005. Bringing together the recommendations resulted in a description of best practices in the implementation of socio-economic rehabilitation programmes, derived from actual experiences in different contexts.

All the 9 programmes focused on supporting individual leprosy-affected beneficiaries or their families. Four projects also supported other marginalised clients. The usual interventions were micro-credit, housing and sponsoring of education for the children.

The recommendations touched upon each of the five steps in individual rehabilitation: Selection of clients, needs assessment, choosing an intervention, monitoring / follow--up of clients during rehabilitation, and separation at the end of the rehabilitation process. The evaluators also suggested ways in which participation of the client in their own rehabilitation might be boosted, made recommendations for the organisational structure of programmes, on maximising community involvement and emphasised the importance of information systems and of investing in the programme staff. A number of recommendations were specific to the types of interventions implemented i.e, housing, education or micro-credit.

Evidence of the impact of SER on the quality of life of clients is limited, but suggests increased self-esteem and increased respect/status in the family and community.

INTRODUCTION

Working to improve the quality of life of leprosy-affected persons involves both medical and socio-economic interventions. During the time when isolation was necessary, the socio-economic interventions were focused on improving the quality of life in so-called leprosy villages, by providing adequate housing, water and sanitation, food production and income generation, as well as education for the children of leprosy-affected parents.

The Leprosy Mission (TLM) has been implementing socio-economic interventions ever since it was founded in 1874. A better understanding of the causes of ulceration was gained in the 1950s and this led to the concept of self-care and the introduction of modern occupational therapy, helping clients to carry out activities in such a way, that damage to the hands and feet would be avoided (1).

Now that there is a consensus that leprosy-affected persons can remain integrated in their communities, interventions to meet basic needs aim at helping those who are marginalised because of leprosy-related disability, while at the same time, helping them to protect their hands and feet. As a result, persons with leprosy-related disability are better appreciated as members of their families and communities, since they become an asset rather than a burden. In this way, integration becomes a more feasible and realistic option. At the same time, many leprosy settlements continue to exist and receive support (2,3).

Many projects of socio-economic rehabilitation (SER) began small. They relied on very few workers who were personally involved with the clients and often arranged things rather informally. As success was achieved with a few clients, the desire to scale up the activity was felt by the staff, by the management or by the donors. In the late 1990s, TLM took a strategic decision to give more importance to SER activities and scale up this type of work - in line with discussions among professsionals involved in leprosy at the international level (4). Scaling up meant involving more staff and so it became necessary to develop written policies and protocols (5,6).

This paper presents an overview of findings from the formal evaluation of nine socio-economic rehabilitation projects in four countries in Africa, in Bangladesh and in India. Projects were in different stages of development and were implemented in different cultural contexts. Naturally, a number of recommendations were specific to the types of interventions implemented such

as housing, education or micro-credit. At the same time, many recommendations addressed issues of organisational structure, staff skills, criteria for the selection of beneficiaries, community linkages etc. which were common to all these projects.

In bringing together the recommendations from different projects, common pitfalls are identified and important lessons in the management of this type of work, emerge. The result is a description of best practices in the implementation of socio-economic rehabilitation projects, which derive from actual experiences in specific projects.

METHOD

The nine evaluations (7-15) were conducted in the years 2002-2005. Table 1 gives an impression of the magnitude of each project. Five other reports were not included because the SER work done was not the focus of the evaluation and therefore, not given adequate attention, or because the work had started only recently as a pilot project. Each project or programme was evaluated by a team of 2-4 evaluators.

Evaluations in Africa and India were informed by the conceptual framework under development during the same period (16, 17), but in Bangladesh this connection was less clear. The Community Housing Programme in India was implemented in 21 locations and three different pairs of evaluators visited four of them. Of 22 evaluators, 11 were TLM staff who were themselves directly involved in project implementation. Four teams included 1-2 evaluators external to TLM (total 7). Four other teams included TLM staff who were involved full-time in evaluation work. Evaluators were medical doctors, social workers, physiotherapists, occupational therapists, public health specialists etc. Virtually all had extensive experience in leprosy and rehabilitation work. Evaluators were not involved in any decision making about the project that they evaluated. Project managers were contacted well in advance of the evaluation visit and had inputs into the drafting of the terms of reference and the evaluation questions. As a general policy, evaluators were encouraged to make positive statements about each project, as well as identify areas for improvement.

Table 1. Size of the projects on socio-economic rehabilitation included in this review

Project/Programme	Definition/Time period	No. of Clients
Africa		
Nigeria	Median number per year over 1999-2001 in all 5 centres	100
Guinee	Group members in 2002	213
Uganda	Median number per year over 2000-2004	59
South Africa	No. supported in 2002	115
Bangladesh		
Dhaka	No. supported in 2003	157
Chittagong	Loans in 2001	96
Gaibandha-Jaypurhat	Median number per year over 2000-2002	150
Education Programme Dhaka (CREAD)	Number added each year over 2002-2004	50
India		
Community Housing Scheme	Number of houses in all, up to 2004 21 centres In 4 centres evaluated	 640 229

As evaluations were tailored to meet the needs of the individual project, the questions asked during the evaluations were not standardised. Most of the information presented in the present report is qualitative in nature. Recommendations from different evaluations have been brought together, to arrive at an overall picture of how this kind of work might best be done.

From every evaluation report, the executive summary, the summary of the conclusions and the complete list of recommendations were copied into a separate computer file. From these, all positive statements about the work evaluated and all recommendations were extracted and copied into the individual cells of a table. Every cell had a label identifying the report from which the statement came. Redundant statements, repeating the same ideas about the same project were deleted while all other statements were categorised according to subject

area. These categories were not pre-determined, but derived from the content of the statements themselves. However, specific attention was given to five steps in the individual rehabilitation process: selection of clients, needs assessment, deciding on an intervention, follow-up to monitor progress, separation.

Positive statements and recommendations for future development were grouped in any of the existing categories, to the extent possible. Although impact assessment was not the specific purpose of any of these evaluations, a number of the positive statements about projects included hints at the effectiveness of the interventions. These were grouped in a category "Impact".

The next step was to compare the categories from different projects and collect in one (computer) document, all statements from all projects that fell into the same category. At this stage, some harmonising of categories was done, but without compromising the data-derived nature of the categories.

Table 2. Classification of recommendations into categories by region

Theme	Africa	Bangladesh	India
Selection of Clients	X	X	X
Needs Assessment	X	X	
Implementing Micro-credit	X	X	
Implementing Housing Schemes			X
Implementing Education Scheme	X	X	
Client Participation/Sustainability	X	X	X
Monitoring	X		X
Separation	X		
Information System	X	X	X
Organisational structure	X	X	
Community Involvement	X	X	
Staff Skills	X	X	X
Impact	X	X	X
Future Directions	X	X	X

Note: An "X" denotes that reports from that particular region included recommendations in the category, as indicated.

These categories have largely determined the outline of the present paper. Within each category, the various statements were scanned to arrive at a summary and to see what conclusions could be drawn.

RESULTS

All the nine projects and programmes evaluated, focussed on supporting individual leprosy-affected beneficiaries or their families. Four projects (7, 9-11) also supported other marginalised clients. Clients had only a limited choice of what benefits were received, often as a donation or grant, sometimes as a loan or a mixture of both.

The usual interventions were micro-credit, housing and sponsoring of education for the children. Education could be anything from primary school, to secondary school to vocational training. Other forms of support were receiving a cow, buffalo or goat, a sewing machine, a riksha (India) or donkey (Uganda) for transport. These interventions are similar to those described by other authors (18, 19, 20, 21).

Selection of clients

Staff need to know and understand (internalise) the objective criteria that should be applied in the selection process to maximise the success of the programme. If the staff do not apply the criteria properly, either because they were not told, or because they misinterpret what has been said, or because supervision is lacking, the programme ends up being criticised by others in the community, who would like to benefit from the programme and do not understand why they do not qualify, or who perceive injustices in the way it is being administered.

Criteria concern, for example, socio-economic status of the family, disease/disability status and residence in a particular project area. Gender as a selection criterion was often emphasised and many projects maintained a good gender balance.

In some cases, a survey was recommended to establish early on the size of the target group and define sub groups according to levels of vulnerability. Surveys are expensive and time-consuming, however, and the actual situation may change quickly, particularly in urban slum areas. There was thus no agreement on this point.

One African project targeting leprosy-affected clients, combined self-care with SER and one criterion for getting a loan was to have ulcer-free feet. The same project experimented

with teaming up a client and another person not disabled nor affected by leprosy, to work together in an income-generating activity and this proved quite successful.

Needs assessment

The next step in the rehabilitation process is an assessment of the client's individual needs. In some projects, this is done informally, as a personal decision of the field worker responsible for this. In bigger projects, standardised formats are used and the written findings are submitted to a supervisor or committee, where a decision is taken.

In some projects, evaluators recommended that some research be done to obtain an overall picture of the socio-economic context of the target group and of possible income generating activities, so that the questions asked during a needs assessment and the interventions offered, are sure to be relevant.

Of course, whilst working with leprosy-affected clients on socio-economic interventions, the underlying assumption is that physical rehabilitation needs are taken care of. Where this is not the case, needs assessment should signal this and appropriate action should be taken.

Srinivasan (22), estimated that 21 to 45 per cent of persons affected by leprosy experience economic deterioration as a consequence of their diagnosis and therefore need assistance. Needing assistance is not synonymous with having impairments, but affects those who experience rejection by their families or communities and those whose impairments limit their capacity for productive work. Withington (21), presents data which suggests that rejection is more likely (although by no means exclusively) encountered by women, by those who have developed impairments, or who are visibly ill. Need for a change in sources of income is also important for those whose work leads to deterioration of their impairment status.

Deciding on an intervention

Depending on the project, clients could propose an income generating project, or choose from a limited number of possible interventions. It was found that many projects do not think to consult with an occupational therapist when choosing an income generating activity or planning a new house for a client. This is important for clients with disability - on the one hand to make sure they choose an activity within their capacity but, even more importantly, to prevent deterioration of the clients' disability status once they get involved in the activity.

Grant or loan

At least two projects in Africa gave grants rather than loans, while in the two other African projects, repayment rates were poor. Recommendations were for moving towards loans or for the development of criteria to decide when a loan should be given and where a grant would be appropriate. Then, there were projects where the amount that could be borrowed was essentially fixed and this meant that some clients got more than they needed, for what they wanted to do, while others complained that they could not realise their plans because the loan amounts were too small. Flexibility was recommended on the understanding, that stricter conditions would be applied when the amounts were higher.

In a project in Bangladesh supporting education of marginalised children, all that was needed (school fees, uniforms, materials) was paid for by the project. Evaluators suggested a financial participation by the parents would be feasible and in fact, beneficial to the success of the project. Similarly, evaluators of the SER work in Nigeria, felt that families should contribute to the cost of board and lodging for clients selected for vocational training.

Again, in the construction of houses for marginalised clients, an assessment of the capacity to repay by the clients and/or their families, should influence a decision as to what extent the subsidy should be granted or repaid.

An updated review of experiences with different approaches to funding for persons with disabilities, has recently been presented by de Klerk (23). He concludes that grant programmes are easier to administer than loan programmes. Ideally, clients should be helped to find their way to commercial micro-credit providers, so that they do not continue to depend on special programmes.

Skills training for clients

Evaluators of the SER programmes in Nigeria recommended, that before they are entrusted with considerable sums of money, clients be trained in business skills so that they have a better ability to handle these resources.

Evaluators in Bangladesh emphasised that where loans are given for income generating activities, training in the skills necessary for that activity (e.g. tailoring, crafts) should also be provided - possibly with the assistance of partner organisations (24).

Implementing education schemes

When children are supported to go to primary and secondary school, the question sooner or later comes up as to what to do for children who would have the capacity to go for tertiary education, but lack the means to do so. Sometimes, but by no means always, this problem can be solved by referring children to other NGOs who will support them.

An interesting question that was raised by an evaluator with expertise in education, is whether a project sponsoring children should make efforts to improve the quality of the teaching that the sponsored children receive, e.g. by providing inputs to the school or the teachers, or by providing extra-curricular tutoring as many parents in Bangladesh would do for their children, if they could afford it.

Client participation

There are many recommendations about actively involving clients in their own rehabilitation. This means that very often this aspect of the programmes was found to be inadequate. At the same time, as most of these evaluations were conducted some years ago, the evaluators contributed to the dissemination of this principle across TLM and its application in practice.

In sponsoring the education of children, community involvement implies involving parents in the development of selection criteria, in choosing the school that their sponsored children will attend and the items the programme will or will not sponsor, as well as regular discussions about the children's well-being and progress in school. It may even take the form of organising the parents in an association, to advocate for their children in situations where they encounter stigma-related difficulties.

In building low cost houses for leprosy-affected clients and their families, community participation means at least involving them in the design of their new house to make sure it is adapted to their handicaps and suitable for the number of people who that will move in. It also means using local materials for the construction and obtaining financial participation from the client, or his/her family.

Little was said in these nine evaluation reports about the influence that recipients of micro credits had in the choice of an income generating activity. However, from a previous survey among project managers in India, it is known that this influence is highly variable (25). In The

Danish Bangladesh Leprosy Mission (DBLM) programme in N.W. Bangladesh, "the form of assistance chosen rested on a joint decision of client, health worker, family and community" (21).

In three instances, evaluators recommended project managers to take steps to facilitate the formation of an association of disabled or leprosy-affected people.

Monitoring / follow-up

Especially where income generating activities are started, but also when education is sponsored or repayment for a new house should be recovered, good follow-up is crucial. Good follow-up means that visits to the client are made regularly and that the field worker knows what to do during those visits, which information to collect and which actions to take when problems are identified. Regular follow-up shows the client that s/he is taken seriously and that the intervention or the repayment is felt to be important by the staff. This is an opportunity to spend quality time with the client, as was particularly practised in South Africa.

Separation

Of course, there are situations where long-term provision of welfare is the only option. Nevertheless, in a number of projects, it was important to emphasise that interventions should have a limited duration and that staff should not continue to work with the same clients endlessly. An end-point should be reached where clients can manage by themselves. Ideally, this end-point should be defined at the beginning of an intervention, either in terms of a fixed time-interval, or in terms of outcomes achieved. This is also the time to assess any progress achieved through the intervention. Alternatively, one can define an end-point in terms of inputs provided. If the intended outcomes have not been achieved even though the rehabilitation plan has been correctly implemented, it is time to think of other interventions, which are more likely to be successful.

Information system

Working with the community is not synonymous with poor recording practices. This means individual client files, regular consolidation and reporting of indicator data and analysis and discussion to make adjustments as necessary. Data to be reported include management information and indicators, but also feedback from the community. Reporting should include comparisons of present indicator values to targets and to values at previous time points.

Of course, this implies that reporting formats are available, which make it easy for staff to collect information quickly and in a standardised way.

Organisational structure

Especially when programmes begin small and informally, a time comes when it is important to define its organisational structure, define who is working for this programme and who is supervising whom. It is then also important to define how this programme relates to the hospital or leprosy control programme, within which it has grown up.

In general, evaluators recommend that important decisions are taken by a committee, in which all stakeholders are represented i.e. the staff, the target group, the community, related TLM programmes, local authorities and possibly partner organisations. It is important that in such a committee, enough expertise is present about the type of work that is being done.

In some projects, the field worker who had the first-line contact with the clients was also responsible for the decision making of which proposals of clients to approve and which to reject. This put too much pressure on the fieldworker and evaluators suggested that the fieldworker should submit the plans to a supervisor or to a committee, who should take the final decisions.

In the case of a project focussing exclusively on sponsoring education, evaluators recommended the creation of an advisory group, which could guide efforts to improve the quality of teaching and of coaching of the children.

An important discussion that has been generated from these evaluations is whether leprosy control workers who detect cases of leprosy and dispense MDT can at the same time be effective in working with clients to develop income generating activities. Although these roles were combined in a number of projects in Bangladesh, and often successfully so, there were also examples of situations where this did not work well. Gradually, a consensus has emerged in Asia, that the two roles should be separated wherever possible. On the other hand, the possibility of re-training leprosy control workers to change to a role of an SER worker has been admitted by all evaluators.

In Nigeria, the evaluators concluded, that the best way to scale up SER activities was to involve the leprosy workers from the local government authority in its process. This concords with national policies, which specify that such workers have a role in rehabilitation. They do

an individual needs assessment after which the client chooses an intervention. The Local Government Authority (LGA) leprosy worker then monitors progress, gives advice and collects repayments of the loan (26).

Community involvement

Involvement of the wider comrnunity in the project, can often be achieved by including community leaders in the steering committees that take the final decisions on the requests for support (cf. under organisational structure). More and more, projects are advised to include representatives both from the target group and from the community in this committee.

Staff skills

The introduction of new ideas and new types of work means that staff need to be oriented to understand what is required. In many projects, recommendations concerned the drawing up of clear, updated job descriptions, protocols, guidelines so that staff would have clear frames of reference for their actions. Of course, drawing up guidelines needs to be followed by instruction and practical training. Staff need to internalise the criteria by which clients are selected, need to be able to ask the right questions to assess what are the needs and resources of a client. The use of standardised data collection formats may help with this. Staff also need to be able to assess what the viability of an income generation plan is likely to be and need to internalise the idea of giving loans and asking clients to repay. Staff need facilitation skills, if they are to work with groups or lead community consultations.

And so, when evaluators recommend scaling up of a programme or introduce new approaches, they usually also recommend (re-)training of staff or the recruitment of new staff that will bring in the necessary new knowledge and skills. Besides facilitation skills, the content of recommended training varies from an understanding of education principles, principles of marketing and economic development, to a better understanding of programme planning, community development and community-based rehabilitation.

In general, the success of a project is ensured, if all staff at all levels know what the objectives of the project are and how these can be achieved.

Impact

There is no doubt that in all SER projects, examples of clients can be cited, who have been quite successful and who have improved their lives thanks to support received from TLM.

At the same time, one may well ask as to what extent such clients would have succeeded without the project. Some people have the qualities and the drive to pursue success by any route that is available to them. It is pleasing to ourselves but probably unrealistic to think that all these clients have succeeded 'because of the support we have provided them', although it is undoubtedly true for a fair number of them.

Looking beyond financial success, therefore, it is encouraging to read in the same reports that clients have clearly increased their self-esteem through the activities that they became involved in, working with 'others and relating to the world around them' in new ways. The same reports speak of the "improvement in attitude, outlook, increased respect and status and role in family decision making".

Gershon and Srinivasan (18) reported increased employment and income after SER interventions; only 12 clients out of 78 said the programme had not benefited them at all. Nine of 13 clients who had experienced problems of being accepted in their families upon diagnosis of leprosy felt these problems had been solved after rehabilitation. Rao et al. (20) describe SER programmes in Andhra Pradesh and Orissa in India, and report that of 120 clients receiving assistance, 53 were restored to their initial economic status, while 58 improved partially. Unfortunately, no details were given on how this was measured. Ebenso et al. (27) interviewed clients of SER programmes in five states in Nigeria and members of their families and communities and reported positive attitudinal changes towards people affected by leprosy as they stopped begging but rather were able to make financial contributions when relatives or neighbours were in need.

FUTURE DIRECTIONS

Evaluators provided lots of ideas for future development of the programmes. Generally, evaluators felt the programmes should be strengthened and consolidated and then extended to serve more clients.

Often, SER interventions aim at providing some income or support to the client, assuming that family members will provide whatever other support is needed. In at least two projects, evaluators recommended that staff should be more ambitious and aim for full economic independence of their clients, by encouraging them to develop income generation activities which had sufficient potential.

Although the proportion of leprosy affected clients varied, evaluators in three programmes suggested that more persons with non-leprosy disability should be included to promote integration and work according to CBR principles.

In four reports, evaluators recommended moving towards a micro-credit programme based on groups. Already, many programmes had a few groups functioning side-by-side with the individual SER work (7,9,10,13) while the programme in Guinee (8) gave individual grants to members of self-care groups.

In the mean time of course, TLM has invested greatly in the formation of self-help groups, not only in India, where financial support for such groups can now be obtained from the government, but also in other countries. Membership of these groups consists of persons with disabilities due to different causes i.e. not exclusively leprosy. Thus, the importance of the traditional SER work reported on here, has waned, although individual SER interventions continue to be used for clients who cannot function in a group, or in situations where a better alternative is not available.

Given the frequent interaction with clients in SER programmes, TLM staff should seize those opportunities to make clients aware of the health and disability issues which are locally relevant. This includes basic understanding of leprosy and stigma, of disability rights, of locally prevalent diseases, of HIV/AIDS and in an education scheme, of child health.

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ACKNOWLEDGEMENT

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DEVELOPMENTAL ARTICLES

REFLECTIONS ON POVERTY AND DISABILITY:
A REVIEW OF LITERATURE

Marlies van Kampen*, Ingrid M. van Zijverden, Tony Emmett**

ABSTRACT

This study carried out a review of literature describing the relationship between poverty and disability, in order to establish the evidence base for this relationship. Several authors seem to accept the existence of this link, even without a sound research basis. Articles and books were scrutinized to find out what sources were used in these publications to conclude that there was evidence for a strong relationship between disability and poverty. Peer-reviewed articles were used as much as possible.

It was found that cultural determinants play the greatest role in the process of disability leading to poverty. Monetary factors are also essential determinants when it comes to poverty as a result of disability. The relationship between disability and poverty seems to be a vicious circle. Most of the literature concerning poverty and disability is based on non-rigorous (literature) studies.

Relating disability to poverty and vice versa is a complex matter that needs to consider several interdependent factors that influence this process.

INTRODUCTION

It is widely accepted that poverty and disability are somehow linked. Much has been written about the existence of a two-way relationship between those two issues; poor people have more chance of becoming disabled and disability adds to the risk of poverty (1,2). However, there often seems to be lack of scientific evidence for the statements and conclusions made in most publications. Most of the sources used in the articles appear to be less accredited or

even anecdotal. It also appears that most studies done on poverty either do not consider disability as a determinant or result of poverty or use different definitions for both issues, making it impossible to compare international data (3). One article contains a good review of the literature (1) about the relationship, but most of the reviewed sources were studies carried out in Western countries, as there was limited amount of accessible data and information on disability in developing countries (1,3).

The aim of the present literature study is to provide a more rigorous basis for the existence of a relationship between poverty and disability. This report, executed during the first part of 2006 for the South African-Netherlands Research Programme on Alternatives in Development (SANPAD) was prepared as part of a two-year research project on the effects of inclusion policies of the South African government as well as (international) non-governmental organisations (NGOs), on the lives of disabled people in South Africa. This research is a collaborative study of the University of Pretoria as lead investigator, and the University of Amsterdam and University for Applied Health Sciences in Leiden, in The Netherlands, playing a supportive role.

METHOD

Definitions of poverty and development, as well as disability and impairment were searched on the Internet and in various publications. Google Scholar was used to trace articles and books, and some articles were also found in the Royal Library in The Hague. Several terms (poverty, disability, handicap, impairment, discrimination, exclusion, stigma, development etc.) were used to search for articles on the link or definition. Articles used were first scrutinized on sources referring to a possible link between disability and poverty and sources that were seen as reliable. The authors made use of the following list with screening questions in order to scrutinize the articles for their usability in this particular literature study, and their reliability and validity.

- What is the central research problem?
- What type of research instrument was used?
- What type of research design was used?
- What is the relationship between the research problem and the research design?
- What is the methodology of the research?

- Are correct conclusions made? → Internal validity
- Can results/conclusions be generalized? → External validity
- What is the quality of results? → Objectivity

DEFINITIONS

Prior to making any comparisons on existing data on incidence of poverty and disability, it is important to define what is understood by poverty and disability. There are many different definitions used in research studies that focus on disability and poverty. This is one of the reasons why there is so little internationally comparable information on this issue (4). For comparative research, it is essential that every country uses the same definition of poverty and disability and the same method for estimation of occurrence, so that the country can measure any progress and plan its poverty programme accordingly (5).

Defining poverty (and development)

"The way that poverty is conceptualised is inherently about value preferences that vary between individuals, organisations and societies" (6).

The United Nations describes poverty as: 'the denial of opportunities and choices most basic to human development - to lead a long, healthy, creative life and to enjoy a decent standard of living, freedom, dignity, self-esteem and the respect of others' (5).

The World Bank created a more "practical", but simplified monetary indicator to identify poverty using a 'poverty line' of income of less than US$1 a day (7).

In order to define poverty it is important to realize that poverty has a multidimensional nature, and to first consider which factors indicate poverty. In the different definitions that exist, many different factors are being mentioned, which makes it hard to indicate one specific definition as being the best or most accurate one. Mention is also made of two sorts of poverty, namely absolute poverty (measured against the bare minimum necessary to maintain a person's physical efficiency) and relative poverty (measured against the average living standard of a particular society) (8).

The CPRC states in its report on Chronic Poverty, that there is no objective way of defining poverty (6). Many countries have defined their own poverty lines, which would represent the

level of income or consumption necessary to meet the minimum requirements, such as clothing, housing and health care. Most countries use the minimum amount of nutritional intake needed in order to measure poverty, but different nutritional norms are used. When every country adopts its own poverty line, it becomes impossible to make cross-country comparisons with regard to poverty, and someone defined as poor in one country, might not be poor according to standards used in other countries (7).

In order to be able to make the cross-country comparisons, the World Bank had introduced an international poverty line (mentioned in the World Development Report, 1990), as being an income of (less than) US$1 a day, expressed in 1985 Purchasing Power Parity (PPP) of dollars and referring to household expenditure per person (6,8). The use of official exchange rates to convert national currency data to US dollars would however not reflect the relative domestic purchasing powers of currencies (7). The PPP reflects how much currency in one country is required to purchase the "same" amount of goods and services as can be bought with one unit of the currency of the base country and is influenced by information about prices and quantities of commodities consumed in third world countries (9).

Not every one agrees with the international poverty line (IPL) as being the right definition for, and tool to identify poverty. Several authors (9,10) report on the deficiencies of the World Bank Poverty Line. The biggest point of criticism is that the IPL only measures poverty in terms of money ('income'). Reddy and Pogge (9) express their criticism with the "money-metric" methodology of the IPL and state that the World Bank "…uses an arbitrary international poverty line that is not adequately anchored in any specification of the real requirements of human beings"(9). Comments are also made about the validity of existing comparative studies. The CRPC states in its 'Global chronic poverty in 2004-2005'-report that: "The validity of cross-country comparisons depends on the accuracy with which these PPP exchange rates are computed, as well as the comparability and reliability of the income or consumption data. Both of these cause serious difficulties. While the currently quoted figures in the 2003 World Development Indicators enable comparisons to be made, there are serious questions about the figures in a number of instances (e.g. Nicaragua, Pakistan, Uganda)"(6).

Reddy and Pogge (9) argue that an IPL should be substantially higher, for a human being to be able to meet the elementary requirements of living (such as food, housing, clothing, etc.),

given the example of the United States. The US Department of Agriculture estimates $3.51 per person per day as the lowest cost required to meet minimal nutritional standards in 1999, in the USA. This concerns only food costs. The poverty line of $1 a day would be an underestimation of the numbers living in poverty in the US. Therefore the question whether international comparison can be made based on the IPL, remains critical (9,11).

As shown, analysis at this point is primarily undertaken of money-metric and other quantitative indicators, concerning the research of chronic poverty (12). This appears to be the easiest solution when measuring poverty, for it is convenient to compare figures that already exist, without having to 'translate' someone's feelings, thoughts and experiences as expressed in quality of life studies. It however, remains questionable if only the comparison of money-metric data gives a good reflection of the reality of lives of scores of people living in poverty.

More attention is given by some authors to the fact that poverty is not only a matter of lack of money, but concerns also social exclusion and powerlessness, arguing that national development policies cannot solely be based on generating more income (4,13). More recently, the World Bank has started to describe poverty in terms of material deprivation, low levels of education and health, exposure to vulnerability and risk, and voicelessness and powerlessness. It is good that these issues are now being taken into consideration, but they still lack the precision and comparability that is shown by income/consumption measures. Since the issues mentioned deal with for example the quality of life, it is hard to quantify them in order to make cross-country comparisons (12). The United Nations has defined poverty as the lack of what is basic to human development, similar to what is being described above (13). Basic needs include not only food, water, shelter and clothing, but also access to other assets or services like education, health, credit, participation in political process, security and dignity (12). The UN states in their World Development Report 2004, that measuring human development extends beyond the national income accounting approach. They argue: "Although useful, national income figures fail to reveal the composition of income or the main beneficiaries of economic growth. In some instances, people may value better nutrition and health services, increased access to knowledge, a greater voice and accountability in decision-making, more secure livelihoods, or better working conditions above absolute income gains. However, these human development gains are not clearly reflected in income or economic growth statistics" (13).

It is evident that more research is needed in order to find ways and means to concretise all aspects that should be considered, and to develop indicators and measure them, in order to get a full view and understanding of poverty.

Defining disability

Poverty is not the only issue that is hard to define. Defining disability is also quite a complex issue, considering all the different aspects, values and interpretations (14). When looking at the term throughout the ages, several attitudes towards disability emerge. It evolves from an 'evil spell' in ancient Greece, and a 'jester' or 'representation of poverty' in the Middle Ages, to 'representation of the irrational; that which cannot be assimilated to a norm without undermining it' in the Classical Period (15).

Till recently, disability used to be seen primarily as a medical condition, with the problem located within the individual (16). Though disability indeed results from physical or mental impairment (being the medical part), it also concerns social and health implications, which is the reason for disability activists to have changed the emphasis from disability as a medical condition to disability referring to socially imposed restrictions, that is, the system of social constraints that are imposed on those with impairments by discriminatory practices of society (17). This 'social model of disability' draws a clear distinction between impairments and disability (18,19).

A more recent definition that is increasingly being accepted and used is stated in the International Classification of Functioning, Disability and Health (known as ICF), a modified version of the International Classification of Impairment, Disability and Handicap (ICIDH) (20, 21).

Although the ICF is a health and health-related classification, it is also used by other sectors such as insurance, social security, labour, education, economics, social policy and general legislation development, and environmental modification. It has been accepted by the World Bank and many other key development organisations and it seems to have become the gold standard for understanding and measuring the extent of disability. DPI (Disabled Peoples' International) are utilising it and the United Nations have also accepted it as one of the social classifications. The ICF incorporates *the Standard Rules on the Equalization of Opportunities for Persons with Disabilities*. Thus it appears that the ICF provides an

appropriate instrument for the implementation of stated international human rights mandates as well as national legislation (21,22,23). However, in one of the publications of disability KaR there is some criticism on the ICF definition. The authors state that the ICF represents little more than medical model thinking clothed in social model language, particularly as many professionals continue to pay little attention to environmental impacts and focus instead on impairments (22, 24).

Despite the criticism, the ICF is becoming more accepted as a global and universal tool. The World Health Organisation argues: "The ICF was developed and refined through a 10 year process involving over 65 Member States, which lead to a broad-based consensus about the terminology and classification, and used more commonly in several countries. Extensive field testing provided for cross-cultural comparability making the ICF a truly international standard for functioning and disability classification" (25).

Models of disability

Several models of disability exist that describe the way people may think about disability. Those ideas on disability can differ from person to person and may be influenced by their belief systems, or culture.

Medical model

In this model, disabled people are defined by their impairment and medical/technical solutions offered to alleviate their condition. Disabled people are seen as 'ill' or 'sick' in this model and are expected to be 'cured' or 'normalised'. Medical professionals are seen as 'disability experts'. According to this model, the disabled person is the one with the problem, and interventions are provided for the person to be rehabilitated, or to find a way to deal with the problem. This model concerns an individualistic approach that does not consider social barriers (4, 26).

Charity model

This model is condemned by critics as disabling, because disability is seen as a personal disaster, disabled people are seen as tragic victims to be pitied and helped by charity in order to survive. Those who manage to be happy and achieve their goals despite their disability, are

seen as brave. Disabled people are expected to be humble and grateful for what they receive and need charity in order to survive. There is no question of recognition of equal rights or the role that discrimination plays (4, 26).

Social model

This model is based on rights. It considers disability as the social consequence of having an impairment. The inequities faced by disabled people can only be overcome if society becomes inclusive. If the problem lies with society and the environment, then society and environment have to change. In this model, disability is not seen as something invoking pity or in need of cure. It implies that the lives of disabled people will improve when attitudinal, physical and institutional barriers are removed. Equality for disabled people is seen in the same light as equality for other under-represented groups (4).

Religious model

In a Western Judea-Christian society, the roots of understanding bodily difference have been grounded in Biblical references, the consequent responses and impacts of the Christian church, and the effect of the enlightenment project underpinning the modern era. These embodied states were seen as the result of evil spirits, the devil, witchcraft or God's displeasure. Alternatively, such people were also signified as reflecting the "suffering Christ", and were often perceived to be of angelic or beyond-human status, to be a blessing for others.

Therefore, themes which embrace notions of sin or sanctity, impurity and wholeness, undesirability and weakness, care and compassion, healing and burden have formed the dominant bases of Western conceptualisations of and responses to, groups of people who in a contemporary context, are described as disabled. In the past, various labels have been used for such people. These include crippled, lame, blind, dumb, deaf, mad, feeble, idiot, imbecile, and moron (26).

Most (science-based) writings relate to the Christian Religion. Other religions, for example traditional African religions or Islam also have certain visions of disability, which might be quite similar to the (historical) Christian beliefs. However, searching for a 'religious model' resulted primarily in the (historical) Christian view, which is the reason that only the Christian

vision is mentioned in this article. Further research should be done before mentioning views of other religions based on scientific research.

Generally, it appears that different religions have inconsistent approaches to disability, as well as different people within each religion, ranging from acceptance of people with disabilities as a gift from god(s) and therefore special, to rejection of those with disabilities as a punishment from god(s). While this varies by religion and family, attitudes can also vary by the type of disability (27).

Devlieger et al have expounded further on different models and the dimensions in which they differ from each other (28).

RELATING POVERTY AND DISABILITY

'The analysis of the relationship between disability and economic status should be interpreted as an association and not necessarily a cause or consequence' (29).

Having reflected on the definitions of both poverty and disability and all the different aspects that should be taken into consideration, an analysis is made of publications referring to the possible link between the two issues.

Several authors mention social exclusion or isolation as a result of disability. A research from sub-Saharan Africa (30) showed the effect of stigma on people with epilepsy. Women with epilepsy were considered as poor wives by the community, for they were not able to cook or take care of the children and in polygamous regions, would therefore not be likely to become first wives. This has its consequences, because unmarried females are particularly vulnerable to sexual exploitation, physical abuse, and extreme poverty (30). This study indicates an indirect link between disability and poverty, where disability leads to stigma, and therefore to exclusion, which subsequently can cause poverty. Stigma seems to be the linking determinant in this case. The example shows that social values of a community appear to be crucial when it comes to disability as a cause of poverty, for stigma and exclusion can only exist because of the notions of the people. Yeo argues that it depends on the society and culture how someone with an impairment feels. In most societies people with impairments are excluded and, according to Yeo, this is what disables them (4,11).

In Uganda, a study focused on the issues of disability and poverty. One of the conclusions of this study was that disabled people face various forms of exclusion, isolation and neglect and this condemns them to perpetual (chronic) poverty. Another conclusion is that different categories of disabled people have different needs and are affected differently by poverty, which supports the statement that social values are very important when it comes to considering who is disabled (19).

Another example concerning disability and social exclusion is the birth of a disabled child in most of the developing countries. This is often seen as a tragedy, a curse or witchcraft (considering the religious model). In developing countries children are supposed to take care of their parents and family in the future. When a disabled child is born, or a child gets disabled, he/she needs more care than a child who is healthy and moreover, he/she will not be able to fulfil assigned tasks in the future. Parents often think it is God's will to have a disabled child and sometimes they refuse to give the child treatment, because of this reason. Other factors like shame, ignorance and lack of monetary means to invest in the child also play a part. Most likely the child will not be sent to school, for which parents have several reasons. First, they would think their child will not be able to manage, even when the child has only a physical impairment. Second, they might think it is not worth their money. School is expensive and they might rather spend their money on the healthy siblings. Subsequently the child will be excluded from 'normal' social life. In the future, the child will therefore not be able to find a job and thus support his/her parents, because of the lack of education (4,19).

A study of eleven household surveys done in nine developing countries confirms the earlier statement with regard to education, arguing that youth with disabilities are less likely to start school, and have lower transition rates in some countries, which results in lower education levels (29).

Somehow, there seems to be a vicious cycle. Several articles illustrate this. One of them is about the barriers to care in (rural) Zambia. Health care is an expensive service that many people in Zambia cannot afford (31). The few people who are able to pay for the transportation and medical fees (most rural economies rely on a bartering system, so the expenses exceed most people's monetary abilities) can be referred to a medical centre with imaging capabilities and neurological expertise. Most people with complaints will not immediately consult a physician, most of the times due to lack of money. For example, people with headaches

caused by mass lesions are often seen by the physician when visual loss has already occurred, or seizures become manifest along with progressive neurological deficits. Delayed evaluation (in this case due to financial issues) often results in advanced disease, no longer amenable to treatment.

The symptoms and consequences of neurological disease will make a person socially and economically vulnerable, which in itself limits their access to care even more (31). This case study shows that poverty may lead to delayed evaluation by a physician and therefore may cause disability. This disability may exclude people socially and economically, which makes them poorer and gives them even less access to care, which in turn may aggravate their disability.

A study done in Cambodia shows that poor people lack access to basic health care which means that simple infections, illnesses and injuries could result in permanent disability because they go untreated or are mistreated (32). All informants who became disabled later in life indicated that they became poorer after they were disabled, and most said they had become much poorer. This might be explained by the fact that disability can have an impact on a person's ability to work and earn a living. It can be illustrated by a case study about a woman who had rice fields and several animals. After carrying a heavy bag, she had a back injury; the doctor gave her an injection, which paralyzed her. She was not able to carry out her work anymore, so she had to rent out her land and sell her animals. The only income she then had was by renting the land. Another reason for this woman becoming poorer is that she was not able to come out of her house to meet and see other people (32). Being poor is seen as a multidimensional concept.

A Chinese study analyses the relationship between poverty and Tuberculosis (TB) (33). Poverty appears to be a key risk factor for TB. This disease has two epidemic profiles; one endemic form, of which the incidence rates vary, depending on access to care, food and hygiene of the population and an epidemic form, within the population at risk: prisoners, people in institutions etc. (34). Poor people are specifically vulnerable when it comes to the endemic form. In this example poor people seem to delay consultation, not only because of the cost of the TB-care, but also because the lack of knowledge of TB and fear of social isolation or stigma (33).

Another disease that is strongly related to poverty is malaria (35). Poverty can keep people from using available methods of cure and control (such as mosquito nets) (36). This can lead to disease in children, whereby cerebral meningitis is a specific threat leading to neurological disorders such as cerebral palsy or even death.

Poverty also appears to be a high risk factor for unintentional injuries, resulting in disability. Research conducted in Vietnam, shows that poverty increases the chances of injuries at home (specifically in children and elderly people), at work (specifically in adults between 15-59 years) and for "other" injuries (37). In this study, it is stated that poor adults are at a greater risk of injuries at work, because people living under harsh economic conditions are willing, or forced, to accept jobs that expose them to extremely high risks or unsafe conditions. Their housing and traffic environments are also often very risky (38, 39).

Research done in Cambodia also showed that poor people appear to be forced to use less safe methods of transport and to work in risky environments (32).

Poverty appears to have its effect on nutrition and thus health and related disability. Booysen and Burger state that there is increasing evidence that poor nutrition in childhood is associated with both short-term and long-term adverse consequences such as poorer immune status, higher incidence of caries and poorer cognitive function and learning ability (40).

HIV/Aids has also been described as a disease of poverty, in close relation with Tuberculosis (41). A research on HIV-infected women in India showed that social position can be a key cause of HIV/Aids in women. Low economic status (due to circumstances or the loss of a primary wage earner) causes vulnerability, which increases the risk of becoming subject to sexual violence and forced prostitution. These are both major contributing factors for HIV-infection (42). After contracting the disease, the women experienced less socioeconomic, spiritual and family support. The worsening of the physical symptoms, emotional and mental anguish forces them into isolation, that negatively affects their mental health (42). People with HIV/Aids also have compromised immune systems that cause them to be easily infected with the TB virus, developing active TB. This has caused an exacerbation of the TB-epidemic (41, 43).

One third of the increase in the number of TB cases internationally in the past five years has been ascribed to HIV. Diagnosis of TB is likely to be equated with HIV. This can result in discrimination, which can be the reason for people to refrain from consultation (41).

Social exclusion can be considered as a form or consequence of discrimination that comes with social values concerning impairment. It has appeared to be the essential link between disability and poverty.

Articles on research done in high income countries also claim that disability leads to discrimination. In the United States for example, it appears that many people with disabilities experience problems with finding employment (44).

Research done in South Africa showed double discrimination of black wheelchair-bound adults during the Apartheid era. It was found that these people lived in poverty and isolation. A small percentage found employment or had received some form of financial compensation for their injury or disability grants (45).

DISCUSSION

Though many articles consider the possible link between poverty and disability, it is not always very clear where and how they got their (scientific) evidence. In order to make a well-founded analysis of the relationship between poverty and disability, the authors had to scrutinize the references and track the primary sources of all articles. In several articles 'visions' were given about the possible link, but most of the ones read by the authors seem to have not been based on scientific research, considering the sources used.

Eventually, the authors searched for articles that did not necessarily look for a link between the two issues, but considered one aspect (for example epilepsy, when it concerns disability) and the issues related to that one aspect (for example poverty). This means that only those articles were studied that really considered the detailed aspects of research methodology instead of giving general viewpoints without providing at least some basis for validity checks.

One general problem encountered was the fact that several different definitions were used for poverty and disability. This made it hard to compare the different results and conclusions of the various studies. The authors decided to only analyse those articles that used similar definitions.

It seems to be clear for most people that there is a link between poverty and disability. The authors however found that many articles were based on assumptions about the link (without reference to evidence) or just based on anecdotal information. Most of the articles had

references whose sources were mostly not referring to scientifically sound research. In many articles the same arguments were used in order to prove the link; possibly because similar - not primary - sources were used in these articles. This somehow implied high quality because there is at least consistency in the explanation of these sources. However, when scrutinizing for validity and reliability, there sometimes was little of either. Many articles appeared to have been based on not well-founded statements by other researchers.

Several of the articles by World Bank and UN, found during this research, were also – partly - based on anecdotal information. Probably other authors also take the "evidence" from such global organisations for granted and do not take a critical view of the reports coming from these bodies.

Some other articles studied seem to have been based on scientific evidence, but some of articles belonging to the primary resources could not be located by the authors. Subsequently the authors were not able to verify the level of evidence of these articles and see whether these were based on primary resources, or again only based on opinion.

Elwan stated in her 'review of the literature' that she was not able to find articles in which a research study was conducted in developing countries. Miles (3) refers to his own bibliography, where a lot of articles are mentioned. The authors of the present study tried to track those articles, in order to use them for this study. Unfortunately, it was indeed very hard to trace the full text articles (through means of internet), mostly because of the year in which these articles were published, and some of them not being formally published. The authors did not have the means (funds and time) to trace the original and primary sources and therefore do acknowledge that there are limitations to this literature study.

The authors have tried in this study to make use of mostly primary resources. These resources, however, concern local studies most of the times. There is of course the doubt if it is possible and correct to generalise the results of local research studies, in order to provide evidence for the link between poverty and disability at a global level. Cultures differ from one to the other. Attitudes towards people with disability may vary from country to country and even within countries. In most countries attitudes result from cultural, traditional and social values that are prevalent in the community. It may very well be that the linking determinants in the relationship between poverty and disability may differ between countries as well.

Not all the references used in this literature study were checked for validity and reliability by using the probing list for screening. This was due to time constraints and difficulty in tracing the primary references. However, the authors tried to scrutinize the articles and their references as much as possible. The reliability may therefore be compromised to some extent.

CONCLUSION

The question whether disability leads to poverty seems culture-related and depends strongly on social values that exist in society. Being disabled also often means being stigmatized (which may lead to exclusion). Subsequently stigma or exclusion makes people more vulnerable towards poverty. Therefore there is a strong indication that disability can indeed lead to poverty. It proves an indirect link, because it only seems to lead to poverty when there is some level of discrimination or social exclusion in the community. This relationship does not only concern developing countries, but can also be seen in developed countries.

Poverty can also lead to disability indirectly, for example, because of poor nutrition. It appears that poor people tend to delay consultation (and have lack of access to health care), when they are ill. This delay (caused by monetary factors, such as inability to pay for transport) can cause exacerbation of disease and therefore, disability. Thus disability can result in more poverty, for the above mentioned reasons (stigma).

Solutions to break the vicious circle of disability and poverty may need to look more into the linking determinants or aggravating factors and thus should largely focus on reduction of stigma, combating discriminatory practices and empowering disabled people. Strategies and interventions to counteract the linking determinants should therefore be those that operate from a social- or human-rights model of disability.

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ACKNOWLEDGEMENT

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DOES COMMUNITY BASED REHABILITATION REALLY WORK? COMMUNITY BASED REHABILITATION AND PARTICIPATION OF DISABLED PEOPLE

Author: Kenji Kuno

WOMEN AND DISABILITY MANAGEMENT IN RURAL HARYANA, INDIA

Nilika Mehrotra*

ABSTRACT

This paper discusses disability from an anthropological perspective by locating it in the social context of rural Haryana State in India. Without going by the prevalent rhetoric of disability movements, an attempt has been made to understand the social conditions of disabled people in the context of their daily lives, where they negotiate physical and social barriers. Critiquing the essentialist notions of social structures as basically oppressive for disabled people, this paper explores the cultural and social resources, which have implications for state policy, community rehabilitation efforts and NGO action.

INTRODUCTION

The term disability is mired with definitional problems just as many other terms like 'impairment', 'physical handicaps', 'physically or mentally challenged' or 'different abilities', are often used to designate certain conditions in a layman's understanding of what is not considered 'normal'. Inherent in these notions is an idea of a perfect body, state of health and mind. Working through cross-cultural data, anthropologists argue that there is no universal definition of disability, rather, multiple meanings exist and in most societies disabled persons do not exist as a social group. People attribute meanings to conditions that construe persons as 'abled' or 'disabled.' Inherent here is the notion of 'normalcy' and 'ability.' People's cultural and cosmological beliefs get shaped by social and economic forces and the requirements of what is considered 'normal' in terms of everyday life, are expressed in terms of values and attitudes and expressed through ideas. Social structures thereby provide individuals with a number of choices to choose from and each individual negotiates and uses the agency to work within the framework of collectivity. It is thus argued here that disability should be understood as culturally constructed and socially negotiated.

Implications of disability for women who constitute almost 50% of the agrarian class are significant, both in terms of the kind of social lives they lead and their participation in the development process. Since a large number of disabled people live in rural areas, the absence of accurate information on the magnitude of the problem, has hampered planning of realistic policies and services for them. Various studies have argued that women with disabilities face multiple disadvantages, through their status as women, as persons with disabilities, and majority numbers as persons living in poverty. Thus, a culture-centred, gender sensitive, holistic approach has been adopted to explore the context of disabled women and their negotiations within the traditional agricultural context and the role of social support mechanisms in rural India. Generalisations from this micro level study may or may not be applicable elsewhere, as they emerge from a specific context.

WHAT IS DISABILITY?

There are several approaches in understanding disability. The medical model views disability as a personal tragedy. Disability such as the impairment of limb, organ or function has traumatic physical and psychological effects on a disabled person. Disabled people in this model, are regarded as people with limitations who cannot ensure a reasonable quality of life because of their impairment. The medical model expects individuals to find ways of adapting to society. In this model, the onus of adjusting and adapting to their environment and to the society is on the disabled people themselves.

The social model on the other hand, presents disability as a consequence of oppression, prejudice and discrimination by society, against disabled people. It is society that constructs economic, social, health, architectural, legal, and cultural and other barriers in order to deliberately prevent people with impairments to enjoy full benefits of the society. The social model shifts the onus from a disabled individual to the society and its disabling attitudes and environment

Adopting a culture centred approach, it is argued here that disability locates the individual in a compromised position which is not only a function of biology, but also the product of a complex interaction among non-biological factors like gender, caste, class, neighbourhood relations and the nature of kinship and family structures.

In an urban context, disabled people are recognised as a separate social category for their special needs. There are attempts to integrate people with disability into the mainstream of society through promotion of technical assistance in a formally institutionalised set-up like a special school or a training centre, to ensure that the individuals make optimal utilisation of their available faculties. The situation is quite different in a rural context. Here, disability does not contribute to the formation of any socially recognised group. In order to understand how people define disability in a rural culture, it is important to recognise its social fabric, work related requirements, cultural notions and the structure of gender relations. No policy can work here unless these factors are properly understood and policies be framed accordingly.

CULTURAL CONCEPTIONS OF DISABILITY

In the Indian context, Hindu scriptures explain causes of human sufferings through the theory of *Karma* i.e. if one has committed misdeeds in the previous births, one has to inevitably bear the consequences. Illness and disability are understood to be a punishment for the sins of previous births and one is called upon to accept it as divine retribution. Belief in the theory of *Karma* has very often led to a ready acceptance of disability, with little effort in the direction of improving the life conditions. It is argued that the acceptance of disability as *Karma* gives people some explanation of their suffering, which cannot be justified otherwise. It has been noted that the belief in *Karma* keeps the faith in a just world alive, even under adverse conditions it reinforces hopes that good deeds will ultimately lead to a good outcome (1). The positive role of religion cannot be dismissed here.

Disability in most academic approaches is understood as the deviance from normalcy. However, in Haryana, it is for theoretical purposes, explained as the 'dependency' of an individual on others in the community *(aashrit)*. In addition to this, in the neighbouring state of Rajasthan, it is also understood in terms of a 'fault' in the individual. The Hindu idea of disability makes a distinction between *'viklang'* and an *'angheen'*. The former is an individual who has organ but without having a use of it, like a deaf man with ears. *'Angheen'* is one who does not have a certain part like an amputee or one born without ears or eyes. For ritual purposes a *viklang* is not discriminated against angheen is considered inauspicious.

The definition of disability remains ambiguous here and is often made synonymous with limb deformities. Haryana, being an extensively agricultural state, depends heavily on manual

labour in the fields. Hence, the sturdiness and robustness of physique in people are highly valued and the question of disability is understood as *viklangta* or *apangta* i.e. in terms of locomotor disorders. Also, a locomotor disorder is visually more prominent. Thus, society ideally maintains that people with limb deformities are the ones who are dependent on others.

The severity of the condition in case of limb deformities is not taken into consideration and in pointing out that the people with minor limb deformity might actually be well capable of looking after themselves, villagers quietly accept this, but such individuals remain in the category of 'disabled'. The blind or deaf are placed in separate categories of '*andhe*' and '*goonge-behre*' respectively. The enquiry as to how a blind individual can be considered as self sufficient is responded to, by conveniently shifting the category of blind into that of disabled. However, there is a constant debate on whether or not people with hearing and speech impairment should be included into the category of 'disabled'. More so, because they are physically able to perform all kinds of laborious tasks and the family of the individual concerned develops a fair amount of communication skills with him or her. The mentally challenged individuals were not included in the category of 'disabled'. They were often referred to as *bhola or bholi*, i.e. innocent. In the case of a mentally slow male, the individual was assigned work that was essentially identified with a woman, like fetching water, weeding in the field etc. Thus a male with reduced mental faculty was supposed to be able to perform the tasks of a woman. When a mentally challenged individual has other physical disability, the individual is included in the category of 'disabled'. Whether a person is considered *angheen* or *viklang* socially, he or she is not debarred from participating in any social ceremony. Moreover physical status holds a more significant value than the social status. Quoted here, are some local sayings to this effect (translated from the local language).

Who would call the king elephant names, even if he spoils all the fields in the area.

One who is weak is always reprimanded for wrong deeds.

A disabled individual is often stereotyped as hot tempered, sexually impotent and unreliable. This is reflected in the local sayings and folk songs. Some of these are as follows:

When a woman with a squint is married into the house, the property of the house is at risk.

A person who is impaired in one leg and one who is impaired in one eye has an extra nerve.

The extra nerve signifies hot temper. They are thought to be temperamental and prone to quick anger.

A folk song challenges a woman to go with a disabled man, saying that she will never be sexually satisfied. A disabled individual is not seen to be sexually capable or competent.

Disabled people are not seen as complete or even normal persons. Their disabilities are often exaggerated and they are made to feel small. They are addressed by terms with negative connotations, instead of their actual names. Disability acquires different meanings according to age and gender.

Causation and Cures

The causation of disability is understood based on a number of different variables. These could be recognised as either mutually exclusive categories, or in combination with each other. What remains true to all these causes is the supervening reality of fate. An individual's condition is essentially understood in terms of his or her fate or *kismat,* which is all pervasive in nature. Besides, there are many magico-religious beliefs and rituals performed by the villagers to avert such calamities. The various parameters responsible for disability in an individual, form a mutual cause and effect relationship with fate. The biomedical system of cure is highly sought after, leaving the people vulnerable to scams by quacks and other non-professionals. Going by local conceptions of disability, all possible resources are availed to find the cure for disability. The effort is towards finding a cure but not rehabilitation.

WOMEN, WORK AND DISABILITY

Historically, Haryana has been notorious for its high rates of female infanticide and lately misuse of sex selection technologies leading to large numbers of foeticides. Clinics performing such tests and consequent abortions are mushrooming in all the towns in Haryana (2). Since the 1981 census, lowering sex ratios have become a serious concern. Large-scale dowries, anti-women attitudes and a strong male preference are the often cited reasons for this. Strong patriarchal traditions, rigid gender segregation, widespread prevalence of the dowry

system, devaluation of women and the life long liability of the girl's family to endow her with gifts throughout her life (after her marriage), connote the girl as a burden. Women largely remain unwanted, as evidenced in the skewed sex ratio.

Dalal (1) writes that extended family as a basic unit, played its crucial role in uniting and supporting its members and giving them a social identity. Being a cohesive and stable social unit, families provided an identity and a sense of social security to its members, irrespective of their physical disabilities. The economic and caste status of the family and family networks also ensured the quality of well being of its members, which included disabled persons. Agriculture being a family based activity, ensured role allocation and division of labour in a common space of work and residence. Through work, one reaffirmed a sense of belongingness to the group. This scenario has not changed much inspite of all global, economic and technological changes affecting the local communities.

In rural Haryana, these propositions also hold true, as the state is dependent on intensive agriculture though there are changes in the traditional joint family structure. Young couples are now separating from the joint family within a few years of marriage, but primogeniture persists in authority. Despite separation in living space and land ownership, the family behaves as one for all other practical purposes. This kind of system helps in easy formation of disability management groups.

Women with disabilities do not form a homogeneous group. For example, the mentally ill and mentally retarded, visual, hearing and speech impaired and those with restricted mobility, all encounter different barriers, of different kinds, which affect them differently and which have to be overcome in different ways. For instance limb deformities are considered to be more disabling than being deaf. Mental illness is not taken as an illness or disability till it totally disables the person. As a group however, they are seen to be stigmatised from several social stereotypes that further marginalise them.

Scholars have pointed out the prevalence of anti-women attitudes in Haryanavi society, expressed through abuses, folk tales and stereotypes (3). Women's contribution to economy is significant in rural Haryana, as every woman is expected to participate in agricultural and household activities. Women not only participate in agricultural fieldwork, but animal husbandry, household chores and childcare is also primarily seen to be women's work. The notions of

good health for women are understood in terms of their capacity to engage in hard manual work. Farm work is seen as her most important responsibility. Stereotypes and folk songs nevertheless devalue women's work. For both men and women, physical strength and endurance are valued more than many other qualities. Physical disabilities are not taken very seriously, unless they threaten to disturb the working potential of the girls. Her capacity to work hard is a key factor for her marriage and future. Socially her contribution to economic activities goes unrecognised and is often devalued. A disabled girl is initiated into all of a woman's traditional responsibilities, to the maximum extent possible. Some concessions may be made regarding specific tasks, including offering her help in doing tasks such as fetching water, or lowering expectations for the intensity and hours of fieldwork. Female relatives, including the disabled girl's mother and sisters, often extend help to enable her to carry out these tasks.

These girls are ordinarily not treated differently from other girls of their age and family background. They are generally not excluded from games. Their siblings are often protective. The restrictions on other 'normal' girls are also applicable to them. There is very little playtime for any of the girls in these communities. Most of them learn to look after other younger children of the household and help their mother in completing household chores.

Girls and women remain discriminated in terms of food distribution and access to health care. It can thus be easily assumed that a girl and that too one with a disability would be totally unwanted. Some case studies reflect initial neglect in the case of a disabled girl child, where in a number of situations the parents actually admitted their eager anticipation of the child losing her life. But what is significant is the fact that when the child is able to cope up, fighting all odds in spite of neglect, the family comes together to support her. This neglect of providing basic health care to women of all ages is due to both gender discrimination and financial difficulties. Among the scheduled castes, economic hardships were mainly found to be working against the survival of the girl child. Women across all castes are accustomed to take their health less seriously.

Young girls are socialised in traditional gender roles, as the capacity to work is a key deciding factor for her marriage and future. Some concessions may be made for a disability as not expecting heavy work etc. They are also being sent to school; however, not much

value is attached to education. In the management of disability the role of family is significant. The mother and other female relatives look after the child and make the early diagnosis.

The location of the household based on caste, economic and social status is one of the main deciding factors determining the availability of resources available to an individual. A disabled person is not identified as an individual or a person, but rather, identified through the context of his/her family background, thereby helping to remove focus from the individual to the group he/she belongs to. Disability in this context is a superimposed category, not recognised as a group. What is important to note here, is that there is no segregation on the basis of one's disability; on the other contrary, there is a constant effort of inclusion of these individuals. It is not to say that there are any special efforts to accommodate them. They are taken as part and parcel of society. The attempt is to motivate the individuals to live life like any other individual placed in the same status –role bracket, though this can prove quite a strenuous experience for the individual as such, but it helps build the individual's self confidence in the long run, especially in the case of women. These adjustments are made more at the level of household, than society. This observation corroborates Erb and Harris White's work (4) who found a clear correlation between poverty and disability in south India by examining the economic costs associated with onset and management of disability. However, besides inadequacy of economic resources, it was found that lack of social capital of poor people also creates barriers in disability management.

A woman's destiny and social security is still being conceived in terms of marriage. The dearth of women in Haryana society, due to male preference actually acts to a disabled woman's advantage. The most support that a woman can get, is the sharing of her responsibilities with her sisters. For this, the disabled girl is often married into the same household as her sister, usually to a brother and at times to the same man as her sister. This type of marriage practice often comes to the aid of a disabled woman. Disabled women are also usually married to a disabled man, a widower, a man whose economic condition is lower than her natal home, or to a man who cannot find a spouse for some reason or the other (illiteracy, low income, caste endogamy etc.). There were also reports of heavy dowries paid by parents of disabled girls. A spouse is found for almost every disabled girl, because there is a scarcity of girls in society.

A disabled woman in the reproductive age group could be seen to be most vulnerable as she is pushed towards performing work like any other individual in society. This is explained in terms of rigid division of labour and indispensability of the woman's work, both within the domestic as well as agricultural sphere, especially after her marriage. No special concessions are made with the disability in mind (i.e. redesigning of house, exempting her from work); a girl child is initiated into all possible responsibilities. She may have a problem fetching water, as she cannot use earthen pots over her head, so she has to carry buckets. She could have a problem in performing agricultural labour. No special care is extended in terms of their specific physical/mental disability. Rural society does not perceive disabled people as people with any special requirements. This is more true in the case of women. Their traditional gender roles as worker and reproducer are strictly enforced, as in the case of any non-disabled woman.

The women of the family, usually the mother and the sisters and other female relatives, distribute the household chores to best accommodate the disabled individual. Efforts are made to ensure that the disabled individual is accompanied at all times. Though she is made to do all possible jobs, there might be a relaxation in the amount of load she carries, or the time she takes to perform a particular task. Work might also be distributed in a manner where the disabled person shares a greater load of the household chores while the others pursue agricultural labour. She often gets lot of support in her natal home, however, in her marital home she is expected to do all the household chores.

The Brahmin women enjoy a slight advantage because they are not expected to contribute in agricultural labour, unless the household is in a dire economic condition. The Jat and Yadav (other backward castes) women face a greater strain, because tending to the animals is also taken to be a part of the household chores. Most of the disabled women continue to perform almost all the household chores, including fetching water from the well, cutting fodder, cooking, cleaning etc.

New technology like fodder machines often work to the disadvantage of women, since a number of cases of amputation were found due to their use. Also, a number of them reported domestic strain and violence on this account.

The condition of a disabled woman changes with her age and status. In childhood, she enjoys parental care and support but is socialised into her duties of a woman. After marriage, she is

rigorously put to work, where this physical and mental exertion is the most strenuous phase of her life. With age, she gains more social and moral authority in household affairs. With the expansion of the family, there are more supporting hands in terms of sons, daughters, daughters-in-law and grand children, for her social and physical support.

The foregoing analysis, clearly reveals that disability is not the primary disadvantage of women in rural Haryana rather it becomes an additional burden to her marginalised gender position. Disability is engendered in specific ways. Though disabled women are stereotyped as incomplete, they are however, expected to fulfill all the gender duties and primarily expected to be working members of society. It is clearly seen here, that apart from extending support and help in their work, families do not necessarily create special opportunities for them in order to cope better. Management of disability in the context of a community is often related to a crisis situation and it is not in a permanent order. The more permanent form of rehabilitation is centred in the household where a disabled woman lives and with the help of several social mechanisms learns to cope with her state. No professional help is sought in most cases.

STATE POLICY ON DISABILITY

The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act 1995 provides a broad framework and directions for state governments to make positive provisions for disabled people. The Disability Act, however, does not recognise the social and gender embeddedness of individuals with disabilities in their families and communities (5). The Act broadly treats disabled people as a group without concern for their stratification along caste and class, urban/rural factors. The Haryana state policy paper in fact talks mainly of concessions, scholarships and job reservations. There is no provision for children and those below eighteen years of age.

Women's education is a highly neglected area, opportunities for girls with disabilities to receive an education or to attend training courses are available to only a few. Girls with disabilities among some backward ethnic minorities virtually do not receive any education. Women's work outside the family is still not taken as a viable option. Therefore, these concessions provided by the State government are hardly relevant, largely due to heavy bias of the policy in favour of the urban educated middle class. Since needs of rural disabled women find no place in the policy framework, they remain marginalised.

The role of State agencies like department of social welfare is limited to disbursing of pensions, whereas village level government officials merely help disabled people to get information and access to concessions by the State. NGO initiatives are also few in this area. Owing to pressure of international agencies on the Indian state there is an emergence of number of governmental and nongovernmental agencies focusing on the different types disabilities in last 3 years, located mainly in more prosperous urban areas and very little extension work is being done in rural areas.

CONCLUSION

Women with disabilities in the rural societies like Haryana have specific needs and requirements. They are at a disadvantage on account of gender, caste and disability, and besides being located in a rural area. Unlike in the urban areas though, family and community support are still available to these people. State policies, however, have largely failed to provide for infrastructural support in education, health and agricultural sector. The programmes and policies for disabled people cannot be implemented unless other inequalities like gender, caste and class are also considered. Women with disabilities working in agriculture related work need extra support. Their educational and health needs require prioritisation. Unless state policies are informed by micro level realities and greater sensitivity to cultural nuances, the desired goals will remain distant.

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ACKNOWLEDGEMENT

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ORIGINAL ARTICLES

INFLUENCE OF THE HOME VISIT PROGRAMME ON THE FUNCTIONAL ABILITIES AND QUALITY OF LIFE OF PEOPLE WITH SPINAL CORD INJURY IN THAILAND

Chinchai, P., * Wittayanin, W. **

ABSTRACT

Despite an increasing number of people with spinal cord injuries (SCI) in Thailand, there is very little concern regarding daily living and quality of life of these people after leaving hospital. The major purpose of this study was to investigate the influence of the home visit programme, conducted by occupational therapists, on the functional abilities and quality of life of this group. Participants were enrolled by random sampling from Maharaj, Mckaen, and Nakornping hospitals, Chiang Mai province. These subjects were divided into two groups of 30. Group one received a home visit and was experimental, while the other group was the control. Data were collected 3 times; at discharge, and at 2 and 6 months post-discharge from hospital. The instruments used were the Test of Activities of Daily Living and World Health Organisation Quality of Life Index, Thai Version. Results demonstrated that the functional abilities in the experimental group were not significantly different while in hospital and at 2 and 6 months at home. In the control group, scores of functional abilities were lower at home than in hospital. There was no significant difference in the quality of life while at home and in hospital, in both groups. All results provided evidence for developing the home visit program to maintain and enhance the functional abilities of people with SCI, after leaving hospital. It would lead to fewer burdens on family members and society.

INTRODUCTION

Health care policy and rehabilitation for people with disabilities in Thailand, focus on early discharge and shorter length of hospitalisation, due to a limitation of government budget. Many people with disabilities leave hospital before they are well enough to go home. The way of life in the community for these people, receives little attention from health care providers. The increasing number of people with spinal cord injury (SCI) in this country, is included as part of this problem (1). It is important that an appropriate mechanism and services from health professionals are put in place, to ensure a smooth transition from hospital to home (2). Inadequate therapy received in hospital and physical and attitudinal barriers that people with disabilities face at home, leads to difficulty in functional performance and poor quality of life.

Rehabilitation professionals have important roles to play in a smooth transition from hospitals to home, especially for people with SCI, who suffer permanent disabilities. It is crucial to enhance not only their independent lives at home, but also instill a positive attitude among family members and relatives toward disability. Therapists can suggest self-care techniques and general health care strategies to prevent complications and promote a good quality of life (QOL).

Occupational therapists form one of the rehabilitation teams, who encourage people with SCI to use their maximum potential in their daily lives, suggest home and environmental modification, and provide information regarding disability, to relatives and neighbours. Home visits would be an opportunity for health professionals to launch all techniques in the real environment, where the clients live.

METHODS

This study was a field experimental research, which aimed to investigate functional abilities and QOL of people with SCI after leaving hospital.

Participants

Sixty participants were enrolled by random sampling from people with SCI, at three major hospitals in Chiang Mai province, Thailand, from November 2004 to May 2005. These

participants were divided equally into two groups of 30. Group one was an experimental group who received the home visit programme, and the other group was the control, who did not receive a home visit.

The inclusion criteria were:

1. Traumatic SCI with complete cord lesion.
2. Male, age range from 15 to 60 years.
3. First admission to rehabilitation.
4. Willing to participate in the study.

Instruments

1. **Functional Ability Assessment Form.** This test was developed by Chinchai, Chinchai, and Bunyamark (3), who worked at the Department of Occupational Therapy, Chiang Mai University, Thailand. The reliability of the instrument as tested by Cronbach's alpha coefficient was .96. Functional abilities were assessed in six areas; bed mobility, self-care, bowel and bladder control, transferring, locomotion and communication. There were 7 levels of measurement. Scores ranged from 1, which represented dependence, to 7, which meant total independence. Possible scores of this instrument were 17-119.

2. **World Health Organisation Quality of Life Brief Test (Thai version).** This instrument was modified from the World Health Organisation Quality of Life Index by Mahatnirunkul, Tantipiwatanasakul, Poompaisanchai, Wongsuwan, and Pornmanarungsan (4). The questionnaire comprised of four aspects of quality of life: 1) physical domain, which focused on the perception of physical condition that affected daily lives; 2) psychological domain, which emphasised perception of the mind, and feelings that effected the person's performance; 3) social relationship, which referred to perception of inter and intra relations including sexual relationships; and 4) environmental domain, which meant perception of barriers from surroundings that affected the person's ability. The reliability of the instrument as tested by Cronbach's alpha coefficient was .8460 and the validity was .6515. Scores ranged from 1, which represented "not at all," to 5, which indicated "most of the time." The possible scores were 26-130. There were three levels of quality of life; poor (scores 26-60); moderate (scores 61-95); and good (scores 96-130).

Data collection

Assessment of the participants' functional abilities in their actual daily lives and an interview on quality of life was conducted three times; at discharge, and 2 and 6 months post-discharge from hospital. Data collection at discharge was performed within 48 hours prior to the client leaving the institution, while the assessment at 2 and 6 months post-discharge was done at home.

The home visit programme

The home visit was an intervention programme of the present study, which was conducted by occupational therapists within 7 days after the participants left the hospital. Only the experimental group received the home visit programme. Information provided for participants and their family members during the home visit were home and environmental modification, assistive device usage, self-care techniques, community participation, and explanation to relatives and neighbours about the abilities of persons with SCI.

Statistics

1. Descriptive statistics.
2. One Way ANOVA for the comparisons of functional abilities and quality of life at three different times; at discharge, and 2 and 6 months post-discharge.

RESULTS

Socio-demographic data of the participants are presented in Table 1, while the comparisons of functional abilities and QOL are demonstrated in Table 2 to 6, which differentiates the experimental and control group.

Data from Table 1 demonstrate that there were similar numbers of participants with tetraplegia and paraplegia in both the experimental and control group. Ages of the participants were mostly between 46 and 60 years. The majority was married and had finished elementary school, which was the same in both groups. Almost all participants were unemployed. The major cause of injury was traffic accident.

Table 1. Socio-demographic Data of Participants with SCI (N = 60)

Socio-demographic data		Numbers (percentage)	
		Experimental group (N=30)	**Control group (N=30)**
Disabilities	Tetraplegia	17 (56.6)	16 (53.4)
	Paraplegia	13 (43.4)	14 (46.6)
Age (year)	15-30	6 (20.0)	7 (23.4)
	31-45	8 (26.6)	11 (36.6)
	46-60	16 (53.4)	12 (40.0)
Marital status	Single	7 (23.4)	10 (33.4)
	Married	18 (60.0)	12 (40.0)
	Divorced	4 (13.4)	4 (13.4)
	Widowed	1 (3.4)	4 (13.4
Education level	Elementary	19 (63.2)	20 (66.6)
	Secondary	6 (20.0)	6 (20.0)
	College and University	2 (6.6)	3 (10.0)
	Others	3 (10.0)	1 (3.4)
Current occupation	Unemployed	25 (83.4)	30 (100.0)
	Government official	5 (16.6)	0 (0.0)
Causes of injury	Traffic accident	15 (50.0)	17 (56.6)
	Fall from height	10 (33.4)	10 (33.4)
	Gun shot wound	4 (13.4)	2 (6.6)
	Others	1 (3.4)	1 (3.4)

Table 2. Summary of ANOVA for the Comparisons of Functional Abilities in the Experimental Group (N=30)

Source	df	Sum of squares	Mean square	F	Sig.
Between groups	2	1676.42	838.21	1.57	0.21
Within groups	87	46506.57	534.56		
Total	89	48182.99			

Data from Table 2 reveal that the value of Sig. = .21 (> .05), indicating no significant difference in functional abilities at three different times; at discharge, and 2 and 6 months post-discharge.

Table 3. Summary of ANOVA for the Comparisons of Quality of Life in the Experimental Group (N=30)

Source	df	Sum of squares	Mean square	F	Sig.
Between groups	2	98.16	49.08	0.65	0.52
Within groups	87	6532.07	75.08		
Total	89	6630.22			

Data from Table 3 reveal that the value of Sig. = .52 (> .05), indicating no significant difference in quality of life at three different times; at discharge, and 2 and 6 months post-discharge.

Table 4. Summary of ANOVA for the Comparisons of Functional Abilities in the Control Group (N=30)

Source	df	Sum of squares	Mean square	F	Sig.
Between groups	2	7802.82	3901.41	9.06	0.00
Within groups	87	37478.30	430.79		
Total	89	45281.12			

Data from Table 4 demonstrate that the value of Sig. of < .05 indicated at least one pair of functional abilities at three different times; at discharge, and 2 and 6 months post-discharge,

with a significant difference between each other. Table 5 shows the results of a post-hoc test by Least Significant Difference (LSD), which identified the difference of functional abilities in each pair.

Table 5. Comparisons of Mean Difference (LSD) in Each Pair of Functional Abilities in the Control Group (N = 30)

	At discharge ($\bar{X}$ =73.93)	2 months post-discharge ($\bar{X}$ =52.03)	6 months post-discharge ($\bar{X}$ =57.47)
At discharge ($\bar{X}$ =73.93)	-		
2 months post-discharge ($\bar{X}$ =52.03)	21.90*	_	
6 months post-discharge ($\bar{X}$ =57.47)	16.47*	5.43	-

*p=.05

Data from Table 5 demonstrate that the mean scores of functional abilities in this group at discharge was significantly higher than that at 2 and 6 months post-discharge, while scores at 2 and 6 months were not different.

Table 6. Summary of ANOVA for the Comparisons of Quality of life in the Control Group (N=30)

Source	df	Sum of squares	Mean square	F	Sig.
Between groups	2	164.62	82.31	1.17	0.32
Within groups	87	6109.17	70.22		
Total	89	6273.79			

Data from Table 6 reveal that the value of Sig. = .32 (> .05), indicating no significant difference in quality of life at three different times; at discharge, and 2 and 6 months post-discharge.

Functional ability

People with SCI, who received the home visit programme at the time of discharge, were able to maintain their abilities in performing activities of daily living at 2 and 6 months post-discharge. This was contrary to the control group, who did not receive a home visit and demonstrated a decline in their functional abilities from the time of discharge to 2 and 6 months post-discharge. This result indicated that home visits for people with disabilities such as SCI, provide benefits prior to or at discharge, and could enhance maintenance and perhaps promotion of their functional abilities. Home visits are an opportunity for therapists to see the real environment, where clients spend most of their lives. Physical and attitudinal barriers could be detected (5), so health professionals can provide information and suggest how people with disabilities and their relatives, modify and adapt to these obstacles (3). In an appropriate environment, clients with disabilities can apply the skills that have been practised in hospitals and use them at home safely and confidently. Encouragement and support to use assistive devices such as the universal cuff, fork and spoon holders, and over head loop etc. can also enhance the functional abilities of these people. During a home visit, health professionals can provide information to not only their clients, but also their relatives and neighbours in order to help them understand more about the performance of people with disabilities. Thai people in rural areas like to help those with disabilities, with the notion that handicapped individuals lack the ability to do things for themselves (6). Therapists suggest that family members and neighbours encourage people with disabilities to carry out activities on their own.

In contrast, persons with SCI in the control group did not receive a home visit from therapists, and their functional abilities decreased from discharge to 2 and 6 months post-discharge. This confirmed the benefit of the home visit programme, conducted by health professionals.

Quality of life

Quality of life was no different between the experimental and control groups at discharge and at 2 and 6 months post-discharge. This might be because QOL involves not only the routine lives of people with disabilities, but also several external factors such as the physical

and social environment, and employment status etc. Both the experimental and control group faced the same problem whether they were in hospital or at home. One of the physical barriers in Thailand is public transportation, as it does not provide special facilities for peole with disabilities. Therefore, most disabled people find it difficult to commute anywhere. In addition, the architectural structure of buildings in public places such as markets, police stations, department stores, streets, or even some hospitals are not designed to suit the needs of people with disabilities, especially those who use wheelchairs. Unemployment is also a big problem for these people, as it affects their QOL. Almost all of them lost or could not perform their previous jobs due to physical and mental limitations, for example, muscle weakness, limited joint range of motion, loss of sensation, depression, poor motivation etc. Another issue, is limited understanding in the sexual relationships of people with SCI and their spouses. A majority of them reported low satisfaction with their sexual abilities. This study was conducted in persons with traumatic SCI, with complete cord lesion; therefore, the pathology at the cord nerve roots affected their sexual performance. However, most people, not only clients but also therapists, were embarrassed to talk about sex in relation to disabled persons. There was no explanation given on this issue to clients with disabilities. It would be of great advantage if health professionals in this country pay more attention in this area, and provide appropriate information which will enhance the quality of life for people with SCI and other disabilities.

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ACKNOWLEDGEMENT

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DISABILITY AND DEVELOPMENT: IS THE RIGHTS MODEL OF DISABILITY VALID IN THE ARAB REGION? AN EVIDENCE-BASED FIELD SURVEY IN LEBANON AND JORDAN

Kozue Kay Nagata*

ABSTRACT

This paper reviews the process and outcome of constructing a "rights model of disability" which is culturally specific to Jordan and Lebanon. The objective of the empirical part was, to survey the current level of attitudes of non-disabled people towards their disabled fellows in Jordan, and to compare the attitudes of Lebanon's university students towards five different categories of disabled people (mentally disabled people, psycho-socially disabled people, physically disabled people, hearing impaired people and visually impaired people) to highlight the variations and diversity among them. It also examined the relationship between the attitudes and various demographic and social characteristics of the respondents. The set of findings was further tested and triangulated through meta-analysis of individual views expressed in the qualitative studies.

In Jordan, the attitude of 191 randomly selected non-disabled people was studied, using a Scale of Attitudes towards Disabled Persons (SADP). The participants from 4 communities of Jordan, exhibited overall negative attitudes towards disabled people. Socio-economic-demographic characteristics showed almost no difference regarding their attitudes towards disabled people.

In Lebanon, a more complex scale, composed of four sub-scales, namely a, "Baseline Survey of Student Attitudes towards People with a Disability" was used, to survey 94 university students' attitudes towards five different categories of disabled people, and a set of indices for future comparison

was constructed. The results indicated the same pattern of gradations of attitude differences (found in other countries) towards persons with physical or sensory impairments (better), intellectual impairment (middle) and mental illness (worse). The main findings of this empirical field research showed particularly negative public attitudes towards people with intellectual impairment and mental illness in Lebanon.

Finally, the validity of the proposed rights model of disability and the empirical findings of this study, were further examined and co-validated through analysis of the collective views of those who took part in the questionnaire surveys and the participatory focus group discussions, which took place in Lebanon in 2005 and 2007, and in Jordan in 2005, as well as a series of intensive on-line and/or telephone interviews of a few informants comprising of disabled persons and experts. The policy implications of the findings are discussed.

INTRODUCTION

A variety of models has been promoted to explain disability and disabled persons, which may be expressed in the dialectic of the medical model vs. the social model. The former model views "disability" as a problem of the individual, which is caused by impairment (including disease and trauma), so that the management of disability requires medical intervention and/ or rehabilitation of the individual. Rehabilitation is viewed as the main intervention, and the principal political response is often reform of the rehabilitation or health care system. The social model of disability views the issue mainly as a social barrier (e.g. negative attitudes, physical barriers, institutional and legal barriers), created by the environment, and it is thus a collective social responsibility to make the environment barrier-free. The issue here, is whether to adopt attitudinal intervention, requiring social change which at the political level, becomes an issue of human rights and anti-discrimination.

The social model is becoming widely accepted by many in academic circles, as well as within the community of both developed and developing countries. The strength of the social model is due to its seeing beyond the specific impairment of individuals. It can encompass socio-economic, cultural and legal dimensions of disability from human rights perspectives.

This complexity of the model will mandate a coherent action for carrying out research, on the existing level of social barriers and legislation/policy, and campaigning to confront social prejudice and discrimination (1).

However, some cautious Arab researchers argue that the social model may not be directly relevant to the daily life of grass-roots disabled Arab women and men, and the model's contribution may be limited to the provision of an insightful view towards a conceptual understanding of disability, in those developing countries (2).

However, these days most people may refer to the social models of disability in a much more dynamic manner, which may be alien even to its original radical version. For example, Hurst (3) refers to the social rights model of disability. Indeed, the radical social model of disability provides one with the insight to describe the way in which society is constructed, to make people with disabilities "disabled".

In middle-income Arab countries like Jordan and Lebanon, a more integrated, comprehensive and developmental model— which captures the complex integration of various perspectives — may be necessary. Such a conceptual model was constructed by the author (Figure 1). It is similar to the updated and revised social model of disability, adopted by the Greater London Action on Disability GLAD (4). It also embraces the WHO-ICF integrated approach to disability (5).

The proposed conceptual model of disability, the rights model, is comprehensive, and is based on an integration of three key perspectives, namely, (1) the mutual and dynamic interaction between a disabled individual and his/her social environments (e.g. social barriers, attitudes, accessibility, etc.); (2) the diversity existing among different types and categories of disabled persons, and thus the difference in their needs and priorities; and (3) the relevance of the human rights-based approach to individual disability experiences in Jordan and Lebanon.

Figure 1: Diagram of the Rights Model of Disability from development perspective
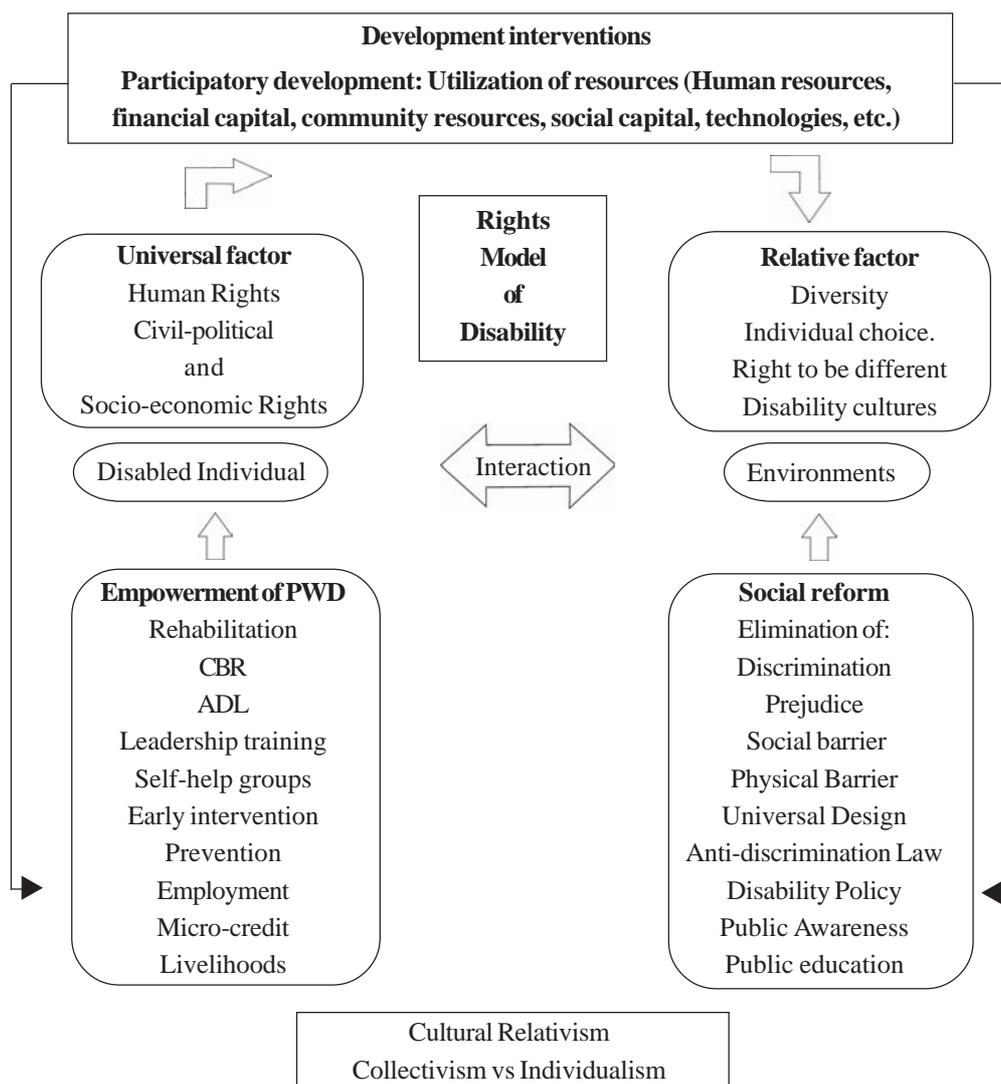
Though the process and mechanism of discrimination and prejudice is mutual and dynamic between a disabled individual and his environment, a mechanism for reinforcing positive public attitudes is a vital key for the success of any interventions for creating an inclusive,

barrier-free and rights-based society (6) . Based on this model, for designing an appropriate national policy and legislation on disability and development, it is critical to first establish a baseline of the current level of social attitudes including discrimination, prejudice, misconception, acceptance and recognition, in a given society. Such a baseline must be established as prerequisite prior to assessing the effectiveness of any kind of rights-based interventions (for changing society and removing social barriers) in the future, with the ultimate goal of institutionalising the equal opportunity concept and inclusion among people in those countries.

With due respect to cultural relativism, each community should study its own attitudes towards people with disability. The attitudes of non-disabled people have been empirically studied world-wide, but almost no studies have been carried out in Jordan and Lebanon.

AIM OF THE STUDY

The study aimed to explore evidence-based information on the current level of social barriers, as well as disabled people's preference of disability approach and model, domestic disability policies and priorities for service delivery in Jordan and Lebanon. Concurrently, the empirical finings were compared to the illustration of individual disability experiences of Arab women and men in the case studies and participatory focus groups. As the ultimate purpose of this study, the proposed rights model of disability was field tested and co-validated in two countries.

METHODOLOGY

The data sources of this study were very comprehensive, which included extensive review of literature, statistics and other documented materials, the quantitative data from two set of questionnaire forms (about attitudes and opinions), the qualitative data from the participatory focus group sessions, the face-to-face interviews, the telephone and on-line interviews, the field visits and the direct experience with and exposure to disabled people of this author, in the region (7 years in Jordan and 4 years in Lebanon respectively).

In Jordan, the Arabic version of Scale of Attitudes toward Disabled People (SADP) was administered by the author, with a total sample of 191 valid data. Details are presented in another paper (7) The data were collected from four communities, namely, Amman (the capital), Karak, Irbed, and Madaba of Jordan (with almost the same proportion of 25 per cent from each community). The research employed a stratified proportional sampling method,

to balance the socio-economic characteristics of the respondents. The sample size was spread across different socio-economic characteristics. For instance, the gender balance was almost equal. The mean age was 33 years with SD of 13.3. To eliminate the sampling bias, people of each community passing-by on the street, were selected and asked to answer the questionnaire, in a systematic manner, thus maintaining a certain level of random selection.

SADP is a reliable self-report scale that consists of 24 items, developed by Antonak (8, 9). The 24 items of the SADP are expressed as statements to which respondents answer on a Likert-type scale. Any incomplete questionnaire was eliminated from the study. The total score ranges from 0, indicative of a very negative attitude, to 144, indicative of a very favourable attitude. Descriptive statistics, the Mann-Whitney Test and the Kruskal-Wallis Test were used to analyse the data using SPSS statistical software. The reliability alpha showed a moderate level of reliability (0.56).

In Lebanon, the "Baseline Survey of Students' Attitudes towards People with a Disability" which was developed by the Equal Opportunity Commission of Hong Kong in 2000 (10), was selected as an instrument. A total of 94 valid questionnaires were collected from three major universities in Beirut, Lebanon. More details are presented in another paper (11).

The Arabic version of the Survey, which was developed in English as the original language, with a total of 5069 samples, by the Equal Opportunity Commission (EOC) of Hong Kong in April 2000, was selected for this research. The Survey's conceptual construct, is based on widely used attitudes scales, including SADP developed by Antonak (8.9). The scale of 47 self-reporting questions is composed of four sub-scales, namely, optimism-human rights (8 items), behavioural misconceptions (13 items), pessimism-hopelessness (9 items) and social acceptance (17 items). In the optimism-human rights component, the statements express positive, optimistic views of people with disabilities and affirmed their human rights to live and work as citizens of society. The behavioral misconceptions component describes common misconceptions about the behaviuor of people with a disability, such as, "they enjoy repetitive work". The pessimism-hopelessness component is about negative beliefs about disabled people and the social acceptance component, is to examine possible reactions of the subjects towards people with a disability in daily social contexts. The EOC-reported sub-scales' reliability ranged from 0.69 to 0.85, and a modest level of the concurrent validity with another (vignette) test was also reported.

In Lebanon, the research employed a convenience sampling method, collecting data from the pre-selected classes from 3 main universities in Beirut, Lebanon, namely American University in Beirut (AUB), St. Joseph University (SJU) and Lebanese University (LU). To maintain a certain level of randomness of sampling and to reduce sampling bias as much as possible, in each class 50 per cent of the students were randomly selected and asked to participate in the research and the rest were eliminated. Among the selected half of each class, the participating students were randomly assigned to the five questionnaire forms for five categories of disabled persons. Out of the total of 120 questionnaire returns, only 94 data were considered valid after elimination of all the ones that were incomplete and inconsistent ones. The gender balance of the sample was about 4-6 (males - females).

Descriptive statistics and ANOVA were used to analyse this set of data using SPSS statistical software. Cronbach's Alphas were computed for the four earlier mentioned attitude sub-scales. All sub-scales had good reliability scores ranging from 0.867 (behavioural misconception) to 0.834 (pessimism-hopelessness). The Correlation Matrix of attitude component sub-scales showed a moderate level of consistency, ranging from 0.53 to 0.68 thus showing the interrelatedness or overlapping among the four conceptual constructs. The concurrent validity of this instrument was tested with a collective opinion expressed in a participatory focus group session held in Lebanon, in January, 2005.

To further validate other components of the proposed rights model of disability, a questionnaire, composed of 57 questions with 35 sub-items on disability approach and model, adequacy of the current domestic disability law and policy, and priorities for service delivery was prepared by the author in English and translated into Arabic by a group of Arab experts. All questions were given as bi-nominal choice of yes/no, tri-nominal multiple choice, or 4 –scale choice. Data collection was based on convenience sampling, i.e., respondents were invited by a field worker to answer the questionnaire on a voluntary basis in Jordan and Lebanon. Over a period of 7 months (June – December 2005), a total of 113 valid data (from 120 collected) from Jordan and 74 valid data (from 85 collected) from Lebanon were used for this analysis.

To triangulate these empirical findings, the qualitative data were collected in a participatory manner, using the selected appropriate tools of participatory rural appraisal (PRA) in Lebanon and Jordan.

The combined data were analysed as typology, comparison and analytical induction. The data from the above-mentioned two sets of questionnaires were verified and analysed, using the SPSS software package for windows, as frequency, percentages, T-test, F-test, Chi-square test, etc. as appropriate.

RESULTS

The results of the questionnaire surveys in Jordan

Two hundred and five people responded to the SADP, out of which, 191 data sets were complete and valid, with 95 males and 96 females with a mean age of 33, with SD of 13.37. The respondents showed overall negative attitudes towards disabled persons with the mean score of 88.67 with SD of 14.63. This score is lower than some other research findings. For instance, Al-Abdulwahab, et. al. (12), reported the equivalent score of 102 + -3.5 for Saudi speech pathologists and 102 + 3.4 for Saudi family medicine physicians. Arab professionals seem to show more positive attitudes towards disability.

The only characteristics to which a difference in attitudes could be attributed, were the participants' residential communities, and their personal experience of interaction with disabled people as a family member. With respect to communities, the mean score of the respondents from the capital city, Amman (with the population size of some 1.33 millions out of 5.8 million of the Jordan's total population), was rated the highest (meaning the most positive attitude score, M=95.63, SD=14.80) in contrast with the equivalent score (M=82.94, SD=12.77) of the town of Karak (most suburban and rural community among the four pilot places, with the population size of some 23 thousands), and the difference among all 4 cities was statistically significant at $p<0.01$ (ANOVA, F=6.846, $p<0.01$). Further, a post hoc analysis was conducted. With both Scheffe Post Hoc analysis and Turkey HSD analysis, the statistically significant difference was found for Amman-Karak and Amman-Madaba (a suburban city with the population of some 88 thousands), but there was no difference between Amman and Irbed (the secondary city with the population of some 328 thousands). Madaba scored M=87.2 with SD=13.08, and Irbed scored M=95.47 with SD=15.22).

The findings supported the common and global view, that disabled people living in rural communities tend to face more serious discrimination and prejudice. So - called CNN and the satellite TV effect (i.e. cultural globalisation) and urban population's relative exposure to

international developments and the universal human rights concept, as well as openness may have had some positive impact on creating the positive attitude of non-disabled population in the urban cities of Jordan.

The respondents in interaction with disabled persons as a family member, scored higher (94.38) than those without (87.53) (p<0.001). Those who had watched or participated in some disability awareness programme/campaigns also scored higher (93.01), than those who had not (86.44) (p<0.001). All other public education schemes had no impact on their attitudes. Also, those whose impression about disabled people came from personal experiences with disabled people, scored higher than those who did not (p<0.05).

RESULTS OF THE QUESTIONNAIRE SURVEY IN LEBANON

The results, shown in Table 1 indicated the same pattern of gradations of attitude differences toward hearing impaired persons, physically disabled persons, and visually impaired persons (better), and those with intellectual impairment and mental illness (worse).

The main findings showed particularly negative attitudes of the respondents towards people with intellectual disability and with mental illness (including the survivours). Among the four sub-scales, all except the behavioural misconception component indicated a statistically significant difference (p<0.05) with the same gradation pattern. The sub-scale of behavioural misconceptions also showed a similar pattern of variation, but it was not statistically significant. Though not statistically significant due to the small sample size, students with previous exposure to and contact with disabled people, namely, those with a disabled family member (mean score of 84.12 vs. 90.57), with a disabled friend (mean score of 85.90 vs. 90.41) and those who had watched a TV awareness programme before (88.40 vs. 90.12) showed slightly more positive attitudes. Other socio-economic characteristics did not support a statistically significant variation, for this small sample size.

The survey was able to differentiate between students' attitudes, both, among different universities and also towards people with different types of disabilities. The scale showed that the students had less favorable attitudes towards people with intellectual impairment and those with mental illness or the survivours. This is the same pattern as the findings in Hong Kong, in 2000 and several other countries. The scores of the survey were also highly correlated with the collective opinion expressed by the focus group which took place in August 2007

and January 2005, and other informed opinions. The participating Lebanese university students were more differentiating than the Hong Kong students, towards people with disabilities.

Table 1. The Result of Baseline Survey of University Students Attitudes towards People with a Disability in Lebanon

Disability type	Non-disabled participants Total (per cent)	Mean score	SD
Intellectually disabled	21 (22.30per cent)	92.95	14.351
Mentally ill people (with mental illness or mental illness history)	19 (20.20per cent)	96.16	19.167
Physically disabled	15 (16.00per cent)	85.73	11.480
Deaf	20 (21.30per cent)	84.65	10.404
Blind	19 (20.00per cent)	86.63	9.447
Total	94 (100per cent)	89.40	13.978

* Lower score indicates more positive attitudes and higher score indicates more negative attitudes.

** ANOVA: F=2.646 p<0.05

TESTIMONIES OF INDIVIDUAL DISABILITY EXPERIENCES: CASE STUDIES

Case study 1. Dynamism of prejudice between society and an individual

"Arab societies always treated certain categories of disabled persons as a negligible quantity, treating them as though it was the end of the road. Disability in Arab culture has traditionally been seen as something shameful, an ordeal to be endured by the family. How to eliminate the negative social attitudes? The only answer is to promote

and protect the human rights and civil rights of disabled citizens. Jordan already signed the new International Convention on the rights of disabled persons. Now, we must swiftly ratify and implement its principles. Rights now, Jordan needs an antidiscrimination law and its enforcement mechanism. We must review and modify the current out-dated law on social welfare of disabled persons (Law No. 12), which is based on the concept of charity and pity." (Author's note: In April 2007, Jordan amended Law No. 12 to introduce the rights-based principle. The revision included a set of anti-discrimination measures and remedy mechanisms in various sectors.)

You know, our fellow citizens who are exposed to disabled people are relatively positive, and this is why the role of public education programmes and mass media is so important, to eliminate our prejudice and misconception. We need both, we need a twin-track approach of non-discrimination and proactive campaign. I think however it is critical to accept the dynamism of prejudice and discrimination of human beings and human nature, so an effort to empower people with disabilities is equally important; we disabled people must be changed. We, disabled people too, must be rehabilitated, educated and empowered. A good leadership training course, for instance, is a very effective tool, as non-disabled people can be influenced by an outstanding leadership and the caliber of a disabled fellow. Nobody will be listening to just nagging and complaining persons in this world. I am taking pride that I myself must have influenced so many non-disabled counterparts through my advocacy work, simply because they were very impressed by me and my achievements. No doubt, I am a charming person, and many people like me. You know I enjoy my family life with 11 kind children — a big family, which is an important achievement in our culture. " (a physically disabled male Jordanian activist).

Case study 2. Diversity among disabilities: Challenges faced by people with intellectual disabilities and the parents

"Th*e diversity among different disabilities exists in this war-torn, sectarian society of Lebanon. There appear to be more differences among the disabled population than similarities in my opinion, disabled women and men, poor and rich, rural and urban, educated and illiterate, disabled veterans and otherwise, you can name it. As a father of two children with severe intellectual impairment, I do not know whether the trust*

among different disabled groups is higher than between mainstream society and the unified "disability group". In my opinion, there is nothing like a unified disability culture in Lebanon, but there are many disability subcultures in this sectarian society with wide income disparity. I myself am a pioneer and founder of a self-help group of parents of intellectually disabled children, but I have so many times faced tension in coalition with so-called cross-disability self-help groups (which are often dominated by a group of physically disabled Western-educated elite men), as they do not see us, the parents' group as a self-help group. But, our children need parents' advocacy and support (they may not be able to articulate their own voice and who will represent their own voice?). Our children are facing a completely different kind and level of discrimination by our society (the able-bodied), and our children have different needs. Yes, an alternative form of education should be made available for our children, as long as it is the choice of the child and/or his/her parents, as inclusive education in our country is not well equipped with support system. Able-bodied students can choose their school, commuting or residential, co-education of single-sex education, why our children must be denied the same choice?" (a medical doctor and father of 2 children with intellectual disability in Beirut).

Case study 3. Gender dimension of disability: the Impact of armed conflicts on Arab women

"*Several countries in the Arab region including Lebanon are war-torn or under civil unrest.From perspective of us, Arab people, Lebanon is regarded as a country which has been occupied by a foreign power for a long time, and devastated by a foreign invasion. Negative perceptions towards physical disability were changed during the civil war and subsequent conflicts in Lebanon, with the fighting of various sectarian groups within this country and the continuing national resistance against the foreign control for our own national cause. The issue of disability became an important political agenda all of sudden. The conflicts increased the number of people with permanent physical disabilities. The disability was a mere stigma traditionally and it now became heroic, at least as a symbol of active resistance. Disability is now perceived as martyrdom where young men or teen-agers sacrificed their lives to live in wheel chairs, or poor young children stepped on landmines to live with prosthetics. However, unfortunately,*

this new focus diverted attention away from Lebanese women with disabilities, who have been most discriminated against traditionally, and who suffered equally from the civil unrest. It also worked against women and men with congenital and non-physical disabilities, such as women with intellectual disabilities. We disabled women are sacrificed in favor of a small number of disabled war veterans" (a physically disabled activist woman in Beirut).

RESULTS OF THE QUESTIONNAIRE SURVEY ON COLLECTIVE OPINIONS OF DISABLED PEOPLE

Of the total of 74 valid data from Jordan, 59.5 per cent were physically disabled persons, 23.0 per cent blind persons, 5.4 per cent deaf persons, 6.8 per cent persons with intellectual disability, 2.7per cent persons with mental illness, and 2.7 per cent multiply disabled persons. Of the total of 113 valid data from Jordan, 18.6 per cent were physically disabled persons, 19.5 per cent blind persons, 15.9 per cent deaf persons, 11.5 per cent persons with intellectual disability, 17.7 per cent persons with mental illness, and 16.8 per cent multiply disabled persons. These two sets of samples are different (p<.01). However, the educational backgrounds of the two sets of samples are very similar (with 44.6 per cent of Lebanese participants being primary school educated or below and 36.3 per cent of Jordanian participants being primary school educated or below). The mean age for Lebanon was 35.41 and that of Jordan was 31.61. In Lebanon, 49 per cent of respondents were Moslem, and 51 per cent were Christians, but in Jordan, the Christian population represents only 22 per cent and the rest was Moslem.

Concerning the question regarding the additional disabled family member, 23.0 per cent of the Lebanese respondents and 34.5 per cent of the Jordanian respondents answered that they had one additional disabled member in the family. Also, 4.1 per cent of Lebanese and 15.0 per cent Jordanians responded that they had two or more additional disabled family members (p<.01), implying the strong possibility of congenital disability which may be related to the consanguinity practice. Regarding the question of, "do you support the social welfare and charity- based approach to disability, or the rights-based approach to disability, or the combination of both approaches", there was a statistically significant difference between two countries (p<0.1).

In Lebanon, only 4.1 per cent of the respondents supported the social welfare/charity approach, 66.2 per cent supported the rights-based approach, and the remaining 29.7 per cent supported the combination of both approaches. On the other hand, in Jordan, 26.5 per cent supported the social welfare/charity approach, 59.3 per cent supported the rights-based approach, and the 14.2 per cent supported the combination. One may attribute this difference to the level of maturity of democracy in Lebanon and the overall rights-based and individualistic style of the Lebanese people in general. Concerning the question of the disability model (social model vs. medical model) and the domestic disability policy in each country, 95 per cent of Lebanese supported the combined socio-medical model, and only a minority supported either the pure medical model or pure social model. However, 27 per cent of the respondents criticised the current Lebanese disability policy, as based on the outdated medical model.

In contrast, in Jordan, 20.4 per cent of the respondents supported the medical model, and 25.7 per cent supported the social model and the majority, 50.4 per cent supported the combined, socio-medical model. This result corresponds to the previous empirical study, in which, the majority of Jordanian disabled people choose the socio-medical model (2). Furthermore, Jordanians fairly evaluated their domestic disability law, as being based on the socio-medical model of disability, the model of their own choice.

Thus, concerning their preference about the disability model as the basis for national policy, there was a statistically significant difference between the two countries (p<0.01). Though Jordanians tend to be more conservative, both Jordanian and Lebanese disabled people supported the rights-based approach to disability over the social welfare approach, and disapproved the medical model of disability, as a basis for national policy.

As anticipated, concerning the knowledge about the domestic disability law, there was a significant correlation between the respondents' knowledge and their educational attainment, both in Lebanon and Jordan.

THE RESULT OF PARTICIPATORY FOCUS GROUP SESSIONS IN JORDAN AND LEBANON

The following is a brief summary of the results of a one gender-balanced focus group composed of 6 disabled persons and 3 professionals, held in Amman, Jordan in January 2005, and another focus group composed of 9 disabled persons (5 disabled women and 4 disabled

men) and 3 parents (2 mothers and 1 father), held in Beirut, Lebanon in January 2005, in addition to the data collected from the latest focus group held in Beirut, in August 2007, composed of 29 PRA participants with individual disability experience (4 blind, 7 deaf, 7 physical disability, 8 parents, 2 intellectual disability, 1 survivor of mental illness).

- The participants showed a preference for "rights approach," over "charity-based social welfare approach" to disability (in both countries, more so in Lebanon).

- Overall preference was for the "social model" or "socio-medical model" of disability over the "medial model of disability" (in both countries, more so for men).

- There was recognition of the diversity among different disabilities (with particular discrimination against people with intellectual disability and/or psycho-social disability, as well as disabled Arab women) in degree and nature.

- More differences than similarities were found among the disabled population in Lebanon

- Lack of trust was found among disabled groups, which is as high as that between mainstream society and the "disability group," in Lebanon.

- There is no single disability culture in Lebanon and there are many disability sub-cultures (depending on disability type, social class, difference in religions, gender, disabled veterans, wealth or poverty, etc).

- The participants acknowledged the preference and priority given to the war victims (often males) as a political agenda, over the rest, particularly those with congenital disability and disabled women (more so in Jordan and Palestine) and some even feel that the majority of disabled persons are sacrificed in favor of the small size of veterans.

- Severe discrimination and prejudice are faced by children with intellectual disabilities and psycho-social disabilities, as voiceless and vulnerable people (they are not well represented in the national forum of cross-disability groups).

- There is lack of recognition of psycho-social disability and the survivours as "disability, disabled" by both non-disabled and other disabled people.

- There is tension in the process of coalition with grass-roots self-help groups and a national forum of multi-disability group, often represented by the urban elites, English-educated men in wheel-chairs (in Lebanon).

- The self-help group of parents of intellectually challenged children have a unique identity (in both countries).

- The importance of self-help groups for striking the balance between their advocacy work and development programme (e.g. micro-credit, income generation, etc.) for their own survival, is stressed in Lebanon.

- There is recognition of the overall effectiveness and relevance of CBR programmes, over other modalities (e.g. institutional model or independent living model), as the most effective tool, to achieve the independence and happiness within the family and the community, as well as to alleviate the negative public attitudes (in both countries, more so in Jordan).

- There is a recognition of the need for comprehensive rehabilitation (particularly the provision of timely and appropriate medical rehabilitation immediately after minor physical operations and interventions, which is critical) as well as adequate medical services.

- There is urgent need for sports rehabilitation to be made easily accessible to women and men at low cost, as early intervention of preventable disabilities (more so in Jordan). Often, disabled Arab women's access to sports, exercise and sports rehabilitation is limited.

- There is natural acceptance of the importance of prevention of the negative causes of disability (including poverty, armed conflicts, lack of micro-nutrients, very high traffic accident rate, too many children and lack of spacing, as well as a cultural factor - consanguinity - which is still common in the Arab region), as a part of the overall development strategy.

- There is need for reviewing the existing comprehensive law on disability in Lebanon and Jordan, in line with the newly adopted international convention on the right of persons with disabilities and its optional protocol.

- There is need for initiating a public debate about the possibility of formulating a Lebanese anti-discrimination law and setting up its national monitoring mechanism ("reactive measure" to enforce non-discrimination).

- There is urgent need to strengthen the public awareness campaigns to improve the prevailing negative public attitudes towards disabled persons ("proactive measure" to remove the attitudinal barrier), using mass media campaigns and inclusion of disability concerns into the school and summer camp curriculum.

- There is need for drastic measures to eliminate the negative cultural elements and traditions to ensure non-discrimination (preference of non-discrimination over perpetuation of the culture).

- Inclusive education (as the idealistic form of education), was accepted as a matter of principle at all levels including tertiary education.

- The concurrent need for alternative forms of education, for some categories of disabled persons (e.g. deaf people, severely and multiply disabled people, people with intellectual disability), by their (or parents') own choice, was recognised.

- There is need for transitional and support measures between alternative education and mainstream education.

- There is recognition of the need for maintaining the "positive measures" such as employment quota scheme (3 per cent in Lebanon, 2 per cent in Jordan), or tax concessions as transitional provisions, until the concept of "reasonable accommodation" is established in both countries.

- There is a high recognition of the validity and relevance of the twin-track approach of disability mainstreaming into development, and empowerment of persons with disabilities through targeted projects.

- The need to adopt universal design (or barrier-free design) in the process of reconstruction and rehabilitation of the war torn Lebanon, was fully recognised as a challenge and opportunity for creating accessible infrastructure. As the devastated areas are in the Hizbollah controlled area, a strong public-private partnership was recommended.

DISCUSSION AND RECOMMENDATIONS

The findings of the study echoed previous research, in that they demonstrate that attitudes should be treated as a multidimensional construct, consisting of the interlocking facets of cognitive, cultural, behavioural and economic factors. The findings also found diversity existing among disabilities and different types of disabled people.

The findings of the present (both from the questionnaire survey and the focus group sessions) may inform policy makers, educators, social workers, and mass-media experts about careful re-thinking of the core messages to be delivered in public awareness programmes and disability-related services. In particular, it is important that due attention be paid to the needs of those with intellectual and psycho-social impairments (mentally ill) and disabled women in Lebanon and Jordan, to rectify the deep-rooted misconceptions about genetic inferiority. To alleviate discrimination, both pro-active measures (e.g. public awareness) and a reactive measure (e.g. law enforcement) may be required.

This study also validated the proposed rights-based model of disability, in which both civil-political and socio-economic rights are to be promoted, in the region. The importance of disabled persons' inclusion, participation and access to services, including education, training, rehabilitation, CBR, medical services, etc. was recognised. Also, the need for prevention of negative causes of impairment, particularly poverty, armed conflict and consanguinity, was singled out. Indeed, prevention may be considered to be a critical element of disability inclusive development cooperation policy.

The limitation of the empirical part of this research includes a small sample size in these two countries of the region, potential sample bias towards voluntary participants, lack of randomness, and a question regarding the accuracy of the Arabic translation of the two instruments. The participatory focus groups were conducted partially with an interpreter (Arabic and English), so a cultural and linguistic shortcoming is another limitation. Following the findings of this small-scale pilot study, a nation-wide public-funded survey with a bigger, less biased and more representative sample should be conducted in Jordan and Lebanon, and elsewhere in the Arab region. However, adoption of the twin-track approach, of disability mainstreaming and empowerment of persons with disabilities is urgently needed.

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ACKNOWLEDGEMENT

for Western Asia (ESCWA) in Beirut, Amman and Baghdad, and from 2003 to 2006, at United Nations Economic and Social Commission for Asia and the Pacific (ESCAP), in Bangkok. However, the views expressed in this article are those of the author and do not necessarily reflect the views of the United Nations or its regional commissions.

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PRACTICE AND PREFERENCES OF SIGN LANGUAGES IN THE INSTRUCTION OF DEAF STUDENTS: SOME REFLECTIONS ON THE MAINSTREAM SECONDARY SCHOOLS OF BOTSWANA

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ABSTRACT

The use of language for every day communication has been and continues to be an essential element of any teaching and learning environment. In this paper, the focus is on the teaching –learning communication in the education of the learners with deafness. While experiences indicate that some people in Botswana are showing more and more interest in Sign Language as a mode of instruction in the classroom, it is also true that many are far from understanding the "Deaf Culture" and to use sign language in the teaching and learning of deaf students. To a great extent, deaf people in Botswana are still disadvantaged and discriminated against, by their condition. A survey carried out in 2004 (1) revealed that some current practices in the mainstream secondary school of Botswana make it difficult for deaf students to progress. While, for example, participants preferred Total Communication; in practise, Signed English is used. Thus, this paper takes a stance that if practices conflict with preference, low performance should be expected. This is currently the situation at the mainstream secondary schools in Botswana, deaf students' inability to hear has become their inability to learn and progress in education. This could be avoided. In this 21st century, being unable to hear is not a barrier to learning, as we are aware that Sign Languages are there as full languages, for the education of deaf.

INTRODUCTION

This paper came as a result of the encounter with deaf students during a teaching practice exercise. Teaching practice is a concept used at the University of Botswana (UB) to refer

to a period where University Lecturers (supervisors) are engaged in a supervisory, monitoring and assessment of teaching by their students across the entire country. UB students are placed in different secondary schools to do the teaching practice. As supervisors, the authors had the opportunity of doing some observations in these schools. Some of the schools visited, had deaf students. These schools employ a system of integration. That is, schools enroll both deaf and "normal" hearing students. Deaf learners are placed in segregated classes. That is 'deaf students' are taught in their own classrooms.

During the time the authors visited these schools, the problems observed for deaf learners included the dearth of literature on sign languages and lack of assistive technologies. On talking with teachers of these deaf students, many more problems were cited. For example, the use of sign language as the language of instruction /teaching of the deaf in the main stream secondary schools of Botswana seem to pose some problems too. Despite the seriousness of a number of problems, what caught the attention of the authors were the communication issues and the language of instruction used with these students. The initial conversation with teachers of deaf students revealed, that there was generally poor performance by deaf learners and this could be attributed to languages used by teachers to communicate with (teach) them. To unearth a true picture of these communication problems a number of data collection techniques were employed, namely, informal interactions, unstructured interviews (informal conversation), semi-structured interviews and some observations. It was believed that problems of teaching the deaf learners can be unearthed and understood when data collection techniques are triangulated.

BACKGROUND OF THE STUDY

Historically, educating children with hearing impairment in Botswana started around 1970, by some Non-Governmental Organisations (NGOs). In those early years, the Government of Botswana showed very little interest in educating children with exceptionality because this was not considered a 'sound investment of resources' (2). However, as education reforms came by and the need for open access and equity was emphasised, the Government declared interest in the education of the population in Botswana, deaf people included. In 1994, a document that brought hope for all i.e. the National Policy On Education, was produced. Its approval by the National Assembly on 7th April 1994, was a sign that Botswana is indeed

committed to embracing the sentiments of the 'right to education' (Education for All), including education of children with disability (3). Since the implementation of this policy, the situation has been steadily changing, although the pace of interest as reflected in policy formulation and implementation is very slow and worrying.

There is also a paucity of research in the area of the "Language of the Deaf". This should be expected because as already mentioned; sign languages are still relatively new in the culture of secondary schools of Botswana and this may have attracted very few researchers and scholars.

However, one positive move has been a shift from the traditional medical model which viewed individuals with hearing disability as problem, to a more comprehensive social model which considers them unique with different needs, from those of normal people. From the social perspectives, the deaf people are people who have a language that is different from languages of other people. They have an alternative to verbal language and that is their preferred sign language. This language is not yet common in Botswana. One laments the fact that the impact of early years when deaf people were considered a problem still lingers on in Botswana. There is, for example, a minority community commonly referred to as "Deaf Community.' Like all minority communities in Botswana, this community is disadvantaged. For example, their language is not made popular in the mainstream secondary schools where some deaf students attend. The authors believe that if the language of the deaf (sign language) is known by some students who are not deaf, this will create an enabling climate that is appreciated by the deaf learners themselves and this can be extremely gratifying for these learners. Policy climate should be formulated to ensure that the language of the deaf is also recognised as a potent language of communication and classroom instruction. Deaf learners need language to socialise and communicate effectively, both inside and outside the classroom. It is crucial that their language be developed and used in school, as tool for enhancing their success.

METHOD

Research design
The project started as an informal discussion between the two researchers discussing the challenges and problems encountered during supervision of teaching practice by the University

of Botswana students. The discussion focused on teaching-learning experiences of the deaf. Problems of the use of (Sign Language) as a potent language of instruction for these learners were cited. An agreement was then reached to engage in a study that explores these problems. The findings of this study are reported in this paper.

The Qualitative nature of this project

Two important principles of the qualitative approach guided this project, namely, the principle of inductive approach and principle of holism. Qualitative researchers use the "principle of inductive approach to indicate that meaning is embedded in people's experience" (4). Thus, in designing this project, we recognized that teachers' experiences matter. These were teachers who were involved in the teaching of deaf students. The authors then engaged in some informal conversation with these "rich cases", the teachers, about their experience of teaching deaf learners in the mainstream school systems. Among other things, they talked about the challenges and problems of using different types of sign languages in their own context. The principle of inductive approach affirmed that it was only through an exploration of these teachers' experiences that researchers could make sense of challenges or problems of using a sign language as a language of instruction. The principle of inductive approach states that understanding of the world begins with the experiences of individuals (5, 6).

The other principle, the principle of holism, reminds qualitative researchers to consider the influence of the practical contexts during the exploration (7). The practical context in this case was the mainstream secondary schools of Botswana with deaf students. This is also a context with lack of resources for deaf students and little interest on the part of other students in language of the deaf. The researchers needed to understand this specific context prior to engaging in research. It was for this reason that the researchers visited the schools to do some observations. Through some observations, it was possible to understand these "natural settings" (secondary schools) and how they may have an impact in the teaching and learning of deaf learners.

Participants

Only teachers who were directly involved in the teaching and learning of the deaf learners participated. Table 1 indicates the pool of these participants. The actual numbers of participants

was arrived at using purposive sampling. Maxwell (8) defines purposive sampling as a "strategy in which particular settings, persons or events are selected deliberately." Following this strategy, two institutions, namely Ramotswa Community Junior Secondary School and Thashatha Community Junior Secondary School were selected as the study sites.

Table 1. Educational Options for students with Hearing Impairment in Botswana

Name of the School	Level	Type	Facilities
Ramotswa Centre for Deaf Education	Primary	Special	Residential
Fransistown Centre for Deaf Education	Primary	Special	Residential
Makolojwane Primary School, Serowe	Primary	Special Unit in Mainstream School	Day
Boyei Primary School, Maun	Primary	Special Unit in Mainstream School	Day
Ramotswa CJSS	Secondary	Special Unit in Mainstream School	Residential
Tashatha CJSS. Francistown	Secondary	Special Unit in Mainstream School	Residential
Maun Senior Secondary School, Maun	Sr. Secondary	Special Unit in Mainstream School	Residential

Ramotswa CJSS is in the South East district hence the closest to researchers' place of work and residents, Gaborone. Moreover, it is the only secondary school for students with Hearing Impairment and Deafness in the Southern Region. The other site was Tashatha CJSS.

It was chosen because of its convenience, in terms of being the only secondary school for students with Hearing Impairment and Deafness in the Northern Region.

The people selected, were experienced in usage of the language for the hard-of-the-hearing, and they were willing to share their experiences. Participation was solicited through some informal discussion. For example, when a conversation was started and the individual showed interest, that individual was directly asked to participate in the study. Blending the conversation with what happened during the teaching-learning session practice was obviously the best strategy to capture respondents' interests and participation.

The timing of the informal conversation with potential respondents was very important. The researcher approached them while the experience was still fresh, that is, immediately after the lesson. These people were information-rich cases, explained by Patton (9) as cases "from which one can learn a great deal about issues of central importance to the purpose of the research." Patton states that if, "one wants to discover, understand, gain insight; [then] one needs to select a sample from which one can learn the most" (9). Thus, the researchers believed that they could get the most or valuable information from teachers who facilitated in classes with deaf learners. Hence, the criteria for selecting this sample were as follows; (i) direct involvement in the teaching and learning of the deaf, (ii) one or more years of experiences in the teaching and learning of the deaf learners (iii) be in a Government/ Government aided school. Five teachers from each school, a total of 10 teachers who met these requirements participated.

Research questions

The main question was:

What language is currently used in the teaching of deaf learners?

Some sub-questions were also asked. These were meant to investigate the following:

(i) Qualifications of teachers of the deaf

    a. Do teachers of deaf learners have relevant training and experiences in teaching these children?

(ii) Preferred language of instruction and communication

    a. Are languages of instruction in compliance with the languages preferred by the deaf learners and other teachers?

The focus was more on how to teach deaf students in a manner that they would realise their potentials to learn. The scope of this research did not allow researchers to address all questions associated with the teaching of deaf learners in the mainstream secondary schools of Botswana.

Data collection techniques

The following data collection techniques were used

(i) Semi-structured questionnaire

A 15 itemed semi-structured questionnaire consisting of forced choice and open ended questions was used. The questionnaire was developed to gather information on the languages used in the classrooms for teaching deaf learners; language preferred by the teachers, problems faced by the teachers of the deaf learners and how some of these problems can be tackled. The questionnaire was also used for collecting the demographic information of the participants.

(ii) Informal Interview

Informal interviews were also used. Whenever an opportunity arose for researchers to have some conversation with the teachers of the deaf, the researcher seized it. The discussion mainly focused on the language used for instructing students who are deaf and the challenges of using Signed English or American Sign Language for the deaf. Teachers were also asked to suggest how the present situation that disadvantaged deaf students should be resolved. This will be reflected in the conclusions and recommendations. The goal was to generate as many ideas as possible, about the problem and challenges of using the language preferred by both deaf learners and their teachers. The informal conversation was carried out with ten teachers of the deaf.

Overall, informal conversations of the researchers allowed teachers of deaf students to talk freely about their feelings regarding the use of sign languages in teaching. The interviewers' probing kept the conversation to the point. Respondents' comments were recorded on a reflective Journal.

RESULTS AND DISCUSSION

The discussion is organised around themes that emerged during data analysis. The data was fed into Microsoft Excel. Frequency counts and percentages were computed for the demographic analysis and displayed in graphical patterns. The transcribed responses of the participants were clustered and researchers came up with the themes and sub-themes.

Personal and professional background of the participants

To teach deaf students, its requires trained teachers. Moreover, teachers have to display a level of interest and enthusiasm to sustain them in this area. Thus, a question "what are the qualifications and experiences of deaf teachers." It was necessary that the researcher should know the teachers' qualifications, because qualifications play a major role in determining whether a person is the right professional for teaching learners with hearing impairment. The majority of participants eight (teachers of deaf learners) have obtained their degree at the University of Botswana. They had done a Bachelor of Special Education with a specialisation in the area of Hearing Impairment. There were a small number of teachers (10) who had attained their Diploma. Two had more than 10 years of experience in teaching students with hearing impairment. Four teachers had 2-5 years of experience and two others had 1-2 years of experience in teaching the students with hearing impairment. As can be seen, all teachers who participated, had significant experiences; they were information rich cases. They were able to share their experiences with the researchers. There were ten teachers, six females and four males. Their distribution was as follows; 5 came from Francistown (2 male, 3 Female) and the other five were from Ramotswa (2 Male 3 Female). Perhaps the ratio of more female than men was expected, as the trends in Botswana has always been that schools are staffed with more female than male teachers.

Language(s) of instruction used in the schools

The second theme that emerged was that of the language of instruction. Researchers were interested in knowing the current languages used for communication with deaf learners during the teaching-learning activities. Two main languages were cited as indicated in Figure 1.

Figure 1. Language Instruction used in the Classroom
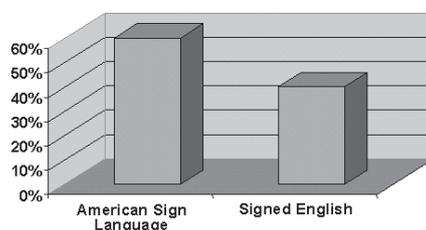
Language Instruction

As indicated in Figure 1, two languages, American Sign Language (ASL) and Signed English are used as languages of instruction for deaf students in these schools. The figure indicates that Sixty percent (60%) of the teachers use ASL in their classrooms while 40% use Signed English. ASL is mostly used for deaf learners, as majority of the teachers are formally trained in ASL.

Teachers' preferred mode of communicating with deaf learners

Respondents of this study were asked to indicate what their preferred language of communicating and teaching deaf learners was. The questionnaire requested that respondents indicate their preference by comparing three options of Sign language, Total communication and SEE (Signing Exact English).The findings are shown in Figure 2.

Figure 2. Communication Options Preferred by Teachers
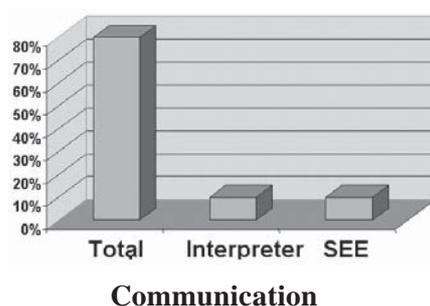
Communication

As reflected in figure 2, the majority of teachers preferred total communication. Total communication is an eclectic approach which uses a combination of different modes of communication. This medium has the potential to be used as a medium of instruction, as all learners are not the same: some are visual; some are auditory-oral. This might be the reason why it is preferred by the majority of the respondents. Other types of sign languages received very little interest from teachers of the deaf learners.

Problems faced by teachers of deaf learners

Teachers were asked to indicate problems that they face as they teach learners with hearing impairment. A number of problems were cited and these were classified into three sub-categories of (i) Comprehension factors (ii) Language use factors and (iii) Resource factors.

These categories are further explained through a graphic presentation of these factors as shown in figure 3. The three critical features of comprehension factors, communication (Language Use) and resources are explained briefly.

Figure 3. Problems faced by the Teachers

| Comprehension Factors | Language Factors | Lack of Resource Materials |

Attention **Deficit**

Memory **Deficit**

Pragmatic **Deficit**

Deficit in the area of Semantic & Syntactic Concepts of Language

L e a r n i n g M a t e r i a l s / Literature

A s s i s t i v e / Instructional Technology
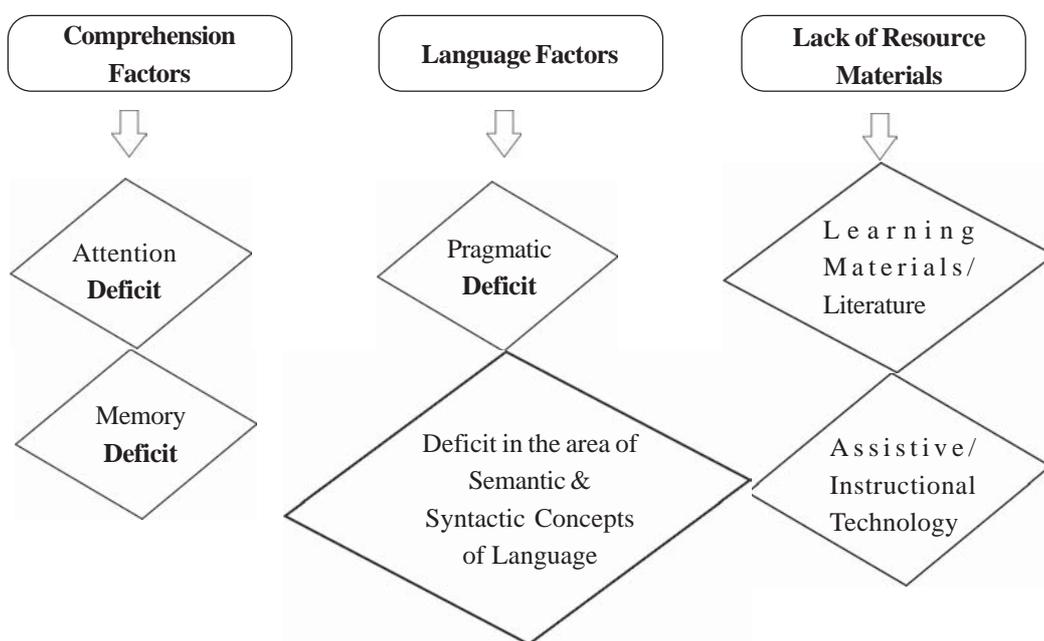
Comprehension factors

Issues mentioned here included lack of comprehension, learners who are attention deficient and memory deficient. Respondents of the study expressed concerns that the majority of deaf learners did not understand them when teaching, since the mode of instruction is usually in either a language that learners do not understand well e.g. Signed English or American Sign Language. One participant, for example, lamented this situation by stating that "learners can't remember what has been taught last week." The sentiment of this respondent was echoed by others, who felt that students with hearing impairment have low memory or they easily forget what they have been taught. Thus, there seems to be a serious lack of comprehension ability that exists in these deaf learners. Learners' attention deficient was

yet another factor that teachers of the deaf learners perceived to be a major problem in the education of the deaf learners. One teacher, for example, was cited as saying, "these students lack concentration." This becomes a problem for the teachers as lack of concentration leads to these students not grasping the concepts of learning. Thus, this is a problem not only to teachers but also learners, who always failed their tests or assessment exercises. They are also reported to have low self-esteem.

Language factors

It was stated by the respondents that the languages they use (American Sign Language and Signed English) are not natural languages of the deaf learners in Botswana. American Sign Language has been developed with the culture and experiences of American deaf people. Obviously, some of the signs would carry a different meaning when applied to the Botswana situation. This kind of confusion or decontextualisation breaks down communication and thus learners do not benefit much in this situation. As can be recalled, earlier on, it was indicated that teachers believe that deaf learners can benefit from the use of total communication. However, the situation in secondary schools of Botswana is that teachers are not well prepared to use this language. Thus, when Signed English and American Sign languages are used, problems of syntax and semantics should be expected as ASL and the Signed English have different grammatical structure. The problem of semantics referred to here, is a situation where a deaf learner is left without understanding or getting the meaning/information that was relayed to him or her. One respondent, for example, interpreted this problem by stating that "these students have language defects". This can be a frustrating experience for the learners.

Resource factors

Respondents of this study mentioned a number of resources, which if made available can make learning experiences meaningful and fruitful for deaf learners. Resources such as relevant learning materials and supporting technologies are absent in many schools. The absence of these resources does not augur well for the education of deaf people. One respondent had this to say "There is not even an overhead projector to present the materials visually."

SUMMARY AND RECOMMENDATIONS

The language of instruction is an element that needs to be considered from the beginning of the learning experiences and be treated as an important and integral aspect of the curriculum of Botswana. If, for example, deaf learners are to benefit fairly from the education system, their ways of communication should be catered for, in the system. Participants emphasised that the language of the deaf can be a major determining factor for their success. Every language is important to its speakers and if all students have to benefit, it has to be used in schools, regardless of the number of learners who speak or use that kind of language. The sign languages, for example, are primary languages for the deaf children and the appropriate genre of sign language should be applied.

Imagine a situation in which a deaf child has to be provided with counseling and guidance sessions to guard against the deadly effects of some diseases such as HIV/AIDS and service providers do not know their language, or worse still, they are not interested in communicating in any language other than Setswana and English. Situations like these can seriously put the lives of the deaf people in danger. Equally important then, is the need to use the preferred sign language that students understand. There is need to ensure that a culture of positive learning for the deaf in secondary schools of Botswana, is developed.

When teachers were asked to indicate their preferences in relation to the language of instruction for deaf learners, total communication was given as number one priority. Total communication includes both oral and manual language. Though by definition total communication mean 'any means of communication' but in real practice, it has become 'simultaneous communication' (11). The reasons for preferring "total communication" are as follows:

- It helps all types of students, as some students are predominantly visual learners, at the same time, some students have residual hearing and use auditory mode.
- All the teachers are not proficient in the two sign languages (Signed English and American Sign Language), so total communication may augment their deficits.

Those who preferred to use total communication as medium of instructions ascribed to the fact that students can understand better.

However, it has to be noted that regardless of the mode of communication used, support services have been cited as factors leading to the failure of deaf learners in secondary schools. For example, teachers who decide to use total communication run the risk of seeing their learners having no supplementary materials. Availability of the materials was thus cited as a critical support. Also, teacher aides were seen as important support. The presence of a teacher aide is crucial. It relieves regular teachers of some tasks such as explaining some concepts, because teacher aides are adults with hearing impairment/deafness. They are proficient in communicating with sign language, thus teacher aides are needed to help with some classroom activities. Also, assistive devices such as hearing aids, FM systems are to be availed. Instructional devices such as over head projectors and computer guided instructions are also needed. Education of the deaf, for example, cannot be successful without the use of assistive and instructional technologies. Other factors that were perceived to be important in enhancing and promoting teaching of the deaf people included inviting resources persons to the classrooms. For example, health and other educational professionals can be called when there is a discussion of a topic relevant to their area of expertise. It was also suggested, that there is need for the school to develop a strong parent teacher association with the goal of promoting the education of the deaf students.

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FACTORS SHAPING ATTITUDES TOWARDS PHYSICAL DISABILITY AND AVAILABILITY OF REHABILITATIVE SUPPORT SYSTEMS FOR DISABLED PERSONS IN RURAL KENYA

Julie Monk*, Joy Wee**

ABSTRACT

This study examines the range of attitudes towards persons with physical disability in a rural community in western Kenya. It also evaluates the availability of services for persons with disabilities in the community. Qualitative data analysis of interview material led to the generation of a model describing the attitudes towards people with disabilities. Availability of services was explored through interview questions and document collection. Perceived cause of disability, perceived characteristics and activities of people with disabilities by the community and perceived role of society, appear to shape the attitudes towards people with disabilities in the community studied. The opinions within these categories contribute to enabling and disabling features of the environment in which people with disabilities live. It appears that services available are underused by disabled members of the community due to poor accessibility and financial barriers. The results yielded relatively enabling attitudes towards PWD. The responses suggest that this community may be ready to support increased participation by its members, possibly through a community based rehabilitation programme.

INTRODUCTION

With the recently signed United Nations Convention on the Rights of Persons with Disabilities (1), integration of disabled persons is being recognised as a pertinent objective, particularly in developing countries where services for persons with disabilities are limited. The International Classification of Functioning (ICF) (2) model of disability describes the external factors that influence an individual's ability to participate in society as environmental factors. These include the individual and societal aspects of physical, social and attitudinal environments in

a person's life (3). Identifying current attitudes is a first step towards establishing an approach to promote the rights of people with disabilities through supportive environments.

Attitudes can be described as "learned dispositions affecting feelings thoughts and actions." (4). The attitudes of community members and of society can impact the ability of people with disabilities to be accepted and integrated in the community (5), both by affecting self efficacy and by influencing their physical and social environment. Community attitudes are particularly important because active community involvement is essential for success and sustainability of a community based rehabilitation (CBR) programme. The community should be involved in all steps of the process, including programme planning, implementation, and evaluation (6).

The prevalence of disability in western Kenya is not known. According to local and national rehabilitation providers, it is thought to be similar to the worldwide average of 10%, estimated by the WHO. The Kenyan Population Census of 1989 reported that 0.7% of the population was disabled (7). This is thought to be an underestimate, possibly due to underdetection, as 80% of persons with disabilities worldwide live in low income countries (8). Without the resources and social structures that some high income countries have to help support persons with disabilities, they can be subjected to decreased participation in the community due to exclusion based on limited resources, accessibility and social acceptance.

Previous studies have examined the attitudes of specific populations towards disability. Many of these studies involved health care workers and health care student populations (4,9,10). while others included close relatives and other community members (5). In these studies it was found that attitudes of health care workers have an impact on expectations, access to health services and on successful rehabilitation. The attitudes of those studied were also influenced by their experiences and interactions with persons with disability (9,10). Literature regarding community attitudes towards persons with physical disability in Africa is limited. A study examining the attitudes towards disability in rural Zimbabwe found that beliefs about the etiologies of physical disabilities did not influence the treatments sought by people with disabilities, as most respondents chose both traditional and western treatment approaches. This study also noted relatively positive attitudes in the population studied (11). Available literature does not appear to provide insight into current perceptions surrounding physical disability in rural Kenya.

This study aims to sample the range of attitudes towards persons with physical disability in a group of rural villages in western Kenya. By exploring the ideas, interests and opinions of community members, there would be an understanding of the range of attitudes that shape the local environment, in which a rehabilitation programme would be initiated. Understanding attitudes may help to guide interventions and enable accurate evaluation of programme effectiveness (5). This study also explores awareness and use of rehabilitation services for people with disabilities in the community.

METHOD

In this study, mixed methods were used to evaluate the attitudes towards disability, as well as to establish what current services are available for disabled persons, and the extent to which these services are used. A qualitative approach was used in an effort to gain an understanding of the full range of opinions present in the study population and to gain insight into how thoughts and opinions of community members relate to community support of people with disabilities. A quantitative approach was taken with respect to use of available services. Available services were identified through a questionnaire, by speaking with the local social services department and through research online. Each participant received an explanation of the study and provided consent prior to taking part in the survey. Ethical approval for the study was obtained through the Queen's University Research Ethics committee.

The questionnaire was developed based on general topics contained in existing quantitative scales on attitudes towards disability (5). The questionnaire consisted of two parts: collection of demographic data and open ended questions relating to persons with physical disabilities. The demographic survey included age, gender, place of residence (rural or urban), occupation, and level of education. Participants were asked about their relationship with individuals with a physical disability. Semi-structured interviews were conducted in the homes or yards of participants, through a local interpreter who was fluent in English, Luo and Kiswahili. The interpreter was trained in advance on the purpose of the study and the aims of the interviews, and agreed to preserve confidentiality. Responses were recorded by the researcher, in English, onto the questionnaire form. At times further probing was done to better understand the responses.

The sample

Participants 18 years of age or older, were selectively chosen from a convenience sample of the 17 villages of the Barkowino sub-location, in the Nyanza province. Guidelines to maximise range of respondents including variation in age, gender, level of education and occupation, within each village, were used for participant selection.

Data Analysis

Data were entered and analysed using the NVivo 7 qualitative data analysis programme. Multiple levels of coding, and triangulation were carried out, and common themes were identified. A model was then created, based on the themes which emerged from the data.

RESULTS

Table 1. Demographic information of participants

Gender	N	%	Mean Age
Male	20	55.6	46.7
Female	16	44.4	36.7
Total	36	100	42.2 years
Occupation			
Farmer	13		
Repair technician, Plumber/water technician	6		
House wife	1		
Businessman/sales	2		
Teacher	3		
Pastor		2	
Healthcare worker	2		
Student	1		
Retired	3		

Level of education			
None	1		
Standard 3-5	5		
Standard 6-8	17		
Secondary	7		
Post secondary	6		
Acquainted with a person with a disability			
Yes	35		
No	1		
Relationship to a person with a physical disability			
Immediate family member	7		
Extended family	13		
Friend	6		
Village mate/Community member	11		
Self	3		
Have seen PWD	1		

8.3% reported they had disability themselves; 97.2% admitted to being acquainted with a person with a disability and 1 participant did not know anyone with a disability. The types of disability noted by community members included hemi paresis, post polio syndrome, crippled, limb amputation, bowed legs, hip fracture, cerebral palsy, epilepsy, short stature and sensory impairments (blind, deaf).

The following three main themes emerged through qualitative analysis of the data: perception of the causes of disability, appreciation of differences and capabilities of disabled persons, and beliefs surrounding societal responsibilities. Quotations provided are as stated by the language interpreter.

a) Perceived causes of physical disability

The most common causes of physical disability described were accidents and disease. Accidents included natural calamities as well as traumatic injury due to falls and motor

vehicle accidents. Disease as a cause of disability was described as having either a genetic, congenital, or external etiology. Some respondents described natural causes of disability relating specifically to genetics: "*Naturally during gene division*"; "*If her grandmother is crippled, [a woman] may give birth to crippled child.*" However, natural causes also encompassed various factors during pregnancy leading to the birth of a disabled child such as "*born with it [disability] due to pills for planning taken while pregnant.*" Maternal illnesses, such as malaria infection, during pregnancy were thought to cause congenital disability, "*some are born crippled due to a disease inside the womb.*" External causes of disease were associated mainly with poor health, infectious diseases, stroke and malnutrition: "*A non balanced diet, especially in small children, can lead to deformity.*" Specific diseases such as polio, measles, rickets and malaria were all listed as causative factors in physical disability.

Traditional and spiritual beliefs also play a role in the understanding of cause of disability. Witchcraft, misfortune, and mysterious causes were all linked to disability. Witchcraft could be carried out by a family member or an acquaintance: "*A relative may use magic power on another relative because of jealousy.*" Human or supernatural elements may lead to misfortune and disability, "*may be human driven or spiritual when you're put in a state of misfortune, for example when fighting for land.*" One respondent explained that when the disability cannot be attributed to genetics, the parents may have opposed a taboo in the past. For example, within a polygamous relationship, if the husband was supposed to sleep in the hut of the second wife, but sleeps in the hut of the first wife, they may have a child with a disability. Traditional medicine practices were also linked to disability: "*If a child is not properly massaged when born to protect him and prevent disease by increasing temperature and relieving tight, sore muscles.*" Finally, physical impairments were linked to mystery, particularly when worries and problems were thought to be the cause of a disability that couldn't be explained any other way.

Spiritual beliefs linked deformity and disability with causes relating to a higher being beyond human control: "*When people are born naturally disabled and the cause can't be explained, it must be God's plan. It can't be any other way.*" Spiritual beliefs also described human behaviours as precipitants of reactions from God. "*Disability is driven by supernatural powers. God reacts differently to people based on behaviours.*"

Causes of disability related to poverty included too much work, malnutrition and lack of health care. Participants explained that poor access to health care can lead to disability because people are then more likely to rely on traditional treatment, which may be unsuccessful. The large distances to the hospital and the absence of organised first aid increases the risk of disability in the case of pre-existing poor health. Respondents also suggested that childhood illnesses such as measles that are left untreated, can result in disability. One respondent expressed distrust in the medical system, identifying it as a cause of disability: "*Swelling after an injection can lead to disability in the leg. The way it was explained to me was that either the [injected] drug didn't work or had expired.*" Participants indicated that some parents are ignorant with regards to raising their children and they do not take their children for immunisations or medical appointments. They felt that this was a significant cause of childhood disability and may be related to poverty, in that, many parents are poor and have little childcare education. The aging process was also thought to play a role in disability as evidenced by the following statement from a respondent: "*As people grow older, they face challenges, work accidents and other accidents.*"

b) The role of persons with disabilities in society

Respondents' descriptions of role differences between persons with and without disabilities ranged from no difference, to various levels of impairment. Participants described visible physical limitations and indicated that people with disabilities require support and have less access to health care facilities and transportation. They also reported reduced function and participation. Disabled persons were described as having fewer opportunities, particularly employment opportunities, and some were described as having different character traits, such as being shy or easily angered. Disability was felt to have an impact on the family, particularly in relation to birth order which is important in Kenya.

"*I prefer the first child should not be disabled [2ⁿᵈ or 3ʳᵈ would be preferred] because everything happens in order of birth, first child does everything first: builds his house, gets married and others must wait until 1ˢᵗ child has done everything, then the door is opened for all the other children.*"

Finally, some respondents indicated that the government does not provide adequate support for disabled persons: "*The government is not concerned. I have written 6 proposals applying for support and have received no response to any of these proposals.*"

Capabilities of persons with disability

The potential capabilities described by respondents, ranged from unable to participate at all to a spectrum of areas of participation, such as community consultants, advising on agricultural issues including which seeds to use for farming and the correct time to plant them. It was suggested that they could be employers, educators and role models both, for disabled and non disabled persons. They could also contribute to community development by mobilising and sensitising the community on pertinent development issues. One participant mentioned that people with disabilities have more time to read and to further their education. They envisioned roles such as leaders, advisors to the government and mediators resolving conflict between other community members.

Because they are home during the day, disabled persons were thought to be able to protect the homes of their neighbours. They were also thought to be able to contribute economically, both by working and by employing others.

"With support, employment and hard work they can contribute materials to the community or to neighbours. If he keeps poultry he can give it to the neighbour when the neighbour has a guest"; "If God blessed him with a job, he will consider other community members because he has also experienced problems." Many respondents viewed employment as an important aspect of life and some said that disabled persons can do any job. One respondent described his success working and supporting his family in the following quote:

"I have a home with my wives and some people without disability don't have this, this can be attributed to success at work. I started in school and when I couldn't continue my studies, I started working commercially. I worked hard and had 3 wives. I had to beg people to carry me to Bondo (nearby town), then I rented a house in Bondo closer to my work."

c) Responsibility of society

Participants indicated that the community, the government and outsiders should all have a role in improving services for disabled persons. Community awareness was discussed as the first step in working and living with disabled persons: *"Educating the locals to understand the disabled and disabilities"*. The importance of learning more about the capabilities of

people with disabilities in order to maximise their participation in the community and help them to achieve their potential was also emphasised. "*They can contribute much, it depends on the level of utilization of their knowledge.*" Suggestions included raising awareness, initiating support groups and interacting with people with disabilities to learn more about them.

It was suggested that community members should meet and problem-solve to improve accessibility. One example given was to alter the bicycle size for someone of short stature. Accessible schools, buildings and services in the community were identified as areas needing improvement. "*Schools must be equipped to encourage them to come: toilets for them and such.*" Education and vocational training were also identified. One respondent suggested training teachers to provide education for persons with disability. Those who are able to work should be supported by providing tools and vocational training, in addition to encouragement and identification of strengths. It was suggested that if volunteers could provide education, disabled persons would be more likely to find paying jobs to support their families and communities.

Respondents also spoke about empowering disabled persons to be self reliant by forming self-help groups. Others noted that assistance for people with disabilities is also important, through material support and services such as government food programmes, transportation, accessible buildings, and rehabilitation centers where they can obtain assistance at different levels. Other participants suggested wheelchair maintenance for those who cannot afford it,

Table 2. Stakeholders in the care of disabled persons

Caring for people with disabilities	Evidence: responses to "Who should care for people with disabilities?"
Family Community Everyone	*"Family members, closest relatives in collaboration with other people", "Everyone in the community should take care of the disabled"*
Teachers	*"teachers should protect the disabled children from fellow pupils taking advantage of them/abuse/beat them"*

Government	*"Depending on the level of poverty in the area, maybe [the community] can't take care of them so the government and churches should"*
	"Government because they have the ability to do everything and if they have an opinion people will listen, they are able to lobby for funds"
Self	*"They should be self reliant, they should form groups where they could support themselves"*

as well as wheelchair and walker donations. Relevant stakeholders identified in the care of people with disabilities include family and community members, teachers, churches, support groups, the government, individual donors, NGOs and other countries (Table 2).

d) Current services

Services currently available in the region, for persons with disability, include:

1. The Association for the Physically Disabled of Kenya (APDK) provides wheelchairs and mobility devices for persons with disability through the Bondo District Hospital. people with disabilities apply through the physiotherapy department at the hospital, and deliveries are made approximately every 3 months.

2. Bondo Association for Persons with Disability is an initiative by the local officer for Community Based Rehabilitation. The association is made up of persons with disability, their families and community members. At present, the major challenges are funding, transportation and logistics for meetings, because members have difficulty travelling to meetings.

3. Bondo District hospital provides physical therapy and medical support for people with disability. The distance to the hospital makes it inaccessible to many. A volunteer group of community based rehabilitation workers provides some assistance; one member of the group gave the example of facilitating communication between a child with a disability and a school for disabled students.

4. Schools for children with disabilities in western Kenya include Nyangoma School for the Deaf, St. Oda School for the Blind and Nyabondo Centre for the Disabled. Participants indicated that these schools were often not accessible either due to distance from the village or financial cost.

5. Government training programme: A national teacher training programme is currently in progress to train teachers to specialise in care for students with disability. The goal is to have 1 trained teacher in every school by 2015. A government funding programme may also be available to improve accessibility for students with disability, by modification such as ramps or accessible latrines in local schools.

Table 3. Services for persons with disability

Participants knowledge of services for disabled persons	N	%
None	13	36.1
"None," but had an idea of a possible support available	5	13.8
Respondent was able to describe available services	17	47.2
Hospital, health centre	(3)	
Schools	(9)	
Associations	(2)	
Kenyan National fund for the disabled	(1)	
APDK Kisumu	(1)	
Government support	(2)	
Youth group programme	(1)	
No response	1	
Total	**36**	

47.2% of respondents listed one or more specific services available for disabled persons. 36.1% of respondents did not know of any services available in the area for disabled persons, 13.8% (5/36) respondents said they had tried to access services or they knew someone who tried to access one of the supports or services in the area. Only 2 of the 5 respondents in the above group reported a successful attempt to access the services.

DISCUSSION

Through data analysis, it became evident that the three categories which emerged, perceived causes of disability; the role of disabled persons; and the responsibilities of society, all contributed to participants' expression of their attitudes towards disabled persons. These attitudes ultimately determined support of participation for disabled persons in the community. The following model was generated from the interview data.

Figure 1. Model

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                    ┌──────────────┐
                    │  Perceived   │
                    │  causes of   │
                    │  disability  │
                    └──────────────┘
                            │
┌──────────────┐          ●          ┌──────────────┐
│  Perceived   │─────────   ─────────│ Perceived role│
│  capabilites │                     │  of society   │
└──────────────┘          │          └──────────────┘
                          ▼
                  ┌──────────────┐
                  │  Support of  │
                  │ participation│
                  └──────────────┘
```
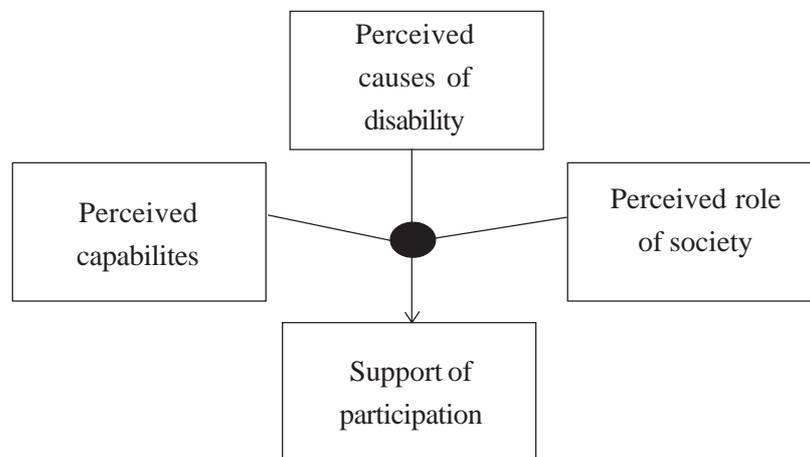
Perceived causes of physical disability

Beliefs surrounding causes of disability were investigated, because it was postulated that perceived cause would affect attitude and thereby have an effect on participation. The primary causes described by study participants were accidents and illness, traditional causes, natural causes, poverty and aging. These results correlate with a study from rural Zimbabwe (11), where 56% of respondents blamed traditional causes such as witchcraft and spirits, and 33% blamed God and a small minority blamed natural causes. In the Zimbabwe study, accidents and illness were not included in the list of causative agents from which participants chose their responses.

In this study, no respondent held the disabled person responsible for his own impairment. The authors would therefore not expect understanding of causes to contribute negatively to attitudes

towards people with disabilities. In the Zimbabwe study, the authors suggested the presence of a stigma attached to disability, as some respondents were found to list different causative agents for disability in their own family, than for disability in general. For example, one respondent indicated that some disabilities arise from witchcraft and ancestral spirits, but he explained that his arthritis was a natural cause of aging and his daughter's polio was a natural disease (11). The authors found that the perceived etiology did not correlate well with treatment choices, as most participants had sought both medical and traditional therapy for their disability; nor did it correlate with rejection of people with disabilities. It appears, therefore, that a rehabilitation programme could be effective, regardless of causal beliefs and that perceived cause may not impact the type of treatment the community would be willing to support. The study in Zimbabwe may have contained some biases, as the small sample was composed solely of disabled persons and their families (11). Further study would be required to determine the direct impact of local perceptions about causes of disability, on support of participation for people with disabilities. If a link was found, then educating community members on the etiologies of disability would be an important consideration for a community rehabilitation programme.

In the current study, no correlation was found between perceived cause and perceived ability to participate in the community. Respondents who indicated that a disability was due to traditional causes such as witchcraft, a curse, or a parent breaking a taboo still recognised a range of capabilities and support options for people with disabilities. In the model described, perceived etiology contributes indirectly to support of participation of people with disabilities, as a component of general attitudes towards disability.

Perceived characteristics and capabilities of people with disabilities

Participants listed a wide range of capabilities that they perceived to be characteristic of people with disabilities. There is little documentation on this topic; however, these responses can be compared with studies describing current participation for people with disabilities. In a study by Gallagher and Mulvany, difficult activities for people with disabilities in Ireland included getting along with people, getting around and general life activities (12). One respondent in this study reported that people with disabilities are shy and easily angered, which coincides with the previously described difficulty in interacting with others. However, this perception was not pervasive among respondents in the current study. Lack of appropriate

participate in politics and the sense that one's participation will influence government decisions. Many people do not take part because they do not see the government being responsive to their needs. Internal efficacy has been found to be a predictor of political participation among persons with and without disability, where as external efficacy only predicted political activity among people with disabilities. Furthermore, employment, education, economic and social factors influence efficacy of people with disabilities (17). In this study, participants suggested that people with disabilities have more time for education, which could perhaps improve outcomes for political participation. Other studies suggest that people with disabilities engage in political action to fight stigma and discrimination (18,19 cited in 17). In this study, however, respondents suggested political participation for the benefit of the community in general, rather than to gain ground in the area of disability.

Social participation has been linked to quality of life of older persons living with physical disability in the community. Interpersonal relationships, responsibilities, fitness and recreation have all been associated with increased quality of life, and social roles have been found to correlate more with quality of life, than do daily activities (20). In this study, many activities listed by respondents related to social participation. Facilitating similar roles and activities in people with disabilities may lead to improved quality of life for community members with disability. As a result, awareness of the capabilities and limitations of people with disabilities will help community members to provide a more enabling environment. This community appeared to have a positive outlook towards the capabilities of people with disabilities. They have indicated that people with disabilities are capable of a wide range of leadership roles including being advisors, community developers, teachers and role models, suggesting a relatively positive attitude towards participation for people with disabilities.

Perceived role of society

The outlook of the community towards its role in supporting participation of people with disabilities provides further insight into social attitudes and expectations, described by Devine and Lashua as social context (21). Social context can factor into the disability experience of people with disabilities by affecting perceived impairment for disabled persons themselves (22). This makes community involvement a particularly important consideration. Respondents in our study made suggestions on the type of support required and about who should help to

make the environment more enabling to improve ability of people with disabilities to fulfill their role within in it. Based on these responses, it is seen that the community recognises that barriers or deficits exist and that community members themselves, can play a part towards breaking down barriers. Due to community limitations, however, they saw the need for a variety of other supporters as well.

Role of the Community

Community and family members were named as primary caregivers, as they are close to people with disabilities and have a better understanding of their needs. Respondents also addressed the need for training of community members. Peterson and Quarstein's study on sensitivity training for employees working with people with disabilities, in which they suggest can be related to the general population, found that training improved understanding of the abilities of people with disabilities and of how to interact with them, leading to increased success for people with disabilities (23). Other studies show that quality interactions (9) and social roles that emphasise valued attributes of people with disabilities (10) improve favourable attitudes towards people with disabilities. Tervo and colleagues also found that for nursing and rehabilitation students, increased work and educational experience with disabled persons helps to improve attitudes (4).

Role of other Supporters

Acknowledging limitations, respondents saw the need for a variety of external supports which extended to the local and national government, NGOs, well wishers and international organisations. As equal citizens, the rights of persons with special needs should be adequately supported by state structures (24). In Kenya, this includes legislation such as the Person's with Disabilities Act (2003), which promotes the rights of people with disabilities, and Labour Law reform proposals described by the International Labour Organization (ILO) in 2004 (25). Family and the local community should not be held solely responsible for the care of people with disabilities. With the recent adoption of the United Nations Convention on Rights of people with disabilities, these rights should be recognised by all member countries, including Kenya who signed the convention in March 2007. Reliance on external sources of aid, such as well wishers and international donors raises sustainability concerns. Responses may have

been biased, as participants were aware that the researchers were foreigners; however, it is important to consider the effects of foreign aid on community projects. Success of development programmes is dependent on support from the community. Ideas, needs assessment and program planning should come from the community in order to promote program sustainability (6). However, these alone may not guarantee sustainability. It is the authors' belief that for long term sustainability, ongoing effective support needs to be provided from within the societies in which people with disabilities live.

Type of Support Required

Respondents made suggestions on much needed types of support, among which were listed accessible buildings, improved transportation services and mobility aids. A study investigating the degree of handicap for people with physical disability in the highlands of Papua New Guinea, found mobility devices, including prosthetic limbs and wheelchairs, to be the most helpful intervention for the group studied. Family members were found to have adequate skills to care for disabled relatives within the context of their community (26). These findings highlight the importance of a needs assessment to ensure that support is directed appropriately. Many respondents thought support groups, formed either by the community or by people with disabilities themselves, would be helpful in their village. Literature suggests that support groups can improve self efficacy and quality of life for people living with a variety of disabilities (27).

The responses discussed above suggest that respondents have adequate knowledge about current needs, but many indicated that they do not have the time, the resources or the skill set to implement them. The ideas alone, demonstrate support for improving participation; however, the authors are unable to comment on what level of action the community would be willing to take as the question was not asked directly.

Services and supports for people with disabilities

Assistance with activities of daily living (ADLs) and instrumental ADLs seems to come mostly from family or community members in the area studied. There were no specific support services for domestic adaptations, aside from anecdotal evidence of funding for school accessibility improvements. By 2015, there is expected to be a teacher in each school,

trained in caring for people with disabilities. There are a number of schools for children with disabilities in the district, but accessibility is limited for members from the community studied, due to financial cost. Some mobility aids and adaptations are available, one respondent with short stature reported that his bicycle was modified, so that he could ride it. The APDK also provides services to people with disabilities by providing tricycle wheelchairs and adapted work tools, although no respondents interviewed, had received the tools.

The social services programme available does not appear to be well used by community members. The cause for this was unclear; one respondent said he applied six times and never received a response. Health services for people with disabilities are available. Physiotherapy can be accessed through the Bondo District Hospital. Patients are assessed first in the hospital, and then referred to the physiotherapy department. Other supports available including Bondo Association for Disabled Persons and Community Rehabilitation Workers, services are limited by finances and transportation.

The National Rehabilitation Programme (1968), is a national initiative which provides vocational rehabilitation (25); it is not well known or used in the area. Only the Kenyan Institute of Special Education (1986), appears to be known as some teachers in the community described funding opportunities for accessibility improvement in schools and for training special education teachers.

In general, it appears that current resources are underused by rural persons with disability in the community studied, generally due to lack of knowledge of the services, high costs and accessibility or transportation difficulties.

Implications of the findings

This community, from an attitudinal perspective, appears to be ready to support substantial participation of people with disabilities, and thereby may be ready to support a CBR programme. The ideas suggested, including vocational rehabilitation, community education, improved accessibility and social participation, are all possible components of a CBR programme. A community needs and resources assessment should be carried out before initiation of a programme. The findings of this study are consistent with the limited current literature on attitudes towards disability in rural Africa, where Jackson and Mupedziswa found that attitudes in rural areas were more positive than they had predicted (11). This study also demonstrates

a fairly positive outlook and good understanding of disability in a rural African community.

The limited supports available are underused due to knowledge and access deficits. Larger national institutions and services are not used by those living in this rural community, as residents are unaware of the available resources. Local health facilities and community based rehabilitation workers are in a good position to assist people with disabilities in the rural community with access to these services.

CONCLUSION

The findings provide insight into the attitudinal factors affecting people with disabilities in a rural Western Kenyan community. The perceptions regarding cause of disability, potential role of the disabled person in society, and role of society towards people with disabilities shape attitudes towards disability. The model presents factors that may influence social and attitudinal components of the environment. This study, shows community attitudes that may support a relatively enabling environment for integration of people with disabilities into more meaningful participation in community life.

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BRIEF REPORTS

PLAY BASED STIMULATION PROGRAMME FOR INFANTS WITH CEREBRAL PALSY AND MENTAL RETARDATION

Suruchi Gupta*, Shruti Bhargava**

ABSTRACT

Formulating, implementing and documenting play based stimulation programmes for children with Cerebral Palsy (CP) and/or Mental Retardation (MR) was the main objective of the study. The study also focused on the mothers and equipped them with knowledge about the conditions. Six infants and their mothers enrolled in the Infant Stimulation Centre, Faculty of Home Science Baroda, India, formed the sample.

The study was conducted in 3 phases, consisting of 4 assessements on Developmental Assessment Scale for Indian Infants (DASII). Based on assessment results, individual need-based programmes were formulated and implemented at the centre and their homes. Additionally, the mothers were interviewed and the areas of concern were identified, around which intervention sessions were planned. Results showed that 66.6% of children showed increase in the motor score and 100% of children showed increase in mental score. Improvement was more in the areas of mental development. Time was a major constraint for giving inputs to the child at home. Increase in scores was more due to home intervention than the mother intervention programme.

INTRODUCTION

Early intervention is planned for children who are at risk, or have established developmental delays of various degrees and associated conditions from birth to 3 years. Research shows that the early years of life are crucial for establishing a foundation of learning and emotional development. If children miss the opportunity to develop intellectually and emotionally during these important years, precious time is lost forever (1).

The major purpose of early intervention is prevention of disability and developmental delays. The ultimate goal of intervention is to enhance normal development and independent functioning of the child. Since the child's development is dependent on genetic qualities and interaction with the environment, it becomes imperative to focus on the child and on the environment in early intervention (2). Similarly, a study by Bronfenbrenner (3), stated that the most effective agent of intervention in fostering and sustaining development, is the family. Research by Trivette and Dunst (4), shows that when intervention is done in a family centred manner, it strengthens the family and gives them the feeling of control and competence.

Intervention can be provided at the home or at a centre or as a combination of both. The home visits provide a perfect opportunity for the service providers and the parents (typically the mother), to establish and maintain rapport, as well as to discuss the effectiveness of the previously planned and implemented activities. In the centre-based intervention, team members can work closely with the child and have an easy access to him/her.

However, the difficulties in involving parents in centre based programmes are that, such programmes are potentially expensive and time consuming. Thus, a combination of both home based and centre based intervention can prove to be advantageous. It has the combined benefit of being able to provide individualised attention, as well as group attention and social interaction. It also provides a natural home environment to the child, to learn things and then generalise them easily. In addition, accessing appropriate toys becomes easier, and the child also gets a new environment to play in, besides giving respite to the parents. (5).

METHOD

The study was quasi-experimental, as the sample was well defined and naturally occurring, comprising of six infants with Cerebral Palsy or Mental Retardation and associated problems, who were enrolled in the Infant Stimulation Centre of the Department of Human Development and Family Studies, Faculty of Home Science, Maharaja Sayajirao University, Baroda, India. The total sample (N=12) consisted of six infants and their mothers. The sampling was purposive as the study was based on the ongoing work of the Infant Stimulation Centre. The children belonged to the age group of 2.5 years to 5 years. The mental ages of the children ranged approximately from 8 months to 2 years while their motor ages were between 5.7 months and 23 months. All children had varied degrees of cerebral palsy and/or mental retardation

with associated visual or auditory and speech deficits. The mothers were housewives with their ages ranging from 26-44 years and their educational levels from 12 class to Master's Degree. All mothers except one, were from nuclear families with an average household size of four.

The tools used were as follows:

1. Developmental Assessment Scale for Indian Infants (DASII)

This is an Indian adaptation of Bayley's Scale of Infant Development. DASII is used for infants in the age range of birth to 30 months and measures their motor and mental ages.

In addition to providing the overall motor and mental developmental scores, DASII also indicates the specific clusters of delay under the broad areas of motor and mental functions. This information can be utilised in planning the individual programmes.

2. Interview schedule for the mothers

The schedule consisted of three domains namely:

a) Understanding of mothers about their child's condition; b) the mother's queries and the constraints faced; c) the mother's coping.

The tool was formulated by the investigator and validated by experts. Part of the tool related to coping was taken from the tool developed by Bhargava and Soudagar (6).

The entire research consisted of five major components namely :

a) Individualised programme formulation; b) programme implementation at the centre and the home; c) interviewing mothers; d) parental intervention and e) testing at different stages.

RESULTS

a) Data related to children

Table 1 shows the clusters that needed interventions under the motor and mental scales, separately for children with CP and for those with MR.

Mental Retardation. It can be attributed to the condition of the child, which limits his understanding the activities in the particular clusters.

The comprehensive results for all the infants consist of their initial and final scores i.e. scores obtained in Testing-1 and Testing-4, under the motor scale as well as the mental scale, as indicated in Figure 1.

Figure 1. Initial and final scores of all the infants (n=6).
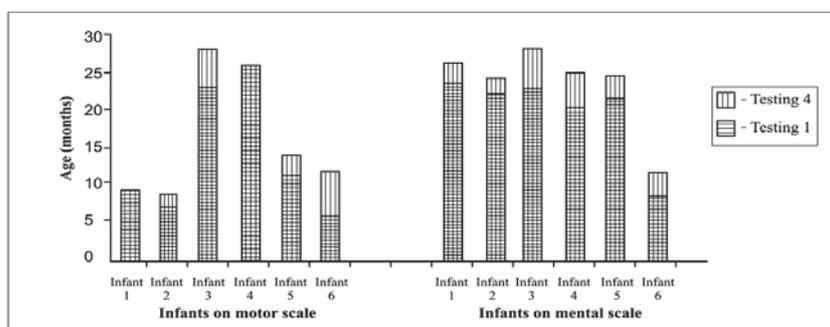
The figure clearly depicts that there was improvement in the mental scores for all the infants, whereas in case of the motor score only 4 out of the 6 infants showed improvement from the first to the last testing.

Among the children with Cerebral Palsy (n=2), child 2 shows less increase in motor score. For child 1 however, there was increase only in the mental score. For the children with Mental Retardation there was more increase in the mental score as was found for child 5. This shows that for the study, there has been more increase in the mental score across all the children, irrespective of their condition.

Data related to mothers

The data obtained from the interview schedule, showed that the mothers were aware about the terms that were used to describe the condition of their child. However, all the mothers were not realistically equipped with knowledge about the limitations of the conditions and thus their expectations from the infants did not match the child's present or future performance. In the words of the mother with a severe MR child, "He will be able to do everything and stand on his feet". Additionally, the mothers needed information on more effective methods

of implementing activities with their children and activities to foster independence in the child. The method of coping that the mothers used was generally approaching the doctors, while a few believed in destiny. All the mothers reported that time was a major constraint and that attending the centre helped them in maintaining a fixed schedule for the child. Based on the information obtained from the mothers through the interview schedule, six sessions were planned.

Session 1: Stimulation and its importance in Cerebral Palsy

Session 2: Mental Retardation

Session 3: Down Syndrome

Session 4-5: Milestones for normative development

Session 6: Activities of Daily Living (ADL)

Some activities of daily living were also included as the mothers ignored it, believing that the academic part was more important for the child. Besides this, appropriate methods of conducting an activity were also discussed.

For all the infants, the home intervention contributed more in the improvement of the test scores as compared to the mother intervention programme. Greater increase in the scores of Testing 3 (after home intervention) was found as compared to Testing 4 (after mother intervention).

DISCUSSION

The issues of concern that emerge from the study are:

Limitations of uses of a standardised scale - In the research DASII was used to assess the children on their motor and mental abilities. The tool is standardised for the children of Baroda and so is culturally relevant. Additionally, it is used for children in the age range of birth to 30 months and was therefore appropriate to be used in the study. However, the results of the research indicated that certain achievements of the child were not being tapped by DASII and so had to be reported descriptively. These gains in the child's performance could neither get reflected in terms of percentage nor in the graphs that depicted the movement in the scores. Thus, in order to assess a wider range of abilities of the child and to keep an

account of the child's other capabilities, use of a battery of tests can be made. The tests like Binet Kamat Test and Vineland's Social Maturity Test can be included for the assessment so as to tap the child's abilities across the various areas of development, and make available comprehensive information for the parents/interventionists.

Understanding between the parents and the professionals - The mothers' data revealed that though they approach the doctors and other professionals for help, these professionals share information in a manner which is not understood by the parents. Use of technical language by the doctors and the inability of the parents to understand, make them all the more apprehensive about the condition of their child. The parents need to be informed about the tests that there child is undergoing and the findings of those tests need to be explained to the parents. The doctors should be made aware about the importance of sharing information with the parents in the way that is easily understood by them. According to the parents, the report of their children highlights the child's incapabilities, making the parents feel more guilty. Thus training should be provided to the professionals, so as to equip them with the ability to deal with the parents, making them feel more comfortable and less apprehensive about the child's condition, about the tests that the child undergoes, his/her future and the best solution that should be suggested for the child.

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TRAINING OF TRAINERS (TOT) PROGRAMME ON INTELLECTUAL DISABILITY FOR CBR WORKERS

Jayanthi Narayan*, P. Sudhakara Reddy**

ABSTRACT

Community Based Rehabilitation (CBR) for persons with intellectual disability is focused more on training in independent living skills when compared to other disabilities, where provision of assistive devices and supports are of prime importance. This requires equipping the CBR workers with skills in training the person with intellectual disability and the family. The present study aimed at training middle level functionaries in an existing CBR programme of Andhra Pradesh State Government in India, using a CBR manual prepared exclusively for this purpose. A ToT package was prepared along with the manual for this purpose. A pre and post test were conducted. A follow up workshop was carried out after 3 months to see the efficacy of the training programme. Site visit and impact and process evaluation were carried out during the follow up workshop and it was found that the training programme was effective in providing knowledge, skills and competencies to the participants.

INTRODUCTION

Intellectual Disability, commonly and legally known as "mental retardation" in India, is a condition requiring special attention in terms of reaching out with services for such persons in various corners of the country. The major difference between community based rehabilitation (CBR) for persons with mental retardation and other disabilities is that the former need appropriate training during the various stages of life for independent living while the latter require suitable aids and appliances, assistive devices and appropriate guidance so that they may function in society with minimal support. To focus on training for persons with mental retardation, the trainers should be well equipped with knowledge, skills and competencies. As rightly noted by Cook et al (1), CBR is not a 'band aid' solution, but rather a solutuion that provides long lasting effects, which is further endorsed by Thomas (2), stating, 'regardless of

what is 'politically correct', CBR today is understood by most stakeholders in the disability sector, as a strategy to promote inclusion, rights and equal opportunities for the persons with disabilities.'

Recognising this need, a training programme was organised by Indira Kranthi Patham(IKP), a project of the state government of Andhra Pradesh in India. The main objective of this project is to enable rural poor people to improve their livelihoods and quality of lives through their own organisations. The project is implemented by Society for Elimination of Rural Poverty (SERP), Department of Rural Development, Government of Andhra Pradesh (3). SERP is an autonomous body that implements the project through District Rural Development Agencies (DRDA) at the district level. Disability rehabilitation is one of the major components of this project. As noted rightly in the IDDC position paper on CBR (4), a CBR programme needs to be closely linked to general development goals such as poverty alleviation and other millennium development goals. The IKP aims precisely at this goal.

Most CBR programmes focus on areas of health, such as provision of aids and appliances, physiotherapy, surgery and medicines, and on education and income generation programmes for persons with disabilities with minimum focus on mental retardation. (5). There is an urgent need to provide an appropriate programme through CBR with focus on skill training for persons with mental retardation. Imparting technical training to already existing functionaries in the CBR system, is one way of reaching out to this group.

METHOD

Participants

In the State of Andhra Pradesh, every district is divided into Mandals, with each Mandal having roughly 50,000 population, 10,000 households and 25 to 35 villages. In the project IKP, every Mandal has one Community Coordinator (CC-D) for activities related to disabilities (CC-D). It is the responsibility of the CC-Ds in the IKP project to enable and empower persons with disabilities, by helping them to build their Self Help Groups (SHG) at village level, form federations of those SHGs at Mandal level and develop strong linkages with other institutions for the poor. The CC-Ds are supported by the Community Development Workers (CDWs) at the grass root level to give intensive facilitation support to persons with disability, their families and their institutions. The work carried out by the CC-Ds is monitored by the

federation of persons with disability, i.e Mandal Vikalangula Samakhya at the Mandal level. They are supported by District Project Managers anchoring the disability programme at District level and State Project Manager(SPM) at the State level.

There were 25 participants for the study including 23 CC-Ds and 2 CDWs from different districts of Andhra Pradesh. Thirteen of them were women. All the CC–Ds had a Masters Degree or a post graduation, while the CDWs had completed intermediate education. Among the participants 4 had a motor disability and 2 were parents of children with disability. In addition to the postgraduate qualification, four of the CC-Ds had special education training, or Orientation and Mobility training. All the participants except one, had worked in IKP for 3 years and more.

Tools/Materials

The manual prepared with the support of Health and Behaviour Unit, WHO, Regional office for South East Asia, New Delhi was used in the current training programme (6). The manual contains general information on mental retardation, characteristics of persons with mental retardation, identification, early intervention, activities for children of an older age group, adolescents and adults. The manual covers activities of daily living, functional academics, domestic and occupational skills and recreational skills. It also includes details on resource mobilisation and tips for trainers. To train the trainers of grass root level functionaries, the manual has a Training of the Trainers (ToT) package, which contains information on trainer competencies, and day-wise training schedule of contents to be covered to prepare the trainers. The ToT along with the training manual was used to train the trainers in the project carried out by IKP.

In addition, basic skill training booklets on mental retardation, adapted material for daily living activities such as clothing, shoes, spoons, glasses and tooth brush and other materials described in the CBR manual which also formed the training tools. Live demonstrations with the help of persons with mental retardation with their or their guardian's consent, were also carried out.

A questionnaire was developed for pre and post test of the participants. The questionnaire was close-ended having multiple choice questions, predominantly on information on mental retardation. The one difference in the pre and post test questions was the open-ended question at the end of the questionnaire. In the pretest, participants were asked to list their

expectations from the training programme, while in the post test, they were asked to list any new learning through the programme and their suggestions for future programmes.

Procedure

On the first day, after introduction of the training programme, all the participants were given a pretest. The first day was devoted to content coverage on trainer competencies, resource mobilisation, team building and leadership skills. On the second day, various aspects including general information on mental retardation, identification, early intervention, and training of older children including activities for daily living and functional academics, were covered. On the third day, adolescence and adulthood related skills including domestic and occupational skills, were covered. On both the days, relevant motor, social and language skills and recreational skills were discussed. In addition, adaptations of material or environment, to compensate for the limited intellectual ability of the target group was focused. Live demonstrations, group and individual exercises and lecture discussions were the methods used for training. All the way through the training programme, emphasis was laid on teaching 'from concrete to abstract', moving from 'easy to difficult' subtasks. On the third day, post test was carried out. The total training was carried out by a qualified, and competent special educator in the area of mental retardation with the logistical support provided by another qualified special educator. On the third day, the participants were asked to provide their feed back.

After three months, a follow up workshop was conducted for three days by the same trainer to find out the impact of the training programme in terms of application in the respective villages. On the first day, a site visit and meeting with the stakeholders were carried out. On the second day, the participants presented and discussed their activities related to mental retardation, which they had carried out for 3 months. On the third day, the gaps found in the training programme were filled and an action plan was drawn for the future.

RESULTS AND DISCUSSION

Training programme

The analysis of pre and post test showed a mean gain of 15% with a mean of 70% in pretest and 85% in the post test. The individual gain ranged from zero (in two participants) to 6 points out of 15 points in one participant. Four participants had gained 5 points out of 15.

Three had lost one point each in the post test. In the post test five participants had all 15 correct answers while none had all correct responses in the pretest. The high pretest mean scores could have been because the participants were already in the field, with access to information about mental retardation and their knowledge in the area was good. The gain was found to be in the skill areas. This suggests that the pre and post test should have an adequate number of questions to check on the skill areas, whereas the questionnaire used had more on knowledge. This was further confirmed by the analysis of responses for open ended questions.

Analysis of their responses for the open ended questions revealed that 20 participants needed information on working with parents and families of persons with mental retardation and the community, while 17 required information on how to train persons with mental retardation on daily living skills. Fourteen participants asked for specific information on rehabilitation and 13 asked for information on how to train the grass root level workers.

In the response of post test, it was noted that 23 participants had expressed confidence in training persons with mental retardation as well as their families. This was also noticed when they had hands-on exposure during the training sessions. They had mentioned that they would carry out the training programme in their mandal for family members, community, Anganwadi workers, CDWs and CBR workers. Sixteen participants had expressed that they learnt how to teach children with mental by using the strategy of 'easy to difficult' with concrete examples and minor adaptations in the environment or material. Eleven participants were confident about identification, early intervention and home based training of persons with mental retardation, while 9 expressed that they learnt about trainer competency and leadership skills. For future programmes, the suggestions included: increase in the number of days of training, more detailed coverage on training children with profound mental retardation, more input on sexuality and more use of local language while training.

During the concluding session, most of the participants expressed that though they were familiar with the concept of mental retardation, they were not aware that persons with mental retardation could be trained to lead an independent life and that with training those with severe mental retardation could look after themselves for their basic needs. They expressed confidence in implementing the training programme in their respective mandals. These responses further endorse the fact that though the participants had knowledge on

mental retardation (as revealed through high pretest scores), they were not aware of skills required to train.

Follow up workshop

During the follow up workshop, the feedback after 3 months revealed the skills of trainers in terms of training persons with mental retardation as well as the trainee group at grass root level. During the programme, both process and impact evaluation were carried out. Process evaluation included collecting information on the number of training programmes carried out for various target population by the CC-Ds, number of new cases identified and programmes planned, new programmes initiated as a result of the training programme and any other note worthy development. Impact evaluation was carried out through site visit and interaction and discussion with the group. Each participant narrated case specific experiences, which reflected the competencies gained by them and the further needs.

On the analysis of the periodic report sent by the CC-Ds, it was noted that 16 out of the 26 participants had responded.

Process evaluation

Sixteen out of 26 CC-Ds sent their reports. All of them had conducted training programmes for parents and CDWs. Eight of them had conducted training programmes for other CCs in their area and 5 had conducted training programmes for others including school teachers, and members of Mandal Mahila Samakhya and Mandal Vikalang Samakhya. All of them had carried out programming for persons with mental retardation, which included identification of new cases, functional assessment and programming for identified cases including individual programme planning and implementing the training programme through parents. Three had difficulty in training children with profound mental retardation and those with cerebral palsy. Two expressed difficulty in toilet training and 2 expressed that parents of children with profound mental retardation and those who are non ambulatory, have difficulty in attending parent group training programme.

Impact evaluation

This was done through listening to reports of each participant. All CC-Ds were convinced that persons with mental retardation could be trained. Each one expressed that before the

training workshop, their role was restricted to identification, certification and informing them about the benefits and helping them to receive the benefits. After the training, they had gained competencies and were able to see the progress in the individuals with mental retardation. During the site visit to a Mandal on the first day, the parents revealed that they had seen specific progress in some areas. One of the mothers said *"My daughter is 23 years and I did not know how to train her in bathing and dressing. I was doing everything for her. Now within a month I could get her to do both because of the training".* Other parents expressed details of specific progress seen in some of the areas such as shopping skills, self feeding, and money concept.

During the interaction with the group on the second day, it was noted that all had conducted training in activities for daily living. Nine participants had worked with adults and they expressed that their training tips to parents were helpful and that the person with intellectual disability once trained learnt faster. Adaptations and modifications suggested for training in activities for daily living(ADLs) proved effective in most of the cases. The training manual prepared with the help of WHO which was a support material for the trainers, was reported to be a good reference material for carrying out the training programme.

Three trainers took the support of special teachers for carrying out the training programme, as they did not feel totally confident. Two reported that they needed further support in working with persons with profound mental retardation and/or with cerebral palsy and 4 expressed the need for support in training very small babies with developmental delays. It was noted that documentation of each case work was not carried out systematically.

On the third day, considering the difficulties expressed by the participants, training tips were provided, assessment, programming and documenting was demonstrated. Following the demonstration, the participants carried out a similar exercise with persons with mental retardation under supervision and reported confidence in carrying out the task in their regions.

Future plans of participants

It was decided collectively that:

- Participants would take up activities including sensitising village leaders and women groups, educating the pre-school workers and school teachers on mental retardation, and forming parents groups.

- Feed back from the participants would be taken every month in writing and after 3 months one more workshop would be conducted for further action.
- Training of Area project managers (APM) and District Project Managers (DPM) would be planned so that they are equipped to supervise the CCs and CDWs.
- The local language version of the manual would be made available to field workers, middle level functionaries, parents and other concerned persons.

CONCLUSION

In conclusion, it can be said that a 3 day training programme using a simple training manual and a ToT for field workers with post graduate qualification and field experience of about 3 years, will help in providing knowledge in the area of training persons with mental retardation and their families. It will make them confident in training grass root level workers, family and community. A follow up workshop is essential to ensure efficacy of the training programme and to fill the gaps if any. In addition, similar training may be carried out in a few more structured CBR programmes where there are middle level functionaries with similar qualifications and experience, to ensure generalisability of the training programme. However, context specific differences should be considered and accommodated. This will help in reaching out to persons with mental retardation with appropriate services in the absence of special schools or other training facility especially in rural areas.

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ASIA PACIFIC DISABILITY REHABILITATION JOURNAL

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