

EDITOR'S COMMENT

All welfare organisations, big and small, perpetually articulate their demand for 'aid'. Although it is assumed that monetary aid results in benefits for the recipients, this is not always the case. Aid can be detrimental in many ways if it is not accompanied by adequate plans for its effective utilisation. To illustrate this further, one can study the example of fund flow to developing countries through development assistance channels.

In 1969, the Pearson Commission recommended 0.7% of the Gross National Product (GNP) of donor countries, as the preferred level of official development assistance to least developed countries. According to some estimates, this would amount to a whopping 175 billion dollars in current terms. Three decades after the Pearson Commission's recommendation however, the current contribution from donor countries is only about 0.22% of their GNP.

Yet, it is important to speculate about what the impact would have been if 0.7% of the GNP of donor countries was to be directed as aid to developing countries. If this money were to be distributed on a per capita basis to all the poor people in the least developed countries, a country like Ethiopia would have received three times the amount of its Gross Domestic Product (GDP) in today's terms. Viewed in another way, if the poverty level is taken as below \$500 per capita annual income, then most recipient countries would have got amounts that are several times their total government expenditure.

Even if the cut off level were raised to \$800 per capita annual income, which would include India and China in the group of recipient countries, the amounts received would have been too high for these countries to absorb easily. If a country like India were to receive such a large aid flow in a year, its foreign exchange reserves would have gone up considerably, resulting in a huge appreciation of currency, and making exports virtually non-viable. Unlike a commercial fund flow, aid is not subject to market disciplines; hence large inflows of money could also result in poor management of funds, leading in turn to poor aid effectiveness.

This example underscores the fact that setting aside a quantum of funds for aid per se does not lead to the intended results. It is necessary to plan a road map to utilise the funds, before the quantum of aid is determined. The aid target needs to be grounded in a credible spending plan. This means that the recipient should have the necessary capacity to absorb and manage the funds effectively. Lack of funds, though often cited, is not the only problem for most recipients of aid. Often it is the lack of capacity to absorb and manage the aid that is the crux of the problem.

This is a universal principle, whether the recipient of aid is big or small, whether it is a large developing country or a small organisation that carries out development work. Because of this, it is incumbent on donors to ensure that they build capacity in the recipients to manage funds effectively, before they disburse aid. Money by itself does not lead to development, unless it is backed by sound policies and planning.

As in the previous issue, this issue also carries an experiential article, the last in the Brief Reports section.

The Editorial Team wishes all readers a Happy New Year!

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GUEST EDITORIAL

**EDUCATION FOR ALL (EFA): AN ELUSIVE GOAL FOR CHILDREN
WITH DISABILITIES IN DEVELOPING COUNTRIES
IN THE ASIAN AND PACIFIC REGION**

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ABSTRACT

The Convention on the Rights of the Child mandates that States make primary education compulsory and available free, to all children. It also requires that children with disabilities have access to and receive education in a manner which will help each child to achieve the fullest possible social integration and individual development. However, the current situation for children with disabilities from developing countries in the Asian and Pacific region is not very encouraging. The target of the Agenda for Action for the Asian and Pacific Decade of Disabled Persons was to increase the enrolment of children and youth with disabilities. This target has not been met. This paper discusses the reasons for non-achievement of the target and emphasises the need for education of children with disabilities to become a priority agenda in all countries in the region.

A gulf seems to exist between the experience of children with disabilities and their families, in developed and developing countries, in terms of gaining access to any form of education – inclusive or separate. In most developed countries, a high percentage of children with disabilities attend school. In the Asian and Pacific region, Japan and New Zealand claim 100 per cent attendance and Australia 86 per cent, in 1999. Most children in Japan attend separate, special schools, in New Zealand most children attend regular, inclusive schools, and in Australia a transition has been taking place for a number of years, from separate to inclusive schools. There is active research and heated debate on the effectiveness of separate and inclusive models, but the trend is towards inclusion.

The picture for children from developing countries in the Asian and Pacific region, is completely different. Evidence from the review of national progress in the implementation of the Agenda for Action for the Asian and Pacific Decade of Disabled Persons, suggests that less than 10 per cent of children and youth with disabilities have access to any form of education (1). Evidence presented by the United Nations Children's Fund (2), Jonsson and Wiman (3) and Jones (4), suggest that the figure may be even lower in many developing countries. This situation compares with an enrolment rate of more than 70 per cent in primary education for

non-disabled children and youth, in the region. The target of the Agenda for Action for the Asian and Pacific Decade of Disabled Persons, was to increase the enrolment of children and youth with disabilities, to close the gap between their current level of enrolment and the net enrolment rate of non-disabled children in each respective country, in the ESCAP region. This target has not been anywhere near being met.

The issue of access must be looked at within the context of human rights. Education is a basic human right and all children, including children with disabilities, have a right to education. This right has been upheld in the Universal Declaration of Human Rights (1948), the Convention on the Rights of the Child (1989), the World Declaration on Education for All (1990), the Dakar Framework for Action on Education For All (2000) and the Millennium Development Goals (2000). The Convention on the Rights of the Child is the most widely ratified human rights treaty in the history of the United Nations and has been ratified by all countries in the Asian and Pacific region. It mandates that States make primary education compulsory and available free, to all children, on the basis of equal opportunity, with protection from all kinds of discrimination, including discrimination on the basis of disability. It also requires that children with disabilities, have access to and receive education in a manner which will help each child to achieve the fullest possible social integration and individual development.

Lack of access to education, remains the key risk factor for poverty and exclusion of all children, both, those with disabilities and those without. For children with disabilities, however, the risk of poverty owing to lack of education is even higher, than for children without disabilities. Exclusion from education for children and youth with disabilities, results in exclusion from opportunities for further personal development, particularly diminishing their access to vocational training, employment, income generation and business development. It limits their active participation in their families and communities and prevents them from contributing to either. Failure to access education and training makes it almost impossible for them to achieve economic and social independence. It increases their vulnerability to long-term, life-long poverty in what can become a self-perpetuating, inter-generational cycle. Children with disabilities who are denied access to an education, almost inevitably live their lives feeling hopeless and powerless.

Barriers for children with disabilities, in getting access to education in the Asian and Pacific region are many. They include actions, or, more often, lack of action, by;

- the international community,
- Governments,
- non-governmental organisations (NGOs),
- communities,
- organisations of persons with disabilities.

The Education For All initiative, launched by UNESCO at the World Conference on Education for All, at Jomtien China, in March 1990, and reaffirmed and strengthened by the World Education Forum, held at Dakar in Senegal, in April 2000, has never emphasised children with disabilities as a specific priority target group for action, in Education For All initiatives. The result is, that 12 years after the initiative was launched, only 7 Governments in the region reported that they specifically included children with disabilities in their national plans on Education For All. The World Bank has promised funding to 23 countries with strong national EFA plans, to fast-track their education development – but it is most unlikely that many – or any – of the 23 countries who are successful in gaining this funding, will have included children with disabilities in their EFA plans. Governments of the region, have not fulfilled their obligations under the various international conventions and declarations that they have signed, to make sure that full access to education for children with disabilities is provided. Twenty Governments (out of 34 who responded to the questionnaire) reported that they have passed, or plan to pass, legislation mandating education for all children, but even where legislation has been passed, it is often not enforced and children with disabilities remain outside the school system. Attitudes of discrimination towards persons with disabilities at all levels of society, work against the enforcement of access to education for children with disabilities. Data collection on children with disabilities is limited and they are seldom included in national statistics, on the number of children attending school. So there is no monitoring of their progress into and within, the educational system. It becomes a vicious circle because the lack of information makes it easy to keep on neglecting the rights of children with disabilities to receive an education. And it helps explain the minimal rate of progress that has been achieved towards their enrolment in schools, during the last Decade. If we do not count them, we do not have to do anything about them.

Most children with disabilities in the Asian and Pacific region who go to school at all, have attended segregated special schools. These are mostly located in urban areas and can only accept relatively small numbers of children. Many are run by NGOs, with or without government financial support. In the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities and the Salamanca Statement and Framework for Action on Special Needs Education, it is stated that integrated or inclusive education, with access to education in the regular local neighbourhood or community school, provides the best opportunity for the majority of children and youth with disabilities, to receive an education, including those in rural areas. It is acknowledged that in some instances, special education may currently be the most appropriate form of education, but it should be aimed at preparing students for education in the general system.

In the ESCAP review of national progress carried out in 2002:

- 27 Governments reported that they provide some funding for the education of children with disabilities,

- 29 Governments reported that they provided education for children with disabilities in separate schools,
- 27 Governments reported some educational provision in inclusive regular schools, for children and youth with disabilities, in a trend that should significantly boost their rate of enrolment in education within the region, during the next decade,
- 15 Governments reported that they had established early intervention services, or, were in the process of planning them.

Early intervention, including early detection and identification, during the first four years of life, is critical for infants with disabilities and their families. Support and training for families gives them the skills to help their children develop as fully as possible and prevents secondary disabling conditions.

Improving the quality of education is relevant in both special and regular schools, if children with disabilities are to receive an education which is appropriate, enables them to achieve satisfactory outcomes and take their place actively in their communities. Some major barriers to the provision of quality education in all educational contexts include:

- lack of early identification and intervention services,
- negative attitudes and exclusionary policies and practices towards children with disabilities,
- inadequate teacher training, particularly for teachers in inclusive regular schools who are expected to teach children with a wide range of abilities,
- lack of support systems for teachers,
- lack of appropriate teaching materials and devices,
- failure to make modifications to the school environment to make it fully accessible,
- a limited curriculum that does not prepare them for vocational training, or an integrated life in the wider community.

Many of these barriers can be overcome through deliberate policy, planning, implementation strategies and allocation of resources to include children and youth with disabilities in all national education development initiatives.

The UN Millennium Development Goal (2000) concerning education states that :

“By the year 2015, children everywhere, boys and girls alike, will be able to complete a full course of primary schooling, and that girls and boys will have equal access to all levels of education.”

The Millennium Development Goals, as with so many mandates before them, did not make specific reference to children or adults or any persons with disabilities.

In the new regional Framework that has been developed to guide action on disability policy and implementation in the next Asian and Pacific Decade of Disabled Persons, 2003 – 2012, the targets set in the seven priority areas for action, explicitly incorporate the millennium development goals to ensure that concerns relating to persons with disabilities, become an integral part of efforts to achieve these goals.

Education is one of the seven priority areas identified for further action, because of the critical concern at the very low rate of enrolment in education of children with disabilities, in the region, at the end of the first Decade.

The Biwako Millennium Framework for Action towards an Inclusive, Barrier-free and Rights-based Society for Persons with Disabilities in Asia and the Pacific, was presented for adoption by Governments of the region at the High-level Inter-governmental Meeting to conclude the Decade, held in Otsu in Japan in October 2002. The following targets have been set, and 14 actions identified, to help achieve them.

1. By 2010, having at least 75 per cent of children and youth with disabilities, completing primary schooling.
2. By 2012, all infants and young children with disabilities, will have received early intervention services, with support for their families.

Many of the 14 actions include measures that must be taken by Governments, as given below:

- Governments need to pass laws to make it compulsory for all children, including children with disabilities, to attend school. The laws must be enforced and children with disabilities included, in national EFA plans.
- Educational policy and planning should be developed which enables children to attend local primary schools. Schools should be prepared for changes to the education system, with the clear understanding that all children have the right to attend school and it is the responsibility of the school to accommodate differences in learners. Families and organisations of people with disabilities and communities should be consulted.
- Adequate funding must be allocated within the education budget. Education of children with disabilities, is not an act of charity, but an obligation of Governments.
- A range of educational options needs to be available.
- Comprehensive data needs to be collected and used, to plan appropriate services and support systems (Early intervention).
- Five year enrolment targets need to be set and monitored.
- Services for early detection, identification and early intervention are needed, with collaboration between all concerned Ministries, communities and families of children with disabilities (community based services).

- Families of children with disabilities, need to be made aware of the right of their children to attend school, particularly in poor and rural areas.
- Many measures need to be taken to improve the quality of education in all schools for all children, including children with disabilities in special and inclusive educational contexts.
- Barrier-free schools and accessible transport.
- Research into effective school management and teaching methodologies.
- Organisations of and for people with disabilities, need to place advocacy for the education of children with disabilities, as a high priority item on their agenda.
- Regional cooperation needs to be strengthened, to facilitate the sharing of experiences and good practices, to support the development of inclusive initiatives.

The actions that need to be taken are clear. Evidence from the Decade suggests, that Governments are beginning to pay more attention to the issue of educating children with disabilities. But the pace is too slow and sustained advocacy is needed. Who will speak for children with disabilities? Unable to advocate for themselves, they are the most vulnerable group of persons with disabilities, the most dependent on others to uphold their human rights, including their right to education.

The international community is increasing its efforts in this area, with a working group that has established a flagship within the global “education for all” effort that would focus on the educational needs of children, youth, and adults with disabilities, in developing and transition nations. The flagship is entitled the “EFA Flagship on the Rights of Persons with Disabilities: Towards Inclusion.” This name was chosen to stress that education is a human right for all, and that “inclusion”, is a primary goal of education strategies and settings.

We are moving to a point where our goal is an inclusive, barrier-free and rights-based society. We want disability issues included as an integral part of all national development policies and plans. We want policy developed in full consultation with representatives of organisations of disabled persons. So, perhaps it is time for organisations of disabled persons to take a leadership role in advocating for the education of all children with disabilities, and place the achievement of this goal as a priority item on their advocacy agenda. An example from Fiji will illustrate the powerful effects that can be achieved.

In 2001, Fiji Disabled Persons Association (FDPA), with the weight of DPI Oceania behind it, challenged the Government’s position on education of children with disabilities, on the basis of the Constitution. The result was the explicit inclusion of children with disabilities in national EFA plans. The Fiji Social Justice Act, 2001, addressing the issue of students with special needs, resulted in a blueprint, ratified by the Government. It established a Special

Education Section within the Ministry of Education, an infrastructure committee to address access issues and teaching resources, curriculum strengthening to meet the needs of all students, community awareness and family support programmes, support for inclusion of children with disabilities into mainstream schools, and strengthening of special schools as appropriate, review of early intervention strategies, teacher training curriculum development and strengthening of vocational training in collaboration with relevant stakeholders, including people with disabilities and the private sector. The extent to which these outcomes were influenced by the fact that the Chairperson of FDPA and Vice-Chair of DPI Oceania had a Master's degree in Education, is not known. It is a strong argument for ensuring that more children with disabilities have the opportunity to attend not only primary school, but secondary and tertiary education as well. We need more leaders with knowledge, expertise, commitment and advocacy skills, to safeguard the future of our children.

Education needs to become a priority agenda item for all organisations of disabled persons in developing countries. The future of disabled children is a cross-disability issue. Parents and families of children with disabilities need to be welcomed by, and to work in close association with self-help organisations. The voice of children with disabilities must be heard.

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DEVELOPMENTAL ARTICLES

**GENDER AND DISABILITY IN THE ARAB REGION: THE CHALLENGES
IN THE NEW MILLENNIUM**

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ABSTRACT

Many women are discriminated against because they are women. Having a disability compounds this gender-based prejudice. Women with disabilities in many regions of the world including Arab countries suffer from this double discrimination. The study upon which this article is based analyzes the status of Arab women in general, gender relations in the Middle East, and the situation of Arab women with disabilities, based on available disability statistics from a few selected countries and the author's observations during her 13-year living experience in Baghdad, Amman, and Beirut.

INTRODUCTION

The status of women varies from one society to another; however, everywhere disability poses additional challenges for women. In conservative societies where the status of women is relatively low, it has a particularly negative impact, creating more challenges in their daily life.

Although state sponsored education accompanied by industrialisation, urbanisation and globalisation has played a major role in creating a generation of more assertive and independent Arab women, the integration of Arab women in this relatively conservative society is still in its formative stage in the new Millennium. For instance, in the industrial sector, Arab women have some of the lowest participation rates in the world. Some Arab countries have made good progress during the last few decades. For instance, during the period of 1990-2000, in a tiny Gulf country, Oman, the country's female adult literacy rate almost doubled from 38 % to 62% (1). In 2000, the total fertility rates for women in the Arab region ranged from 2.3 (Lebanon) to 7.6 (Yemen) just to indicate the difference among individual countries, in contrast with the world average (2.8 per woman) and the average of industrialized nations (1.7 per woman) (1) The birth rate in Arab families remains relatively high, as children are considered to be valuable. The reproductive function of the Arab family, and particularly of Arab women, thus remains one of the most important functions.

Regarding literacy, adult literacy levels among Arab men continued to be higher than women. For instance, in Egypt, in 2000, female literacy rate was only 44 per cent compared to the male literacy rate of 67 per cent. Illiterate women are over-represented among older women in the region (1).

Recently there has been a significant increase in the number of Arab women participating in all levels of education in the Arab region. In this regard, Lebanon, Egypt and some liberal Gulf countries are pioneers in setting up educational systems integrating women. In fact, in some oil-rich Gulf countries, such as Kuwait and Bahrain, women's enrollment rate in higher education is higher than that of men. In Kuwait, in 1998, for every 100 boys, 214 girls were enrolled in higher education including universities (2). The oil money might have been the turning point for the Gulf countries. Educated women are more conscious of their human rights and more courageous in demanding them.

A gradual but steady increase in Arab women's participation in the labour force has also been witnessed in the last few decades. Their participation in formal employment has played a major role in changing status and gender relations. On the other hand, the dual functions of working mothers have imposed psychological pressure on them, as they have to cope with more than one role.

Generally, Arab women tend to get married much earlier than their male counterparts and they tend to get married to older men. Before, the early marriage of girls used to be an indication of the lower value of girl's education vis-à-vis other priorities which can be achieved through early marriage. First of all, it protects a girl in the traditional Arab culture, which still values "family honour". In poor families, the marriage of daughters reduces the financial burden of her family and eases their responsibilities. Another important factor is that a new family would become another source of "Arab Children" to enrich the nation's population. In war torn countries, some have encouraged births in a state of political tension or armed conflicts (e.g. the outbreak of the Gulf wars and continuing tensions, and the Israeli occupation of Palestine). Of course, in line with the changing role of women, changes in patterns of their marriage and life style emerge. However, new options and chances are open to the small proportion of the female population; namely the urban female population of the middle or upper middle class.

The situation of Arab women with disabilities is not changing at the same rate and often their problems are compounded by the traditional and impoverished segment of Arab society in which they live.

LITERACY AND EDUCATION OF WOMEN WITH DISABILITIES

According to the official statistics, a while ago, in Syria, only 20 % of women with disabilities were literate, compared to 66% of the total female population who are literate and 40% for

men with disabilities (who are literate). In Bahrain, only 12% of women with disabilities were literate, in contrast with 59 % of the total population of Bahraini women, 79% of the total population of Bahraini men, and 36% of Bahraini men with disabilities. Literacy among women with disabilities was far lower than that of men with disabilities. On the other hand, in both countries, the percentage of women with disabilities who completed higher education was only one-third of the equivalent rate of men with disabilities. The gloomy picture is almost the same as of today (3).

According to a study in Lebanon, within households where more than one person is disabled (these households are quite common in Lebanon and other Arab countries due to common practice of kinship marriage) a disabled son is treated differently from his disabled sister. He is sent to school and she is not. One such example is a case of a brother and sister, both with motor disability. While the family managed to secure a wheelchair for the son, no such efforts were considered necessary for his sister (4).

EMPLOYMENT

Employment and income security are prerequisites for living a dignified life. However, Labour force participation of Arab women with disabilities is still very limited. For instance, according to the national census, a while ago, the "active" Kuwaiti women with disabilities was only 2 % compared to 10 % for the total Kuwaiti women, 20 % for Kuwaiti men with disabilities and 67 % for the total Kuwaiti male population. However, out of the 98 % economically "inactive" female population with disabilities, 20% are homemakers. This category of women with disabilities may well be involved in some kind of productive and meaningful activities at home (3).

The rate of 2% active women with disabilities looks hopeless. However, among economically active women with disabilities, 52 % were employed in professional and technical fields, and 35 % were in the clerical field. On the other hand, Kuwaiti men with disabilities tend to be employed in the field of services (38%), clerical work (25%) and labourers (16%) (3).

This gender-based difference may be a characteristic of oil rich Gulf countries where though a tiny portion, the majority of employed women with disabilities are in professional categories, with a high percentage of them earning good salaries and maintaining good social prestige. These relatively privileged Gulf women with disabilities may work for human dignity, personal satisfaction, intellectual stimulation, social prestige, and her own personal development, etc., for compound reasons. On the other hand, there seems to be more pressure on Gulf men (with or without disabilities) to earn an income, no matter what

occupations are available to them. Whether this is right or not, sometimes, a Gulf woman with disability and with a high academic background holds a unique position and develops her career on long-term basis. She can find a niche in this rather traditional society.

On the contrary, in resource poor non-oil producing and labour exporting Arab countries, such as Jordan and Egypt, the vocational training of women with disabilities must be accompanied by an immediate incentive of income generation upon completion, in order to invite support and cooperation from families who might otherwise be reluctant.

In Lebanon (resource poor non oil producing country), women with disabilities feel that the vocational training courses offered to them are too traditional and of questionable value. Even in this relatively modern Arab country, there is a strong assumption that it would be appropriate for women with disabilities to learn sewing and cooking and for their male counterparts to learn computer skills and electrical engineering, etc. It is very difficult for educated and trained Lebanese women with disabilities to attain respected positions in the private or public sector. Those few lucky ones who are able to find jobs often report discrimination in salary, and verbal, physical and sexual harassment at work and in public transportation. When active Non Governmental Organisations (NGOs) lobby for recruitment of people with disabilities in the government or private sector, the majority of recruits are men, and with very few women benefiting from employment mainstreaming.

MARRIAGE AND SEXUALITY

Arab women with disabilities face more discrimination and difficulty in marriage. The only exception to this practice is the case of very mildly retarded women. Men may accept a young and pretty mildly retarded woman although women tend to refuse marriage to a mentally retarded man

According to the statistics in Jordan, a while ago, 62% of women with disabilities were single, 18% widowed, 16 % married and 3 % divorced. In Jordan, the ratios of the percentage of divorced Arab women with disabilities and of widowed women with disabilities, to the corresponding percentages for men with disabilities were extremely high (3 times and 6 times respectively). In the case of deaf and non-verbal persons, the rate of divorce is eight times more for women than men. This is a common phenomenon for women with all categories of disability and all countries in the Middle East. Some literature has confirmed this statistical trend (3).

Percentage distribution of people with disabilities by marital status, 1983, Jordan

Marital status	Total No.of women with disabilities	Total No.of men with disabilities	% of Deaf and mute men	% of Deaf and mute women
Single	62%	59%	67%	73%
Married	16%	37%	31%	15%
Divorced	3%	1%	0.4%	3%
Widowed	18%	3%	2%	9%

In the Arab region, marriage of women with disabilities is described as "very problematic", particularly when there is a doubt about a "genetic" cause for a disease such as muscular atrophy. For such women it is easier to find a partner in the West, where friendship and affection is more valued as the basis for marriage.

Arab women with disabilities are denied the most fundamental human rights including the right to love. Society in general fails to recognise the sexuality of women with disabilities and discourages the expression of their sexuality. In some cases, some parents have taken care of their disabled girls with affection and devotion through early childhood and often are astonished to find signs of adolescent sexuality later. They tend to over-protect them from aspirations that may not be achieved in the Arab world, even in the new millennium.

IMPACT OF ARMED CONFLICTS ON ARAB WOMEN WITH DISABILITIES

Several countries in the region are war-torn or under civil unrest. For instance, from the perspective of Arab people, Palestine is regarded as an occupied territory by Israel. In this society, traditionally, disability has been considered to be shameful. However, negative perceptions of physical disability were changed first during the Intifada, the mass uprising of Palestinian people in 1987 and the continuing resistance. The issue of disability became an important political agenda all of a sudden. Retaliation by the Israeli military on Palestinian young men and teen-age boys throwing stones caused a sudden, huge increase in the number of people with permanent physical disabilities. The group most affected was youth who now suffered permanent physical disabilities. Though disability had a stigma before, it now became heroic, as a symbol of active resistance to the occupation.

The subsequent quick spread and development of rehabilitation services for people with physical disabilities in the West Bank and Gaza is a result of the emerging number of Intifada

war veterans. However, this politically high profile event now gave people with disabilities a different focus to the physical injuries of young war veterans. Disability was now perceived as "martyrdom", where young men sacrificed their lives to live in wheelchairs. This new focus diverted attention away from women with disabilities who suffered equally from the civil unrest. It also worked against those women and men with congenital and non-physical disabilities, such as mentally retarded women.

SOME CHALLENGES AND GOOD PRACTICES

Mainstreaming disability concerns

The issue of Arab women with disabilities should be tackled within the overall framework of women's development in the Arab world. Mainstreaming of Arab women with disabilities in education, training and employment should be a priority action. Many disability activists in Lebanon felt that mainstream women's movement in Lebanon failed to incorporate concerns of women with disabilities, and concurrently the weakness and immaturity of the mainstreaming women's movement in the country is limiting advancement and social integration of women with disabilities. However, some organisations such as the Youth Association of Blind in Lebanon is pursuing the disability mainstreaming strategy in order to legitimatise their cause and contribute to the diversity and also balance and strengthen the mainstream women's movement in the new millennium. These young assertive women with disabilities believe that the Lebanese women's movement and the disability movement have both gained increased visibility and empowerment through networking and alliances across the sectors, overcoming political differences.

Mainstreaming gender

Not many activities in organisations of people with disabilities or self-help groups in the Arab region have been exposed to the concept of gender mainstreaming or gender training. There is a need for gender training and capacity building. A number of leaders and associations have started seeing it as the top priority to improve their organisation's visions and programmes in the new millennium. The Lebanese Sitting Handicapped Association is a pioneer for instance in Lebanon, to initiate gender training and capacity building within the civil society of people with disabilities. They have organised computer training courses and more than 50 Lebanese women with disabilities were trained, in a mainstreaming setting together with men. Upon completion, they have lobbied for the recruitment of 27 women and 28 men graduates with the Ministry of Communication (5).

Information Technology

Recent technological advance with regard to Information Technology and globalisation in the Arab region have motivated the United Nations ESCAP disability programme to empower

women and men with disabilities. ESCWA is an active UN agency to promote minimising the existing gender-divide of Information Technology among people with disabilities. ESCWA is challenging the stereotypes about what is "appropriate" training and employment for Arab women with disabilities. They aim to encourage the active participation of women and men in the use of the Internet, e-commerce, virtual learning and e-livelihood. The organisation's activities aim to raise public awareness and to improve access to all types of electronic information for Arab women and men with disabilities. ESCWA implemented its first regional training centre for Braille computer, targeting blind girls and women, in the period of 1996-1999. The Centre is still highly regarded in the Arab region and the project was replicated in many places. In the New Millennium, in 2001, the second phase project to promote accessible Information Technology was launched. A new training Centre for Arabic Braille computer with link to Internet and Arabic speech synthesizer was opened in Beirut, with priority given to blind girls. A regional on-line electronic Braille documentation centre will complement this facility and blind Arab end users (from remote or conservative communities) will have full online access to Arabic/English documentation Centre. The majority of beneficiaries of this project are Arab women.

Public awareness

Arab women with disabilities are under-enumerated due to prevailing negative social attitudes. Also, available literature on gender and disability is limited. Public awareness of capabilities and dignity of women and men with disabilities should be boosted and their social integration should be promoted. Recently, some TV companies in Egypt and Lebanon, such as Future TV in Lebanon, have begun to be pro-active to promote the positive image of Arab women with disabilities, not through the traditional method of focusing on individual problems and needs but through mainstreaming them in dramas, comedies, and other entertainment TV programmes.

Disability prevention and kinship marriage

Kinship marriage which still prevails in the Arab region in this new millennium is a negative socio-cultural factor for inherited disabilities. In Jordan, the rate of consanguinity is about 50%, even in this new millennium. It was reported by Janson Staffan that kinship marriage rate of 67% in the experiment groups of parents with severely mentally retarded Jordanian children was higher than the national average (50%)(6). Even in liberal Lebanon, in 1990, 20 % of ever-married women and 24% of illiterate women liberal Lebanon were married to close relatives.

It is important to alert public opinion to the danger of intermarriage among close relatives. Education of women should be further emphasised as it has proved more effective than

educating men of the harm cause by consanguineous marriages. A new, open minded, yet culturally balanced genetic and sex counseling method should be developed and such services should be made available.

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PARTICIPATION IN COMMUNITY BASED REHABILITATION PROGRAMMES IN ZIMBABWE: WHERE ARE WE?

Myezwa H*, M'kumbuzi VRP**

ABSTRACT

Primary health care and community-based rehabilitation emphasise community participation. Many health care and community programmes attempt to develop participation. However, insufficient analysis of the processes of participation has taken place. This paper presents preliminary observations of participation in Community Based Rehabilitation (CBR). Based on the experiences of the two authors in implementing over 20 CBR programmes in Zimbabwe, the paper identifies the type and development of participation within CBR. It is hoped that lessons can be drawn from the experiences of the CBR process in Zimbabwe and further questions can be asked, to help develop a conceptual approach for planners and implementers working with communities.

INTRODUCTION

Community based rehabilitation is a process of empowering persons with disability (PWD) and their families, to take care of their needs in every sphere of their lives (1). This implies that PWDs and their families have a key role, which will require participation to a greater extent, in various processes of CBR.

A whole range of interpretations of participation has been reviewed. It has been proposed that participation exists at a series of levels ranging from information giving to initiating action - true empowerment (2, 3, 4). A review of the literature reveals interchangeable use of the terms “community involvement” and “community participation.” While community participation was the term used in the original Alma-Ata document of 1978, community involvement is now the preferred term because, “to participate may be simply a passive response” (5).

Compliance, contribution and collaboration are other descriptors used, to outline the linear process of community participation/involvement from a one-way process of receiving information, or nothing at all, to control and collaboration with other key players, for all decisions (6).

Nevertheless, the essence of community participation has been described as highlighting principles of inclusion and “starting where the people are”, in terms of their perceived needs, rather than with the needs and goals of the change agency (7). Genuine involvement in the social change process is important, because participants become empowered by their ownership of the programme. Several authors view community involvement as a means of empowering communities (5, 8, 9, 10).

Implementers in CBR, recognise that community participation is in a dynamic rather than static state. After reviewing a number of programmes, it was concluded that people in the same programme over a period of time and with increasing experience, might not hold the same definition today, as they did five years ago (11).

In implementing CBR in Zimbabwe, there has been no attempt to define community participation, but rather, efforts to identify the fundamental principles that would underlie community participation and ensure that the programme embraced them. These included not just a commitment of professionalism and expertise, but a move back, to fundamental principles such as:

- An effort to remove the blinkers that professionalism has imposed upon individuals.
- A dismantling of the structure whereby others within the community have come to have more power over the PWDs, than they have over themselves. For example, in the past, the PWDs were often dependent on visits to the institution-based service for treatment and the professional determined the progress.
- A practice of CBR wherein a concerted effort is made towards empowering the client, the family and community, in dealing with the problems of disability.
- The efforts in shifting the power base to community level and trying to make the system and structures support these efforts. Examples include the legal, para-legal and social systems.
- The financial base in CBR remains largely at district and provincial level and therefore, innovative ideas on how to effectively shift some resources to the community level, are still needed.

THE CBR PROCESS

The process of community based rehabilitation emphasises integration and provides an opportunity for people with disability to have full participation and equalisation of opportunity within their society (1). During this process, the people with disability are exposed to day-to-day risks. This equips them with confidence and teaches them skills to negotiate and overcome problems and achieve their own rehabilitation through self-help.

The major steps followed in the implementation of CBR in Zimbabwe were:

1. Social mobilisation and awareness raising

The process of social mobilisation began by informing the community on the use of existing community channels and structures. This often involved meetings between rehabilitation staff and chiefs, councillors or other political leaders, and attending various development meetings, where the required special arrangements were made. For example, the sensitisation of PWDs', their families and other community support systems, schools, and community workers commenced at individual treatment contacts and in the home. Following this, needs could be identified and training programmes planned.

2. Education and training

The need-based training of community based workers such as village community workers (VCW), community health workers, family members, the person with disability, community members and community leaders was carried out. The areas of concern most often were education on the types and causes of disability, and training in the processes and interventions involved in rehabilitation. A key component in the training methodology was to inspire positive attitudes toward PWDs.

3. Survey and needs analysis

After training the key players, a rapid assessment of the status of disability and the situation of disabled persons was conducted. This survey was carried out by community workers selected by the community. They used screening tools that were developed and refined jointly with the professional rehabilitation staff.

4. Implementation

Examples of some activities to meet the identified needs include:

- Client, local facilitator, therapist and technician training sessions.
- Income generating facilitation either directly through community based health workers, such as environmental health technicians and extension workers from other ministries or departments.
- Home visits and outreach consultations to take care of individual needs and reassessments of chronic and new referrals.
- Regular attendance of inter-sectoral and development meetings by clients, VCWs and periodically, technical rehabilitation staff, to allow facilitation of developmental issues for PWDs.

- Referral of clients in need of services not available in the community, such as audiology services and orthotic and prosthetic fittings.

PARTICIPATION IN CBR

The process of rehabilitation includes prevention, identification and referral, treatment, resettlement and integration, vocational training and the provision of aids and appliances. Planning of implementation and evaluation must be synchronised at individual and community level, for a successful rehabilitation outcome.

One of three types of participation could be chosen during the different stages of CBR namely, compliance, contribution and collaboration. While collaboration was the desired type of participation, it became evident that communities found the contribution type more tangible and hence, more meaningful type of participation. Often, this was in the form of labour contribution, and on occasion, took the form of material resources.

Participation in identification and referral

In the past, one of the problems for rehabilitation and dealing with disability, was the lack of knowledge on the part of the community, more specifically, the community health workers. The emphasis on prevention of disability, early identification and intervention in primary health care (PHC), will not only reduce the incidence of disability, but will also reduce the prevalence and intensity of disabling and handicapping factors. Early intervention also encourages an early integration process, which helps to reach the ultimate goal of the rehabilitation process (12). After the intensive education and awareness programme, these same community members continue to play a vital role in the identification and referral of PWDs. Forty-one percent (n=100) of clients presenting themselves to rehabilitation departments in the Mashonaland Central province of Zimbabwe, were found to have been referred by the community health worker (10).

Participation in CBR programme planning

A CBR programme gives the community an opportunity to develop an awareness on:

- Development needs of disabled people.
- Skills PWDs need to acquire, in order to cope with their physical, psychological and environmental problems.
- Knowledge regarding the methods, process and advantages of integration. This continuous realisation by the community and family is paramount to the success of CBR, because disability is not a static situation. "...Disabled children become disabled adults with great vulnerabilities and needs... CBR can evolve and adapt to such fluid situations,

while the rehabilitation centres will often only be able to “take a photo” i.e. deal with one set of problems at one point in the life of a disabled person” (13). However, our experience in implementing over twenty CBR programmes shows that once they were aware, the community participated actively in planning, by defining the parameters, both geographical and at times, programme design. The community would through discussion, identify implementers, participants and priority areas. The community leaders would participate in awareness raising and community mobilisation, before the community and facilitators could start active implementation of the programme.

Participation in programme implementation

In CBR, the person with disability and his family, are expected to take the leading role in determining the key objectives of their rehabilitation process. For example, in identifying the problems faced by the PWD, the professionals’ role would be one of guiding the process and teaching the family and client, simple and appropriate technologies for coping with disability. The areas of guidance expressed by the community in the national evaluation in Zimbabwe, were:

- Materials and financial support.
- Assisting in running income generating projects.
- Identifying and referring PWDs.
- Moral support.
- Motivation of the community by local leaders.
- Setting up of community centres for self help activities (14).

Thereafter, the family and client determine where and when, to get subsequent assistance. The focus is being, to minimise the dependency on the professional, allow active participation of the PWD and family, and through these activities facilitate ongoing and sustainable rehabilitation.

Participation in programme evaluation

The direction of CBR is determined by the ongoing evaluation carried out by the family, client and community. In CBR, it is hoped that participation will be enhanced if the clients and community see that the progress and direction of the programme is determined primarily by their inputs. In the process of CBR, focus group discussions are held regularly with community workers, family members and with clients themselves, to gain an insight and to provide inputs on what they perceive as key problem areas. In this process, some of the obstacles to CBR become apparent.

OBSTACLES TO PARTICIPATION IN CBR

In the process of CBR implementation, it was anticipated that collaborative participation would occur. However, some issues, which hindered participation, became apparent in the process.

The poor knowledge of CBR: The historical background and orientation of most communities with regard to disability was that of disabled people being objects of charity, looked after in institutions, away from the community and in many cases, hidden away from the public eye. This discouraged the concept of empowerment and self-help, of both the community and individual, and discouraged participation of community members in their programmes.

The cultural orientation with regard to disability: The cultural beliefs with regard to disability did not encourage a positive outlook towards people with disability. The person with disability has always been considered as an outcast as evidenced by the episodes of the hidden child or member of the family, and the attitude of, “not worth investing in”. The parents in most rural areas of Zimbabwe and elsewhere in Africa, will educate their child with the expectation of gain, once this child is gainfully employed in adulthood.

Expectations of the community: Most communities still had expectations based on previous beliefs, experience and exposure. Disability has always been an area well endowed with charity and handouts. This has generally efficiently killed any element of self-help reliance and involvement in programmes by the person with disability and their family. It was extremely difficult to convince the people with disability and their family to participate in CBR, in areas where organisations with a charity orientation had previously operated, as they openly expressed the preference for the “easier route” i.e. “handouts”. Other authors have also alluded to this culture of dependency, where communities expect charity, rather than empowerment (8).

The poverty within communities: For most rural people, survival is their greatest challenge (2). This was found to consume most of their energies, leaving precious little time to participate in community development programmes.

The social environment: Health and social problems such as communicable diseases, HIV, poor sanitation and hygiene proved to be obstacles for participation in community development issues, including disability issues. Most key people, with influence in the direction of community participation, would invest energy dealing with one or other of these overwhelming problems. From personal experience, where community workers or parents and family, would, in the past, spend some time participating in CBR, their time was now occupied, in some cases, with social obligations such as attending funerals and in a drought situation, looking for alternative sources of food.

Health workers' attitudes: Health workers, by virtue of their training orientation and the paradigm within which they work, often wittingly or unwittingly find themselves assuming a position of authority. It has also been observed, that some health professionals find developments in promoting participation threatening, while others find them irrelevant and a matter for scorn (15). In CBR, education for the professional in order to overcome some of these attitudes, which hinder progress, have been integral parts of the programme.

The health organisation orientation: Until recently, the health departments' organisation was largely centralised and only now, with the advent of decentralisation in Zimbabwe, does the organisational structure go some way towards supporting participation.

In spite of all these obstacles, seen as a real hindrance to community participation, successes have been observed. However, in these circumstances, issues that emerged impacted negatively on the CBR process itself.

EMERGING ISSUES AGAINST PARTICIPATION IN CBR

The authors' experience has shown:

- The risk of providing substandard service due to the decreased use of professionally trained workers, exists. As illustrated by one VCW " *You cannot expect us to be precise on things we learnt without background training...* ".
- A dilution of quality and poor rehabilitation outcomes may result. The stated objectives in CBR need to be closely monitored and more so, the systems put in place, to fulfill these objectives. Community members were in most cases, perhaps ill equipped to cope with this aspect, which requires both skill and experience. In the management of CBR, this was true for trained personnel and therefore, to a greater extent, the community members.
- A dilution of the benefits and advances in technology occurred in the course of translating the technology into simple technical terms, to be implemented by families and grassroots level workers.
- The existing infrastructure in the various implementing agencies such as health and social welfare, in some cases, have not been ready to integrate CBR. This has affected the participation of clients and key facilitators such as community leaders as well as the health workers themselves. Furthermore, multi-sectoral decentralisation was inadequate at the grassroots level and this seemed to hinder participation in a broader sense.

ARGUMENTS FOR PARTICIPATION

The broader arguments for participation have been grouped under the following:

- Efficiency,
- Effectiveness,
- Self- reliance,
- Coverage,
- Sustainability (2).

The authors have looked at each of these arguments for participation and attempt to describe the extent to which they have been fulfilled, in CBR.

Efficiency

Participation implies a greater chance that resources available to any development project will be used more efficiently (2). In the authors' experience, the participation of one group in CBR has often saved the staff from explaining or lobbying for a programme in an area of need. This is because the communities often see the area where the programme has been implemented as a paradigm. Community members already involved, often act as educators for new areas and hence catalyse the process.

The participation of the client, family and community in the programme, allows them to take responsibility for the programme and the needs of PWDs. This, therefore, allows the professional staff more time to deal with other areas of need. The trade-off however, is that the government may then start to allocate less resources and time, to community based development work because of the perceived saving. This places the burden of the CBR programme costs, squarely on the local community and in particular, on the family and PWD and thus endangering sustainability.

Effectiveness

Many evaluations have shown that CBR has been instrumental in dealing with a large number of the problems faced by PWDs (10, 14). After implementation of CBR, PWDs have perceived a more positive attitude towards them by the community, and have reported physical and functional improvement and the ability to sustain this improvement, in the home or community. Also of interest, is the progress in the objectives which involve the larger community, such as accessibility to schools and other community amenities.

Self Reliance

Self-reliance has been described as referring to the positive effects of participation in development projects, on rural people (2, 11, 16, 17). Participation helps to break the mentality of dependence, which historically characterised much development work. It also promotes awareness and self-confidence and encourages rural people to examine their problems and to think positively about solutions (18). Participation is therefore, concerned with human development and increases peoples' sense of control over issues, which affect their lives. This helps them to plan and implement programmes and prepares them for participation even at national and regional levels.

In the CBR programmes that were evaluated, many people with disability reported a sense of control that they did not have before. Even where the disability was severe and irreversible, the client and his/her family expressed a sense of control and self-sufficiency, where the necessary support for them was available, when sought.

Coverage

There is no doubt that the process of CBR has increased coverage and more people have access to services, that were previously available only to those residing in the cities and urban areas. This is evidenced by the growth of rehabilitation services from nine departments in the cities in 1980, to sixty in the year 2000. Forty-five to sixty percent of all geographical wards in the sixty districts in Zimbabwe, have been covered by CBR (14).

Sustainability

Experience suggests, that externally motivated development projects frequently fail to sustain themselves, once the initial level of project support or inputs diminish, or, are withdrawn. Participation is seen as being able to counter this (2). In CBR, sustainability is seen through the ability of the community and family to maintain the delivery systems and to maintain the status of community awareness and involvement in disability issues, with little, or no external support. Currently, the CBR programme is over thirteen years old in Zimbabwe. Its continued existence and activity is still very dependent on external inputs, albeit, with a different focus to the original role played. The question asked in CBR is: Are community programmes sustainable, if left entirely alone? Or, is the input of external catalysts necessary, provided their role does not remain static, but changes to suit the stage of development of the community?

CONCLUSION

Sustainability and community participation are linked strongly by the literature. The arguments that link sustainability with participation are largely economic i.e. "the maintenance of an acceptable flow of benefits from the project's investments after its completion" (2). Some include project ownership, political support, and/ or the maintenance of delivery systems. In

CBR, all these things are crucial to meeting the multifaceted needs of the person with disability. The flow of benefits can be both material, but other qualitative benefits are of significant importance for the sustainability of the programme (10, 14). One notable benefit that has been observed, is the sustenance of good and positive community attitudes in promoting community participation and sustaining CBR.

In conclusion, there are two points made by the authors. Firstly, that although some authors believe that it is difficult to tell whether genuine community participation has been initiated (19), it has been found that the communities' participation in CBR is clear, as far as the family and the community workers are concerned. The difficulty arises from the many grey areas in translating this participation to the entire health system and the total CBR programme.

Secondly, do community leaders and the systems of community development including health, really embrace participation into the mainstream development? The understanding of the types and process of community participation will be enhanced by an in depth analysis of specific systems within the CBR process.

Finally, the authors propose that planners and implementers of CBR need to develop a comprehensive model of enhancing community participation around three sets of fundamentals described in this paper. These are:

- The obstacles to participation,
- The emerging issues against participation,
- The arguments for participation.

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ORIGINAL ARTICLES

**FUNCTIONAL PERFORMANCE, DEPRESSION, ANXIETY, AND STRESS
IN PEOPLE WITH SPINAL CORD INJURIES IN THAILAND:
A TRANSITION FROM HOSPITAL TO HOME**

Pisak Chinchai*, Ruth Marquis, Anne Passmore

ABSTRACT

The numbers of people with spinal cord injuries (SCI) in Thailand are on the increase. Thai traditional rehabilitation focuses its treatment in acute care with little attention to the lives of clients after their discharge from institutions. In addition to functional disability, emotional states of depression, anxiety, and stress are often involved in SCI. The purpose of this study is to identify and compare the outcomes of functional performance, depression, anxiety and stress of people with SCI, both at discharge and at post-discharge from hospital. It also identifies factors influencing these issues, for this group. The study participants were 121 people with SCI, recruited from ten major hospitals in Thailand. Data was collected at 48 hours pre-discharge and again at three months post-discharge, using the Functional Independence Measure (FIM) and the Depression, Anxiety, and Stress Scale (DASS). The results demonstrated that functional performance at discharge was significantly higher, than at three months post-discharge. Depression and anxiety at discharge were significantly lower than depression and anxiety at three months post-discharge. However, stress had not significantly changed from discharge to post-discharge. Factors influencing functional performance were marital status, number of architectural barriers, fulfilment of occupational therapy (OT) needs, and the number of service needs remaining unmet. Factors influencing depression, anxiety and stress were marital and economic status, education level, fulfilment of OT needs, and numbers of service needs remaining unmet. Rehabilitation professionals can eliminate these problems by bridging the gap of transition from hospital to home, for people with SCI.

INTRODUCTION

The number of people with spinal cord injuries (SCI), is increasing in Thailand (1, 2). These people are generally admitted for rehabilitation mainly for motor function training (3). The

role of health providers, such as occupational therapy (OT) professionals, is to support each person with disability, to resume living their life as normally as possible, within the constraints of disease or the aftermath of trauma. In this sense, “living,” involves functional performance (4). The principal measure of functional performance relevant to medical rehabilitation is the ability to perform activities of everyday life (4, 5). In addition, early studies identify that adjustment to SCI is accompanied by depression, anxiety, and stress (6, 7, 8, 9). Kennedy and Rogers (7) stated that there were as many as 100 per cent of people with SCI in their study, suffering from deep depression and anxiety. Therefore, functional performance and the emotional states of depression, anxiety, and stress as rehabilitation outcomes, are important issues for rehabilitation professionals involved in service delivery.

Factors considered most relevant to rehabilitation outcomes in people with SCI, include various personal, medical, and environmental components (10, 11). These factors as independent variables in this study, can be classified into five dimensions, including socio-demographic, disability-related, environmental, interface, and service related variables. Table 1 summarises the factors associated with each dimension, adapted from the model proposed by DeJong et al (10).

Table 1: Model of factors influencing rehabilitation outcomes of people with SCI (10)

Outcome variables	Independent variables				
	Socio-demographic	Disability-related	Environmental	Interface	Service-related
-Functional performance -Depression -Anxiety -Stress	Age Sex Education Marital status	Age at onset Duration of disability Communication problems Discharge status	Attendant care Housing Transportation Hospitalisation Medical supervision Services received/ needed	Unmet equipment needs	Vocational services Presence of OT needs

Data shown in Table 1 demonstrate five groups of independent variables that potentially influence rehabilitation outcomes in people with SCI (10). These variables can be explained as follows:

1. Socio-demographic data consisting of age, gender, education level, and marital status.
2. Disability-related variables consisting of age at onset, duration of disability, communication problems, and discharge status.
3. Environmental variables consisting of attendant care, as measured by the presence or absence of needed in-home assistance; housing as determined by the number of architectural barriers; transportation as measured by availability of accessible public or private transportation; assumption of the patient's role as measured by the length of hospitalisation and the degree of medical supervision; and services received/needed as determined by the number of services received and number of service needs remaining unmet. Services needed for people with SCI basically include occupational therapy (OT), physiotherapy (PT), psychotherapy, and services from medical doctors, nurses, prosthetists, orthotists, vocational counsellors, and social workers (12).
4. An interface variable measured by whether the respondents reported unmet equipment needs. This variable reflected the role of assistive devices needed to bridge the gap between functional limitations and environmental barriers.
5. Service-related variables consisting of vocational rehabilitation services received, as measured by the number of vocational services received during rehabilitation and occupational therapy (OT) needs, as measured by the presence or absence of unmet OT needs. OT interventions for people with SCI usually include activities of daily living (ADL) training, physical endurance training, prevocational assessment, recreational skill programmes, adaptive equipment for ADL, and home visiting and environmental adaptation (12).

Community integration and return to previous roles, are rehabilitation goals for clients with SCI. Achievement of such goals is known to require continued provision of services following discharge (13). In Thailand, however, emphasis on follow-up community based service is only now emerging. The major purpose of this study, is to identify and compare functional performance, depression, anxiety and stress, both, at discharge and at three months post-discharge of people with SCI. It also identifies factors influencing these issues within this group.

RESEARCH QUESTIONS

1. Is there a difference in the functional performance and the emotional states of depression, anxiety, and stress of people with SCI at discharge and at three months post-discharge from hospitals?
2. What factors influence these rehabilitation outcomes?

METHODS

This descriptive and exploratory study followed a cohort of 121 males with SCI, prospectively for three months. The primary rehabilitation outcomes included functional performance and emotional states of depression, anxiety, and stress. Based on the literature, key variables influencing rehabilitation outcomes (socio-demographic, disability-related, environmental, an interface, and service-related variables) were measured to examine their relationship to the primary rehabilitation outcomes.

Sample: Participants were recruited from rehabilitation units in ten major hospitals in northern Thailand, using purposive sampling techniques. One hundred and twenty one males between the ages of 15 and 60, with a primary diagnosis of traumatic SCI, with good orientation, and willing to participate, were selected. Subjects with additional medical problems were excluded. The majority of subjects (57 %) ranged from age 15-30 and many had completed secondary school (42.1 %). Almost half (48.8 %) of the subjects were single at the time of the accident and most (88.5 %) lived with parents and families after leaving hospitals. The main cause of injuries was motor vehicle accident (61.2 %).

Instruments: The Functional Independence Measure (FIM) is one of the most widely used instruments to measure functional performance (14). The FIM includes 18 items, each with a maximum score of 7 and a minimum score of 1. Total possible FIM scores range from 18 to 126. The intra-class correlation of the FIM is 0.96 (15). The Depression, Anxiety, and Stress Scale (DASS) was used to measure depression, anxiety, and stress (16). The DASS is a 21-item self-report inventory (short version), developed in Australia, that yields three factors including depression, anxiety, and stress. Each item was measured on a likert scale with a maximum score of 4 and a minimum score of 1. This instrument had high internal consistency for all subscales, with Cronbach's alpha ranging from 0.73 to 0.81 (16). A semi-structured interview, developed from a model proposed by DeJong et al. (10), provided measures of the independent variables. Three bi-lingual translators translated these instruments into Thai and the transcripts were compared and any discrepancies resolved. Back translation confirmed validity (17, 18). A pilot study involving 15 participants was conducted in Thailand, providing an opportunity to evaluate the accuracy of the translated questionnaires in terms of wording, assessment time, and cultural aspects.

Data collection and analysis: Data were collected in two stages. The first measure was collected at the hospitals 48 hours before discharge and the second collected in individuals' homes, three months post-discharge. A paired t-test identified differences between discharge and post-discharge outcome measures of functional performance, depression, anxiety and stress. The DASS severity ratings provided a simple means of converting raw scores to Z scores, enabling comparisons between depression, anxiety, and stress (16). There are five levels of emotional status according to the DASS severity ratings including normal, mild, moderate, severe, and extremely severe, based on normative samples.

In addition, multiple regression analysis was conducted to explore the predictive nature of the independent variables on the four outcome measures and to assess the significance and strength of these predictors. Four regression models were tested in total and the fit of these models is reported with a coefficient of determination, indicating the total variance in the outcome measures explained by the individual models.

RESULTS

1. The comparisons of functional performance, depression, anxiety, and stress at discharge and at three months post-discharge.

Assumptions of linearity, normality, and homogeneity were tested prior to statistical operation, by exploring the data and confirmed the use of parametric analysis. The effect size statistics provide an indication of the magnitude of the differences of means between groups. The most commonly used is eta squared, with values ranging from 0 to 1 (19). Cohen (20) interpreted the strength of eta squared values into three levels, .01 as small effect, .06 as moderate effect, and .14 as large effect. The larger effect sizes the better results.

Table 2: Functional performance, depression, anxiety, and stress in participants with SCI at discharge and at three months post-discharge (N = 121)

Variables	Mean (SD)		T-value	Sig. (2-tail)	Eta squared
	Discharge	Post-discharge			
Functional performance	96.74 (18.42)	91.17 (19.79)	7.02	0.00	0.30
Depression	16.13 (5.69)	19.52 (5.97)	-6.08	0.00	0.24
Anxiety	10.73 (5.01)	14.40 (4.29)	-8.75	0.00	0.39
Stress	16.20 (4.47)	17.24 (5.66)	-1.92	0.06	0.03

Results of paired t-test reported in Table 2 demonstrate that the mean of functional performance at discharge ($M = 96.74$) is significantly higher, than at three months post-discharge ($m = 91.17$) at $p < .05$. The large effect size shown by the eta squared value of .30 further supports these findings. The mean score of depression at discharge ($M = 16.13$) is significantly lower than the mean score at three months post-discharge ($M = 19.52$). This suggests that this group of participants tends to have a greater level of depression when they re-entered their community, than when in hospital settings. The large effect size shown by the eta squared at .24 indicates a substantial difference between these two means. In addition, the mean score of anxiety at discharge ($M = 10.73$) is also significantly lower than at three months post-discharge ($M = 14.40$). This confirms that these participants are not only depressed at home, but also have higher level of anxiety. The large effect size of the eta squared of .39 also supports this result. Data also reveal that the mean stress score at discharge ($M = 16.20$) is lower than the mean stress score at three months post-discharge ($M = 17.24$), but this is not statistically significant.

2. Tests of factors influencing functional performance, depression, anxiety, and stress.

Multiple regression analysis was used to identify factors (independent variables) affecting rehabilitation outcomes (dependent variables), in this study. Potential independent variables included in the final models were marital and economic status, education level, number of architectural barriers, fulfillment of OT needs, and number of service needs remaining unmet. Table 3 demonstrates variables in their abilities to predict changes of functional performance, depression, anxiety, and stress.

Table 3: Multiple regression models of factors influencing functional performance, depression, anxiety, and stress in participants with SCI (N = 121)

Variables	Functional performance	Depression	Anxiety	Stress
Marital status	-0.14*	-0.29*	-0.25*	-0.35*
Economic status	-0.08	-0.32*	-0.05	-0.24*
Education level	0.11	-0.26*	-0.38*	-0.24*
No of architectural barriers	-0.20*	0.04	0.04	0.04
Fulfilment of OT needs	0.46*	-0.19*	-0.04	-0.08
No of service needs remaining unmet	-0.18*	0.10	0.45*	0.07
R^2 **	0.51	0.59	0.66	0.42

* $p < .05$

** R^2 = the coefficient of determination

The results reported in Table 3 indicate four factors influencing functional performance. Fulfillment of OT needs had a significant positive effect ($b = 0.46$) while marital status ($b = -0.14$), number of architectural barriers ($b = -0.20$), and number of service needs remaining unmet ($b = -0.18$), all had significant negative effects on functional performance. Outcomes demonstrated that participants who had their OT needs met, had higher scores of functional performance than participants who did not have these needs met. Participants who were not married had higher scores than participants who were married. In addition, participants who reported greater numbers of architectural barriers at home, tended to have lower scores of functional performance than participants who had fewer numbers of architectural barriers. Participants who had greater unmet service needs, had lower scores of functional performance than participants who had fewer service needs remaining unmet.

The results also indicate that a person's marital and economic status, education level, and fulfillment of OT needs, significantly affected the emotional states of depression, anxiety, and stress. This meant that participants who were married had lower levels of depression, anxiety, and stress. The higher the education level and the better the economic circumstances of these people, the lower the levels of depression, anxiety, and stress. The fulfillment of OT needs also had a positive effect in reducing levels of depression, anxiety, and stress. The coefficient of determination (R^2), indicates how much of the variance in the outcome measures is explained by the independent variables included in the models.

DISCUSSION

The comparisons of rehabilitation outcomes in this study, revealed better functional performance at hospital than at home. This could be explained by the different environments between these two places. Environments at rehabilitation hospitals are designed for people with disabilities, while individuals' homes are not environmentally modified to accommodate the needs of a person with a disability (21, 22, 23). In addition, family members, relatives and even neighbours, volunteer to give physical assistance to people with disabilities, in almost all activities of daily living as a result of Thai societal expectations (22, 24). This situation results in low motivation of persons with disability, to be independent in their daily lives (25). Furthermore, Buddhism, the major religion in Thailand, promotes a belief whereby, helping others, will lead to personal benefit and this encourages able-bodied persons to try to physically assist people with disability, in order to be rewarded in the next life (26). Education and training programmes that demonstrate the value of fostering independence for persons with disability, should be provided for individuals, together with family members, neighbours and other relatives.

Comparisons of emotional states of people with SCI in this study, revealed that these participants suffered more depression and anxiety at home, than at hospital and also reported stress, both at discharge and post-discharge. However, the mean score of depression at discharge was 16.13 and at three months post-discharge was 19.52, both falling into the moderate level of the DASS severity ratings, which range from 14 to 20 (16). In addition, the mean score of anxiety at discharge was 10.73 and at three months post-discharge was 14.40, both falling into the moderate level of the DASS severity ratings, which range from 10 to 14 (16). The mean score of stress at discharge was 16.20 and at three months post-discharge was 17.24, both falling into the mild level of the DASS severity ratings, which range from 15 to 18 (16). Although scores of depression and anxiety appear to have increased from discharge to three months post-discharge, when using a paired t-test, they are still of the same level when using the DASS severity ratings as the measurement tool. However, the study provides certain evidence that depression, anxiety and stress existed, both at discharge and at three months post-discharge. This can be explained by people becoming more dependent and lacking social supports external to the family, such as work opportunity, availability of transportation and recreational pursuits, especially on returning home after institutional rehabilitation (13). A study of the personal experience of persons with paraplegia in Thailand (27), revealed that these people experienced intense grief due to the loss of their ability to walk. Chuenklin (27), stated that people with disability had depression while they were at home, because they could not perform activities properly and were frequently left alone for most of their days. In addition, most people became unemployed after sustaining a disability, that caused the loss of income to support their families (23). Occupational therapists can have a major impact in this area, by providing pre-vocational assessment to ascertain work abilities and supplying information about the issues surrounding seeking gainful employment.

In looking at factors influencing rehabilitation outcomes, the strongest variable affecting functional performance is the fulfillment of OT needs. Occupational therapy is directly connected with the day-to-day activities of people and encourages these individuals to pursue independence (28). A person's marital status and education level are strong variables influencing emotional states of depression, anxiety, and stress. People who were married, received support and assistance from their spouses and this had a positive effect on the individual's emotional status. People with higher education tended to believe that they could be independent in their lives and were more optimistic than people with lower education and this increased self-worth and decreased depression (29). In addition, educated people were more likely to be involved in community organisations and hold leadership positions and these roles increased self-esteem and helped reduce anxiety and stress (10).

In conclusion, rehabilitation professionals, policy makers and service planners in Thailand should pay attention to lives of people with disability not only in institutional settings, but also

at home and in the community. Rehabilitation services such as occupational therapy, should address the entire needs of people with SCI. Follow-up programmes from rehabilitation team members are essential to fulfill rehabilitation outcomes. Rehabilitation services need to address the key issues of reachable OT and other rehabilitation services, environmental considerations, educational opportunity, and retraining for income-generating occupations.

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**THE EFFECTIVENESS OF SELF-CARE SUPPORT GROUPS
IN THE PREVENTION AND MANAGEMENT OF ULCER:
AN EVALUATION STUDY IN ETHIOPIA**

Motbainor Abera*, Girma Lemma

ABSTRACT

A sixteen-item pre-tested structured interview was used to assess the attitude of self-care group members (n=61), involved in the self-care programme of All Africa Leprosy, Tuberculosis and Rehabilitation Training Centre (ALERT). An open-ended item for assessing the opinion of health personnel working in leprosy affiliated institutions and case-studies, was also used to collect data. Results showed that beneficiaries have a positive attitude towards the various aspects of the programme.

Health personnel also favoured the programme in many ways, despite their disappointment regarding the organisation and management of the programme. Analysis of coping efforts employed by the self-care group, revealed the importance of behavioural modification techniques, followed by the use of material sources as important strategies in the area of prevention of disability. Recommendations for future research and intervention are made, based on results obtained.

INTRODUCTION

A major issue in the treatment of leprosy, is the prevention and management of ulcers, particularly plantar ulcers (1). Plantar ulceration is a major complication of leprosy. Untreated simple ulcers will develop into complicated, chronic ulcers, resulting in bone infection and destruction, further impairment and even amputation, often with extended periods of hospitalisation (2). Even after completion of treatment, the 'care tradition' also continues through the provision of antiseptic, vaseline, bandages, wound trimming and dressing which has resulted in an increasing number of people becoming dependent on institutional based services and thereby, resulting in a big drain of resources (3).

In Ethiopia, in the course of multi-drug therapy (MDT) implementation, between 1983-1999, a total of 107,311 patients have been released from treatment as cured (4). This means, taking the average disability grade I and II (5) recorded among these people (that is 20%), other things being equal, about 21,462 released from treatment as cured, would require life-long care for the management and prevention of their ulcers. Moreover, given the current

incidence rate of leprosy in the country (0.75 per 10,000 population), about 4000 new patients are detected yearly, of whom, conservatively 18% (720) have some disabilities grade I and II. Many of these people would require the "usual" care for their ulcers, provided by the health workers from health institutions.

In response to this demand and due to the shift from bio-medical to the bio-psycho-social approach, a new line of thought emerged, as a tool to guide research and explain health related problems. The integration of behavioural and bio-medical knowledge, thus emphasised a patient's continuous contribution to his/her own existence, health and well-being. From an interactionist and developmental perspective, the patient or client is seen as one who is biologically and socially functional and primarily responsible for his/her health (6,7). Hence, active participation and contribution of individuals to maintain overall well-being, is highly encouraged as a health promotion activity.

The formation of support groups was found to be a useful coping strategy. Under such shared environment, where love, companionship and emotional bonding between the support group members are developed, collective action with regard to common health concerns is better achieved (8). Support groups cultivate individual and collective responsibility and maximum (efforts towards) striving for self-determined health activities (8,9). They also enhance the adoption of a wide variety of cognitive and behavioural efforts to manage internal and external demands, that tax resources at their disposal (9). Empirical studies elsewhere, have shown that the use and choice of health services is better understood and communicated, among self-care support group members (10).

It is in the light of this conceptual framework, that ALERT launched a self-care group programme, using a community based rehabilitation approach. In its unpublished material, the ALERT research team reported that, "a comparison of the foot ulcer situation at intake in two sub-groups (420 group members followed for six months and 173 followed for 28 months), against the situation in all 474 group members at intake, showed significant changes in terms of ulcer healing count: 'it was able to reduce their [members'] total number of ulcer count at intake, by almost 68%" (3).

An evaluation study was conducted on the cost-effectiveness and psychological changes brought about by the self-care programme, in the management and prevention of ulcers. The effectiveness of a health programme can be evaluated partly by the change it has brought about in the attitude (belief system) of the clients. A shift from the conventional approach that encourages dependency on an institution, to a self-care approach, and encourages the use of better coping mechanisms, is an aspect of the health programme evaluation. This paper attempts to answer the following questions:

- Has the self-care programme brought about any change in the attitude of clients in wound healing?
- Is there statistically significant attitudinal difference between the two settlement patterns?
- What coping mechanisms do clients employ, in order to alleviate their ulcer problem?

METHODS

Description of study area

The study was conducted in Shashemene and Wolkeite, that are semi-urban and rural areas respectively of Ethiopia, where the ALERT self-care programme had been actively engaged in promoting a pioneering leprosy control strategy. (As of January 1, 2001, the programme is being run by the respective regional TB/leprosy control programmes, integrated with the general health services).

The inhabitants of Shashemene are settled in nearby located villages, called "colonies". In Wolkeite, they live in scattered groups, integrated within the larger community. Therefore, this settlement pattern is assumed to bring about "attitudinal differences" in accepting a novel leprosy control Prevention of Disability (POD) strategy. The entire population in the two areas where the ALERT self-care leprosy programme is active, comprises 302 males and 177 females.

Sample

Nineteen in Shashemene, and nine in Wolkeite, self-care groups were functioning at the time of the study. Each group comprised of 9 - 13 members. Five out of nineteen, and four out of nine self-care support groups, were randomly selected. The attitudinal measurement interview was administered to 61 self-care group members who were available during their monthly session.

All 61 cases have been released from treatment for leprosy. Forty-seven of them, claimed to have taken dapsone (DDS), and to have been released from treatment before, or, at the start of MDT (1983) in their area. The remaining fourteen, had taken MDT ranging from periods between 6-24 months, and released thereafter. The sample population consisted of "cold cases", who were released from treatment for leprosy long ago, the minimum time being 13 years ago.

To rank their coping mechanisms in the order of merit, all 9 groups were presented with 5 strategies. The members in each group discussed the relative importance of the five coping strategies and put them in the order of merit, reached by a consensus.

Health personnel serving in leprosy affiliated organisations, were grouped into nine different strata, based on their profession. Twenty four respondents out of 51, were taken on a proportionate random sampling technique from ALERT, Shashemene TB/Leprosy unit, Shashemene Hospital, GLRA Medical Department and the Shashemene branch of the Ethiopian National Association of Ex-Leprosy Patients (ENAELP).

Data Collection

To achieve greater methodological validity, a mixture of qualitative and quantitative techniques of data gathering was used. The instrument used in this study has two parts that include the following sections: a measure of attitude towards self-care leprosy control programme and a measure of coping mechanisms used by self-care groups.

By incorporating ideas suggested by the programme holder and adopting attitudinal statements taken from current literature (6,11), sixteen items for surveying the attitude of self-care group members was prepared. The attitude measurement instrument included aspects like self-care programme efficiency, its contribution in bringing change in the belief system, the role of the support group in ameliorating ulcer problems and other related issues as perceived by respondents. The attitude schedule was also augmented by open-ended items to dig out additional information regarding problems, encountered since their establishment and suggestions concerning other socio-economic development programmes, that could go side-by-side with the health programme, meant to bring change in the living condition as perceived by the respondents.

To ensure validity, the schedules were thoroughly examined and commented upon by programme holders and by experts in the area, for content, item wording, choice of words and ambiguity, and pre-tested on randomly selected fifteen leprosy affected individuals, during April 5 -7, 2000. The items used in assessing the attitude of respondents had three choices i.e. 'agree', 'undecided', 'disagree', with weights three, two and one respectively. The statements were written in such a way, that reaction to the positives are weighted three, two and one and the negatives as one, two and three. These two kinds of statements were distributed alternatively. Statements phrased in such a way reduce response bias (12).

As a measure of reliability, Crombach's alpha was computed for the sixteen items. The computed reliability coefficient was found to be 0.952. This result is evidence for the internal consistency of the attitude measurement schedule.

A four-item open-ended self-report questionnaire was distributed to health personnel, to assess their opinion about health management, especially on the management and prevention of ulcers (of leprosy), or of chronic diseases in general. The perception of the health personnel about the buffering effect of self-help and support groups against distress resulting from

leprosy, is essential in implementing such a health programme. It is because of this general assumption that their opinion was surveyed (questionnaire appended).

A list of coping mechanisms assumed to have a wound healing effect, was also prepared and included as data gathering tool.

Questionnaires were distributed to self-care groups and members, and the authors distributed all case-discussions held with cases. The actual data collection in Shashemene area was carried out from April 15 to 20, and in Wolkeite area from May 2 to 5, 2000.

Statistical methods

Descriptive statistics like frequency count, percentage, ranking and t-test were analytical methods used in the study.

Analysis of Results

Self-Care Group Members' Attitude towards the Programme

Table 1: Results of a questionnaire based attitude survey among members of prevention of disability self-care groups in Ethiopia (N=61)

Item no	Attitude measurement items	Agree		Undecided		Disagree	
		n	%	n	%	n	%
1	The skill/knowledge/ acquired in the self care programme has largely improved my health status	35	57.4	11	18.0	15	24.6
2	Personally, I feel satisfied with the treatment of ulcer exercised in the self-care programme	38	62.3	10	16.5	13	21.3
3	Self-care programme is an alternate to treating ulcer/wound in hospitals/ health centres	30	49.2	9	14.8	22	36.1
4	The use of self-care programme to deal with ulcer management /treatment/ is one of urgent needs of ulcer patients	45	73.8	10	16.4	6	9.8
5	The service I get from support group is better than the service I had been getting from health centres	20	32.8	13	21.3	28	45.9

Item no	Attitude measurement items	Agree		Undecided		Disagree	
		n	%	n	%	n	%
6	It is my belief that I should continue to participate actively in the self-care health programme	40	65.6	9	14.8	12	19.7
7	The service I get from self-care programme is not as such different from the service I had been getting from health centres	21	34	11	18.0	29	47.5
8	I didn't see any new thing in the self-care programme to treat and manage ulcers	32	52.5	13	21.3	16	26.2
9	Since my involvement in managing my own wound my self-esteem is boosted	40	65.6	11	18.0	10	16.4
10	Members of the self-care group are very helpful to me in ameliorating my ulcer problem	45	73.8	6	9.8	10	16.4
11	Since my participation in the self-care programme, I feel my health is improving gradually	38	62.3	12	19.7	11	18.0
12	Ulcer treatment and management is better achieved individually than working in groups	43	70.5	10	16.4	8	13.1
13	The wound became more painful after I started managing it in the self-care programme	42	68.9	6	9.8	13	21.3
14	It is very difficult to learn and apply ulcer treatment skills learned in the self-care programme	52	85.2	2	3.3	7	11.5
15	It is waste of time to discuss health related problems in the self-care programme group	42	68.9	9	14.8	10	16.4
16	I feel relaxed when I work together and share experiences with my colleagues in the support group	38	62.3	8	13.1	15	24.6

Items 1,2,3,4,5,6,9,10,11,16 are positively stated items

Items 7,8,12,13,14,15 are negatively stated items

To assess the degree of positive or negative trends associated with the self-care programme, frequencies were counted on a 3 point response scale (agree, undecided, disagree). The distribution of frequencies along the continuum showed that relatively few respondents fall under the 'agree' category, for the positive statements. Comparatively, counts were relatively higher under the 'disagree' category. This distribution indicates, that the majority of respondents seem to be in favour of the programme. In the case of item 5 and item 7 the respondents' rating is different from the rest of the frequency distribution.

Regarding distribution of the respondents' suggestion on strengthening the programme in the future, 44% expressed that health education (facilitation by the programme holders) needs to continue. It is interesting to note here, that this figure is in line with the high percentage value falling under the 'agree' category in item 1. Concerning other development activities likely to be incorporated as part of the main health programme, 79% of the respondents suggested incorporation of credit facilities.

To investigate the difference between the two study sites with regard to their attitude towards the programme, mean comparison was made using the 't'-test. Though the analysis did not reveal a statistically significant difference between the two study sites, the mean value for Wolkeite was larger than that of Shashemene. This result is interesting in itself. In Wolkeite, the researchers came across some self-care group members travelling two or more hours on foot, or on horseback, to attend their scheduled meeting. Tolerance to hardship and such commitment, is further evidence for the programme beneficiaries' positive attitude towards the health/self-care programme. Results are given in Table 2.

Table 2: Mean comparison between the two study sites

Study sites	n	Mean	SD	df	t
Shahemene	41	37.22	10.63	9	1.235*
Wolkeite	20	40.10	7.33		

$P > 0.05$

Analysis of health personnel response

In general, qualitative data analysis showed that majority of the respondents (about 78%) were in favour of the self-care programme for the prevention and management of ulcers, despite the fact that only five respondents criticised it for its vertical organisation, where planning, implementation and monitoring of the programme was carried out by few staff members without adequate participation and consultation of other concerned partners. They also commented that the programme was lacking in well-defined guidelines and feedback resulting from continuous assessment.

Analysis of coping mechanism

Five coping mechanisms frequently used by self-care programme groups that were identified during the pilot study, were ranked in the order of their potency to alleviate ulcers /wounds. The most efficient coping mechanism being ranked 1 and, the least efficient being ranked 5.

Table 3: Coping mechanisms frequently used by self-care programme groups

Code	Coping mechanisms
A	Changing some routines and habits, which cause and aggravate ulcer problem. (Not to walk without shoes, always inspect that shoes are free from foreign substance i.e., gravel, sand; not to walk long distance etc)
B	By learning more about the treatment and management of ulcer from the group members and the health personnel [facilitators] (soaking, trimming, bandaging)
C	By talking (discussing) over the problem situation with family (husband, wife, children)
D	By talking (discussing) about ulcer problem with other friends/people 'in the same boat'
E	Accepting (admitting) limits and shutting oneself in home

Table 4: Coping mechanisms ranked in their order of merit

Self care groups		Coping mechanisms				
		A	B	C	D	E
G.K Group	Rank	2	1	4	3	5
W.Y Group	Rank	3	2	4	1	5
M.K Group	Rank	2	1	3	4	5
M.T Group	Rank	1	2	4	3	5
A.E Group	Rank	2	1	4	3	5
N.S Group	Rank	2	1	3	4	5
J.M Group	Rank	3	1	4	2	5
C.N Group	Rank	1	1	4	3	5
M.A Group	Rank	1	2	4	3	5
Sum of ranks		17	12	34	26	45
Order of merit		2	1	4	3	5

As can be easily observed, the self-care groups make use of a mixture of psychological and material resources as palliatives to confront their ulcer related problems. The emphasis appears to rely more on personal and inter personal resources rather than passively waiting for miracles to happen. The finding suggests that coping mechanisms employed by the self-care groups has two aspects. First, it is concerned with changing attitude and the belief system – psychosocial stigma with leprosy. Secondly, it suggests the importance of social support activities, such as talking over ulcer related problems with friends/husband/wife and using others as a sounding board. The fact that the coping mechanism which states, “accepting limits and shutting oneself in the home,” and ranked 5th by all support groups, testifies that mature coping mechanisms seem to have considerable importance, than defensive attempts that precipitate ulcer related problems.

DISCUSSION

As is evident from the analysis of the self-care group members’ attitude, only two items were found to veer towards the negative side. From this result we can safely conclude, that the overall evaluation of the programme beneficiaries’ attitude towards the self-care programme, showed the potency of the programme.

Although it is difficult to ascertain as to what extent the response of the respondents reflects in their day-to-day activities, which shows how they actually behave in real life situations, the results however, indicated that the programme has brought about a modification in their thinking and life style.

This general explanation, however, should not shadow exceptions. Although results of the data analysis revealed the overall strength of the programme, it cannot be said that the programme is free from any shortcomings. The response of health personnel to the open-ended items substantiates this idea. Health personnel were asked to give their opinion regarding the concept that the self-care leprosy control programme, is an alternate strategy to healing wounds/ulcers. Apart from enhancing a patient’s own responsibility for his/her own well-being and its cost-effectiveness, some respondents criticised it for its vertical organisation where planning, implementation and monitoring of the programme is carried out by a few staff members without adequate participation and consultation of other concerned partners. In addition, the programme was said to be lacking in well-defined guidelines and feedback, resulting from continuous assessment.

Furthermore, the need for credit service expressed by a high percentage (79 percent) of the beneficiaries, suggests the need to establish other community based rehabilitation activities that would supplement the target goal. The fact that this health programme should go side-by-side with clinical services, as suggested by beneficiaries and health personnel, indicates

that the programme is not uni-dimensional. In spite of this multi-sectorial feature of the programme, creation of new interests, upgrading of skills and all other working procedures give a purposive direction to programme holders and help the group members to build a positive self-image and live a better life.

Results from this study also highlighted the significance of conscious and rational ways of dealing with ulcer related problems. It is worth mentioning the programme members' coping strategies, which are directed at preventive measures, rather than endeavours to change the aftermath effect of the ulcer. A close scrutiny of the coping strategies in the order of merit assigned, shows that behavioural strategies appear to be more important than the use of material resources. One possible explanation of the prioritisation of the behavioural aspects of coping efforts, might be the participatory method of the health education programme with the aim of promoting awareness. The use of locally available material (for example, the use of 'Zanza', *the soft inner most part of the stem of 'Enset'- false banana.*) as a substitute to bandage and the softening of hands and feet using edible oil or Vaseline, bought from local shops appear to be appreciated. However, there is a need to weigh the side effects, so that the practice of ulcer management would not go astray and possibly aggravate the situation, as suggested by some of the health professionals. Strengthening the referral system and occasional visits by an experienced physician, seems to be an inseparable part of the support group self-care practices. The work of facilitators alone, will not bring the desired outcome.

It may be argued here, that the five coping strategies employed by self-care group members are not adequate enough to meet all needs. Both, self-care group members and health personnel underlined that provision of appropriate, acceptable commercial footwear, is probably as important as other practices in the management of ulcers. Although refraining from walking long distances, is one of the behavioural aspects of coping strategies, without mobility, the chances of earning their daily bread will be difficult. They must be able to get to work from their home and to other community activities. Hence, coping efforts can neither be uniquely behavioural, nor uniquely material, but should be a mutually supportive combination of the two. In other words, footwear provision and the facilitation (health education) programme need to go side-by- side.

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APPENDIX 1 : CASE STUDY (METHOD)

To substantiate the evaluation data, five cases found with special information were identified during interview sessions. Open-ended items framed by the researchers were used to elicit information. Accuracy and reliability of data were maximised by posing counter questions. A sample case study, possessing rich information on the overall aspects of the programme is given below.

Case Study

The person is a 53 year old widowed lady who had contracted leprosy at the age of 14. She lives in Kuyera/ Shashemene leprosy settlement. The case reads:

“I have never been admitted in the hospital nor been treated in clinics, as an out patient, for ulcer case. However, occasionally I used to have small ulcers in my feet, which I mostly treat at home by bandaging for two, three days only. As regards to my occupation, I am a housewife engaged in household activity including farming. Besides, I am engaged in retail trade as side income. I buy and sell farm products (grain, potato, onion and other vegetables) by travelling to open markets in the locality. Especially, after the death of my husband, I am inclined to this trade. I travel a lot, both on foot and by bus depending on the market place. And since my transaction is mostly with other “healthy people” [*people not affected by leprosy*], until recently I used to wear ordinary [*normal*] shoes, even though I knew that I have insensitivity of feet and small ulcers. Because I didn’t want my clients/ buyers to know that I had leprosy and ulcer”.

“Meanwhile, I developed two deep sole wounds in my right foot. I didn’t do anything to them, but I continued to wear same shoes and run for my business. After a few days, the two sole wounds got bigger and deeper and were developing in to one very big and deep ulcer. I went to the clinic and showed to the doctors my ulcer. There, I was told that my ulcer would require a minimum of two weeks treatment with rest to heal; and they advised me to be admitted in the hospital. Since I thought my business would collapse while admitted (and for that matter I didn’t like hospital admission), I refused the admission and came home with one time dressing. But, my wound was getting worse and smelling”.

“One day I was travelling with a public minibus to Negele market [near by town]. My seat was almost in the middle of the minibus seats. The mini-bus was full, and because of the rain showers all the windows were closed”.

After few minutes of our drive, I saw the passengers next to me and on other seats, beside and in front, holding their noses with their *netella* (a traditional cloth that people put on mostly over their shoulders.) and handkerchiefs. I was a bit panic by the behavior they showed; I had forgotten about my smelling wound in my foot. Nobody looked at me, and it

seemed that no one had recognised where the smell was from. There is a saying: “own wound will not smell unless you intend to smell it”. I didn’t smell any (wound smell) until I bowed and confirmed that it was mine. I bowed down to my feet [*foot steps*] and inspected my shoe by slightly pressing down the ulcerated-foot with my other foot and take off the back side of the shoe. It smelled very stinky. I was ashamed, but didn’t want to show this up nor did I want the passengers to know that the smell was from my wound. I tried to cover up by holding my nose with my *netella* as others did. Not only this, I loudly said, “Uff! Uff! ... what a smell?... Is there any hide [*animal skin*] in this bus?” No body replied, except some turned their heads towards me and looked surprised. This also disturbed me more. I got frustrated and was disturbed the whole day. This in turn had affected my business on that day, since I was not in the right business-mood to deal with my clients/buyers. After the market I came home but didn’t do any thing to my wound. It remained as it was. Two weeks later, my husband passed away, and per the culture of our community, we have to sit at home for mourning for about 10 to 15 days; a tent will be erected in the compound to accommodate friends and neighbors who come for the mourning. Coffee, tea, roasted beans/grain and food will be served by the *Idir* (a traditional self-help association of neighborhoods the primary aim of which is consoling bereaved families). Unlike men, women sit on the floor- covered with mattresses or carpets—and take off their shoes. Accordingly, as a wife and woman, after the funeral ceremony, I had to sit in the tent, take off my shoes and receive friends and neighbors. So, I sat on the mattress prepared for me and my close friends, exposing my wounds to the public; sometimes I was trying to cover them up with my *netella*, if not to stop the smell.”

“Meanwhile, at night, the daughter of my husband’s friend brought a bucket of water with salt in it and advised me to soak my ulcerated feet for about half an hour. After soaking, she oiled and covered the ulcer with clean cloth. Next morning too, she helped me do same process before I went to sit in the tent. Also at night, I did same thing with her. In two days time the smell went off (had gone). After ten days, my ulcer healed, only a small part (tissue) was left. I said to myself, ‘It is me who spoiled my leg. If I care for it, I can prevent it from destruction and amputation.’”

“Few days later, people affected by leprosy in our neighborhood were approached by ALERT medical team to form a self-care group after they had given us orientation about the programme. In that meeting, I was the first to support the programme, and volunteered to provide my compound and the necessary benches and chairs for self-care group activity. I joined my present group and since then I am actively involved in my self-care group activities.

“To-date I haven’t developed any new ulcers. Inshallah! [*Thanks God*] now I advice, assist and encourage my colleagues and others on the programme. As you can observe, my feet

and hands are 'clean' [*free from ulcer*]; I wear canvas shoes with special sole in it. In my group, we are 10 members, 7 male and 3 female; the group meets here weekly [*i.e. in her compound*]."

APPENDIX 2: QUESTIONNAIRE ON SELF CARE PROGRAMME FOR HEALTH PERSONNEL

Opinion Assessment : Self-Care Programme
[For Health Personnel]

1. Have you heard of (come across) a "support group" in any of the chronic diseases ?
.....
If Yes, (mention)
2. Do you agree that the self-care programme can be an alternate health strategy to healing ulcers/wound ?
If Yes, Why ?
If No, Why ?
3. Do you think the self-care programme is cost-effective than institutioning ulcer ?
.....
4. Generally, how do you appraise the self-care programme of ALERT?
.....

Your profession Specialty (if any)

Position (in your organisation)

Years of service in present organisation/ position

**THE ROLE OF SUPPORT GROUPS IN RAISING THE
SELF- CONCEPT OF PEOPLE AFFECTED BY LEPROSY:
AN EVALUATION STUDY IN ETHIOPIA**

Motbainor Abera*, Girma Lema

ABSTRACT

A pre-tested structured interview was administered to a sample of twenty-four pairs of leprosy affected self-care group members and matched subjects around Shashemene, to evaluate any perceived changes regarding themselves, and their disease resulting from membership of the self-care leprosy control programme, undertaken by All Africa Leprosy, Tuberculosis and Rehabilitation Training Centre (ALERT). Besides this, a case study and observation reports were used, to complement the quantitative information from an interview questionnaire. The 24 self-care members perceived themselves and their ulcer problem more modestly than their counterparts not in the programme. The difference between the mean 'self-concept sum scores' was significant ($t=10.19$, $P<0.005$ $df=46$, and $x=30.083$, $P<0.001$ respectively). Case and observation reports qualified this finding, indicating that the health promotion activity undertaken by the self-care programme has raised the clients' sense of worth and self-esteem. Further recommendations have been given for conducting studies of a similar nature in the future.

INTRODUCTION

A factor of cardinal importance in understanding the dynamic component of health, is the client's sense of worth (1,2). Different authors have suggested that a person's sense of place in a community, is central to understanding how health can be achieved and maintained, and how illness can be overcome. They stated that people tend to lose assertiveness, become less alert, develop more illness and are more likely to die, when they are deprived of making their choices (1, 2,3).

Individuals who have a positive self-concept and appraise their environment realistically, tend to use more mature coping strategies, than individuals who view their environment passively (4, 5). Linda K. George, cited (4) in Menaghan, stated that "more education appears to foster a cognitive complexity that facilitates realistic stress perception and problem -

solving skills". Other investigators also found on the one hand, a strong relationship between sustained education and on the other hand, a more positive self-perception, greater readiness and intellectual flexibility to deal with complex and novel situations"(4).

The effectiveness of any health promotion programme can be evaluated in terms of the relative value the individual places on himself and his social environment. A potentially important variable in assessing the effectiveness of a self-care programme, is the change it has brought in self-esteem or, more generally speaking, self-concept among beneficiaries. Self-concept is operationally defined in this study as, "overall evaluation of leprosy affected individuals about themselves and their environment, in light of the social stigma associated with the disease" (4, 5). To investigate whether the programme has brought about any meaningful behavioural change with regard to ulcer management and prevention among the self-care group members, it was considered essential to compare samples of people who had participated in the programme, with those who had not.

Though variations in methodology designs can be attributed to purposes and resources available at hand, most social action evaluation studies, make use of surveys, case studies and field experiments in an attempt to fulfill objectives stated in the respective studies. Project evaluation research designs, reviewed by different authors show that interviewer or questionnaire techniques, use of documents and observation techniques, are principal data gathering tools (6).

METHODS

Sample

Cases: the primary sampling unit for the case (self-care group members) comprises a total of 35 self-care support groups working in Shashemene. From this first level sampling frame, nine groups were randomly identified. Twenty-four individuals were selected with proportionate random sampling from the nine groups.

Matched groups : the selection of subjects who had not participated in the self-care programme was facilitated by a social worker working for ALERT - Ethiopia Leprosy Control. Household selection proceeded systematically, until twenty-four household heads matched for sex, age and occupation with the case subjects. Where selected individuals were not immediately available for interview, the next household head was taken. All interviews were conducted in private.

Data collection

Construction and Development of the Instrument: A thirteen - item interviewer questionnaire was developed, pre-tested and completed by the authors. The items were framed on a three choice response dimension (questionnaire appended). Themes included ability to maintain self-control, level of efficiency in wound management, overall perception of the self and environment. To assess validity, the initial form of the schedule was examined by the self-care programme managers and by experts for content, item wording, choice of words and ambiguity. After shaping the initial form, the schedule was administered to fifteen randomly selected, leprosy-affected individuals from April 5 to 7, 2000. The pre-testing, highlighted ambiguity and deficiencies in wording the items and the average time needed to complete the schedule. This prior adjustment, provided the necessary quality control and minimised the occurrence of error in administering the final form.

Translation from the English language to Amharic (a local language) and translation back to English, was done by two experts who could speak and write the two languages fluently. Later, differences in translation were identified and discussed between the translators, which enabled them to reach a consensus. To minimise the problem of interview bias, the schedule was administered to the comparison groups in a constant manner, by one interviewer.

The total score for each subject was obtained by summing up the assigned weights to all items. The maximum possible score becomes 39 and the minimum 13. A respondent's total score was computed from the score sheet. As a measure of internal consistency, Crombach's alpha was computed and found to be 0.72, indicating that the instrument would suffice the purpose of the study. Frequency counts; median, 't' and chi-square tests were used to crystallise quantitative data.

Case Study

A case with an interesting history was identified during the interview session. Open-ended questions were formulated by the researchers, to elicit information. A summary of the case report is included in the analysis.

Observation

The researchers observed the proceedings of the nine self-care groups' weekly sessions, recording all the events that took place from the introductory part of a session to the closing coffee reception, which features the warm and affectionate attachment among group members. Events were systematically recorded, organised and analysed.

ANALYSIS OF RESULTS

Self-care and matched group comparison

It is hypothesised that the self-care groups, which have undergone extensive health education, would have acquired knowledge and skills that eventually raised their self-esteem. Hence, only a one-tailed significance test was done. The mean difference of 8.08 was found statistically highly significant at 0.0005 level ($t = 10.19$, $P < 0.0005$ $df = 46$).

The median sign test was used to compare the level of self-concept of the two groups. The means of the two groups were pooled together, and a common median was found. If the programme had no effect on the perception of the self-care programme participants about themselves and their environment, it was expected that half of the scores in the two independent samples should lie above and half below the common median.

Table 1 gives the scores of the two groups. A positive sign indicates a score above the common median and the negative sign a score below the common median. The common median was 29.50.

Table 1: Median test applied to self-care and matched groups (N = 48)

Self-care group members (n=24)				Matched group members (n=24)			
Score	Sign	Score	Sign	Score	Sign	Score	Sign
37	+	35	+	26	-	27	-
32	+	37	+	19	-	21	-
31	+	33	+	22	-	30	+
34	+	34	+	27	-	21	-
35	+	37	+	27	-	23	-
33	+	35	+	22	-	22	-
30	+	37	+	24	-	26	-
33	+	31	+	25	-	30	+
28	-	32	+	28	-	28	-
30	+	31	+	22	-	25	-
33	+	29	-	24	-	26	-
32	+	32	+	26	-	20	-

From Table 1 in the self-care group, 22 observations are above the common median value. In the matched group, exactly the opposite, is observed.

A chi-square with correction for small samples was computed from the two by two contingency table based on data from Table 1. A statistically highly significant value ($\chi^2 = 30.083$, $P < 0.001$) was obtained, indicating that self-care programme participants have a better level of self-concept compared to the matched subjects, as measured by the questionnaire.

Case result

Analysis of case information from a 52 year old self-care group member, who had been taking dapsone for more than ten years and admitted twice for an ulcer problem, further substantiated the result obtained from quantitative data.

The integration of leprosy control with TB and the general health services coupled with the introduction of the self-care programme, were the driving motives to treat ulcer problem through support groups. In spite of this new approach and all sorts of help offered from colleagues, the 52-year case subject claimed that he was saved from amputation. As a concluding remark the subject stated: "Ah! We would have benefited more from such 'health group' [self-care] had we had it some fifteen years ago".

Observation

Unlike other self-care groups (e.g. diabetes, cancer, AIDS associations etc.), ulcer-care discussion is not dominated by health professionals or social workers. Instead, each member was encouraged to share his/her practice of ulcer management used at home. As a procedure, every member was invited by the chairperson to inspect, comment and suggest on the status of eyes, hands and feet of his/her colleagues. Improved ulcer condition was rewarded by the group. If no progress has been made since the last session, the individual is criticised. Punishment involves withholding of moral rewards, and at times it goes to the extent of fining some amount of money.

The progress in self-concept can be witnessed in individuals, by no sign of reservation in their comment and no sign of hesitation to touch cracked, dirty and wounded feet of someone whom he/she had not known for years and had not had close relationship with. It is here that an outsider would observe the emotional attachment prevalent among self-care members. One member said, "It is such support or emotional attachment that controls my behaviour".

DISCUSSION

Evaluation of the level of self-concept between self-care and matched groups revealed that self-care group members were found to have a better image and assessment of themselves and their ulcer problem.

The degree to which one values oneself has certain implication as far as health is concerned. Low self-esteem on the part of matched group members might imply fewer competencies in manipulating their environment and less ability to manage and treat their ulcer.

What the authors found to be uncertain, though, is that it is difficult to state emphatically the cause and effect relationship. Whether lowered self-concept as measured by the items among the matched group might be attributed to a lack of health education (through participatory learning and action method), or any other disadvantageous position compared to the self-

care group, is not exactly known. Since multivariate analysis was not within the remit of this research design, explaining the intricate relationships between the selected variables was not possible. Like any other exploratory surveys of similar nature, the purpose of this study was to describe events in a simple way and to provide information on the psychosocial environment under which the programme is run. Yet, it is the authors' belief that they threw fresh light on the strengths of the programme that would furnish programme holders to make decisions as objective as possible, in the future.

In the future, there is a need to develop a valid instrument and see the interrelationship between selected variables and weigh the net effect of these variables, by employing a multi-variant statistical analysis.

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APPENDIX I :SELF-CONCEPT QUESTIONNAIRE (FOR SELF-CARE GROUP MEMBERS AND MATCHED GROUPS)

	Self concept measurement items			
1	To what extent do you easily get upset when you think of your ulcer problems?	Very much	Moderately	Not at all
2	How often do you have negative feelings such as despair, anxiety and depression?	Very often	Sometimes	Not at all
3	To what extent do you feel inferior to other people in the community when you think of your ulcer?	Very much	Moderately	Not at all
4	How strongly do you feel trust, worthiness and optimism in you?	Very much (strongly)	Moderately	Not at all
5	How satisfied are you with your ability to perform your daily living activities?	Very satisfied	Mildly satisfied	Not satisfied
6	Are you currently enjoying life ?	Yes I do	Undecided (I don't know)	No I don't
7	To what extent do you believe that ulcer treatment can be done independently with minimum aid from the health personnel?	Strongly believe	Somewhat believe	Don't believe
8	Do you now admit your limits more easily than when you first experienced (saw) ulcer on your body?	Yes I do	Undecided (I don't know)	No I don't
9	Do you believe that health personnel's daily supervision is very indispensable for the management of ulcer?	Believe	Undecided (I don't know)	No I don't
10	Do you agree that ulcer/wound/ need not be exposed to non-leprosy affected people other than the health personnel?	Agree	Undecided (I don't know)	Disagree

	Self concept measurement items			
11	To what extent do you believe that the support from family and friends (colleagues) helps to cope with ulcer problems?	Strongly believe	Somewhat believe	Don'tbelieve
12	How suitable is the condition of your living place for the management of ulcer?	Very suitable	Moderately suitable	Not at all
13	How satisfied are you with your personal Relationship with people not affected by leprosy?	Very satisfied	Moderately satisfied	Not satisfied

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ATTITUDES OF SAUDI ARABIAN HEALTH CARE PROFESSIONALS TOWARDS PEOPLE WITH PHYSICAL DISABILITIES

*Sami S. Al- Abdulwahab , Salah I. Al-Gain

ABSTRACT

Negative attitudes of health care professionals towards persons with disability are considered to be an invisible barrier to rehabilitation and integration. In contrast, positive attitudes are a key to successful integration. The attitudes of health care professionals towards people with disability have been studied worldwide, but not in Saudi Arabia. It is believed that cultural values, traditional beliefs, educational environment and religion are factors affecting attitudes towards disabilities. This may indicate that each community should study its own attitudes towards people with disability, separately. Therefore, the objective of this study was to determine the attitudes of health care professionals towards people with physical disabilities in Saudi Arabia. Attitudes of a sample of 130 Saudi Arabian health care professionals was investigated using a Scale of Attitudes Towards Disabled Persons (SADP). All participants worked with various types of disabilities including the physically disabled. Descriptive statistics, the Kruskal-Wallis and the Spearman's correlation coefficient were used to analyse the data of this study using SPSS statistical programme. The participants exhibited positive attitudes towards physically disabled people with mean score of 100 ± 17 . Attitudes among health care professionals were not significantly different ($p < 0.40$). Educational degrees showed no significant effect on attitudes of participants towards people with disabilities ($p < 0.45$). A poor relationship was found between attitude scores and both age ($r = 0.03$) and experience ($r = 0.003$). This study concluded that Saudi Arabian health care professionals displayed positive attitudes towards people with disability as do other health care professionals worldwide. This may indicate that cultural values, traditional beliefs, educational environment and religion have little effect on attitudes of health care professionals.

INTRODUCTION

The attitude of health care professionals can have a direct influence on aspects of care. When health care professionals interact with persons with disabilities, attitudes and feelings

are reflected in the interaction. In general, the attitudes of health care professionals can influence how patients with disabilities feel about themselves and their progression with rehabilitation. It is well known that health professionals who work with persons with disabilities significantly affect the patient's treatment and rehabilitation potential. Negative attitudes of health care professionals can inhibit patient adaptation and acceptance of their disability and limit the development of positive staff - concept, irrespective of the limitation of disability. In contrast, a positive attitude increases patients' motivation to recover, adapt to and accept disability. Several studies worldwide have investigated the attitudes of health professionals toward disabilities (1, 2, 3, 4, 5). Roush (1) reported that negative attitudes towards people with disabilities are common in society, but are not directly voiced. They are expressed in different ways and serve as barriers to the full realisation of human potential. It has been agreed that health care professionals hold attitudes toward people with disabilities that are similar to those of society as a whole, and they may be actual perpetrators of this limiting practice (1). This conclusion is at variance with the findings reported by Paris (2) who reported that health-care professionals and medical students, similarly, had positive attitudes toward individuals with physical disabilities. Moreover, Gething (3) found that Australian nurses and nursing students' attitudes are more positive than those of the general population and that nursing education strategies are effective in promoting positive attitudes. Also, Brillhart et. al. (4) found that nursing faculty, fresh nursing students, graduating nursing students and registered nurses had positive attitudes toward people with disabilities. However, the faculty held the least positive attitude, followed closely by graduating nursing students. Registered nurses had more positive attitudes than fresh student nurses, graduating nurses and nursing faculty. On the contrary, Biley (6) reported that nurses had negative attitudes and a general lack of awareness of the needs of people with physical disabilities. He concluded that there is a need for increased awareness among nurses, of the needs of people with disability.

This variation in attitudes found in these studies may indicate that practice sites, age, clinical experience, educational level, belief and cultural aspects may affect the attitudes of health care professionals.

In other studies, rehabilitation professionals including 150 rehabilitation nurses, 57 occupational therapists, and 43 physical therapists in southeast Texas, reported to have positive attitudes toward people with disabilities (5). In fact, occupational therapists had significantly higher scores than the rehabilitation nurses and physical therapists. Attitude scores among rehabilitation professionals have been reported to not be significantly affected by practice setting, age, educational level, and duration of experience (5). Such positive attitudes among rehabilitation professionals were also documented by Benham (3), who investigated the attitudes of 619 occupational therapists.

Attitudes have been measured with various scales 1-29. However, the most commonly used attitude measure is Scale of Attitudes Toward Disabled Persons (SADP) (7, 9, 10). This scale has been reported to be a reliable, valid and a simple measure of attitudes (7, 9, 10, 11).

Attitudes towards people with disabilities are debatable and vary among health care professionals and within specialities worldwide. It is believed that the variation in attitudes towards people with disabilities result from cultural values, traditional beliefs, educational environment, religion, age, working experience and sex (4, 10, 12, 15). Therefore, it is important for each community to have its own data on attitudes towards people with disabilities. Consequently, the attitudes of Saudi health care professionals towards people with disabilities must be addressed. Therefore, the purpose of this study was to characterise the attitudes of Saudi Arabian health care professionals towards people with physical disabilities and to determine the relationships between attitude and age and working experience.

METHODS

Scale of Attitudes Towards Disabled Persons (SADP) was personally distributed among a sample of 130 Saudi health care professionals in four hospitals, including King Fasal Specialist Hospital and Research Centre, King Kalid University Hospital, King Fahad National Guard Hospital and Security Forces Hospital in Riyadh city. All participants worked with various types of disabilities including physical disabilities. The SADP is a reliable self-report scale which consists of 24 items, developed by Antonak (9). It provides a convenient and effective tool for evaluating attitudes towards people with disabilities. The 24 items of the SADP are expressed as statements to which participants respond on a Likert-type scale. The participants were asked to circle the appropriate number which best corresponds with how they felt about the statement. There were no right or wrong answers. There was no time limit. They were asked to respond to every statement. The participants were also asked to respond to the scale statements according to their personal reaction, but not to professional reaction. Any participant who did not respond to all of the scale statements was omitted from the study. The total scores ranged from 0, indicative of a very negative attitude, to 144, indicative of a very favourable attitude.

DATA ANALYSIS

Descriptive statistics, Kruskal-Wallis and Spearman's correlation coefficient tests, were used to analyse the data of this study with alpha level 0.05, using the SPSS statistical programme.

Results

One hundred and one out of 130 participants responded to the SADP as instructed. They were 51 males and 50 females, with a mean age of 32.4±6.4 years and working experience

of 8.0 ± 2.2 years. Fifty of them were physical therapists, 28 speech pathologists and 23 family medicine physicians. 60 had a BSc and 41 had either a Professional fellowship or MSc/PhD.

The participants had positive attitudes towards physically disabled persons with mean score 100 ± 17 . Chi Square test showed that there was no significant difference ($p < 0.08$) between males (97 ± 6.4) and females (105 ± 2.6). Attitudes among health professionals were not significantly different ($p < 0.40$) (Table 1).

Table 1: Attitudes of health care professionals toward person with disability (mean \pm standard deviation)

Physical therapists	98 ± 2.5
Speech pathologists	102 ± 3.4
Family medicine physicians	102 ± 3.5
p-value	0.4

Educational degrees showed no significant effect ($p < 0.45$) in the attitudes of participants towards people with disabilities (Table 2).

Table 2: Attitudes of health care professionals toward person with disability based on educational degrees (mean \pm standard deviation)

BSc./MD	99 ± 2.10
MSc.	109 ± 5.94
Ph.D/Professional fellowship	98 ± 3.66
p-value	0.45

Spearman's correlation coefficient showed a poor relationship between attitude scores and either age ($r = 0.03$) or experience ($r = 0.003$).

DISCUSSION

The present study showed that Saudi Arabian healthcare professionals had a positive attitude towards people with disability. The positive attitudes reported, could be due to the influence of contact of the participants with disabled people (16) and a chance to obtain accurate information (17, 18). Researchers reported that those who experience more contact with people with disabilities, appeared to have more positive attitudes (19, 20, 21). This contact appears to decrease the fear of the unknown and erase negative stereotypes. The positive attitudes toward people with disability in this study, may also be due to the knowledge and education regarding disability issues. Attitudes towards people with disability are reported to

be improved with increased knowledge and education regarding disability issues (22, 23). while negative attitudes are based on the lack of knowledge(24). Therefore, people including health professionals, view disability depending on their personal experience of interacting with such people, as well as on the basis of the art and literature they are exposed to. Attitudes such as determining of behaviour can be negative or positive, depending on the perceptions held by the person, and the behaviour he or she expresses pertaining to these perceptions. Those who have no concept of what disability entails, and have not made any previous contact or attempt to learn, are more subject to form a negative perception concerning beliefs about persons with disability. Anderson and Antonak (25) state that persons who have less frequent and less intimate contact with people with disabilities are more likely to develop stereotypical negative attitudes.

Positive attitudes towards people with disability have also been reported among healthcare professionals worldwide (7, 10, 26, 27), which may indicate that culture and beliefs of different societies have little effect on attitudes towards people with disability. Dentists, occupational therapists and nurses were reported to express positive attitudes toward people with disabilities (7, 10, 26, 27). It seems that healthcare educational programmes in various universities, regardless of speciality, result in positive attitudes toward people with disabilities. It has been reported that teaching values, understanding the possible effect on patients and their families, and information about disability gained during academic experience in undergraduate programmes, affect attitudes (13). This could explain why health professionals have positive attitudes toward people with disabilities.

The participants' age was not a determining factor that affected attitudes in the present and other studies (14).(14) This may be attributed to the small age range of the participants.

Working experience in this study showed no association with attitudes. This is in contrast to the findings of a previous study where registered nurses had more positive attitude than either fresh student nurses or graduate nurses (4). This may be due to the fact that the participants in this study had a limited range of working experience and they may have reached the plateau of a positive attitude towards people with disabilities during 8.0 ± 2.2 years of their work in the disability field.

There were no significant differences observed between men and women, in this study. A similar result was found in other studies (14). This could indicate, that the gender of general public or health care professionals has little influence on attitudes towards people with disabilities.

The positive attitudes of health professionals in this study, can be used to encourage non-disabled people, who have no contact or experience with disability, to treat a person with disability in a genuine, warm and accepting manner, welcoming interactions. This can be

worked out, as the voice of health professionals is usually acceptable and welcomed by society, if properly highlighted in the media. Kirchman (23). reported, that attitudes of health care professionals, both, mirrors and shapes societal attitudes towards people with disabilities. Public attitudes including health care professionals, influence authority policy and allocation of resources such as health care services (28). and access to education, transportation, governmental building and employment (29). These issues need to be investigated in Saudi Arabia.

A positive attitude reflects a desire to be nice, helpful and to treat a person with disability in an equal manner. Thus, these people may be perceived by persons with disability to be expressing negative attitudes, when they are really trying to express their own conceptualisation of a positive attitude. Therefore, these issues should be discussed thoroughly between health professionals, people with disability and their families.

The limitation of this study includes a small sample size, based on four hospitals in one city. There were only three healthcare disciplines involved in this study. Moreover, the majority of participants were physical therapists.

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BRIEF REPORTS

**CAREER AND EMPLOYMENT OPPORTUNITIES FOR WOMEN
WITH DISABILITIES IN MALAYSIA**

Faridah Serajul Haq*

ABSTRACT

Recent studies indicated a gender bias in employment opportunities between men with disabilities and women with disabilities (1,2) More men with disabilities are in the work force as compared to women with disabilities, who are either unemployed, or work part-time (3). Women with disabilities are typically viewed as dependent, passive, incompetent and unsuitable for economically productive roles (4). The objectives of this study are to examine employment and career opportunities for women with disabilities in Malaysia, in terms of the level of education and vocational training, categories of disabilities and barriers for employment. A semi-structured interview is designed to elicit qualitative data from three respondents. The findings reported here are based on a pilot study of a larger research project. The findings of this pioneer study are expected to have important economic and social implications, for reducing unemployment among women with disabilities, in Malaysia.

INTRODUCTION

Employment of women with disabilities is a neglected area of disability studies. Studies on special needs of people with disabilities have examined dimensions of ethnicity, socio-economic status, but have ignored the issue of gender. Women with disabilities seeking employment, faced the double discrimination of gender and disability. Employers regard women with disabilities as unproductive workers who are unable to adjust to the workplace. The unsupportive attitude of employers is further enhanced by their reluctance to make the necessary accommodations to the workplace, such as installation of lifts and ramps and provision of accessible transportation and housing.

According to Stoddard (5) one-third of the population of women with disabilities live in poverty. The women are also employed in low wage jobs, or part-time work with few benefits (6). The monthly income for women with disabilities is \$1,000 per month or \$470 less than women without disabilities and \$300 less per month than men with disabilities. Married women with disabilities earn \$270 per week or \$100 less than married men with disabilities (7).

However, the gap in the workforce participation for women with disabilities and women without disabilities is narrower than the gap between men with disabilities and men without disabilities (8). The Centre for an Accessible Society (2001) provided further information on the employment and income status for both men and women with disabilities. Since 1995, the employment rate for women without disabilities is 80.06% and 33.06% for women with disabilities (9). In contrast, the rate of employment for men without disabilities is 94.96% and 36.21% for men with disabilities. The median income of women with disabilities is \$13,974, as compared to 28,518 for women without disabilities. Men with disabilities earn \$15,275, while men without disabilities earn 31,068. It is evident that unemployment is persistent among both men and women with disabilities, and both their incomes are significantly lower than that of their able-bodied co-workers.

Women with disabilities are employed at higher rates in service, managerial and professional occupations as compared to men with disabilities. Yelin (10) indicated that 1.8 million or 18.7% of the female workforce in service occupations, are women with disabilities in comparison to 1.1 million or 15.3% of men with disabilities. In managerial and professional positions, 1.6 million or 10.7% of the workforce are women with disabilities in comparison with 1.3 million or 9.2% men with disabilities. However, the overall rate of employment for women with disabilities is significantly lower than for men with disabilities. According to Bowe (11) 42% of men with disabilities are in the workforce in comparison with 24% of women with disabilities. More men with disabilities are employed full-time (30%), than women with disabilities (12%). Women with disabilities who work full-time earn 56% less pay, than men with disabilities on full-time employment.

A gender bias attitude is also reflected in training programmes for employment. Women with disabilities are rehabilitated for part-time work, or to be homemakers (12). Only 34% women participated in supported employment programmes for developmental disabilities in comparison with 66% male participation (13). In addition, 70% of men with developmental disabilities retain their jobs after 6 months, as compared to 55% of women with a similar disability.

In Malaysia, no statistics are available to distinguish the participation of men and women with disabilities, in the workforce. It is estimated that 1.0% or 210,000 of the total population of 21 million are people with disabilities (14). A total of 73,353 people with disabilities, are presently registered with the Department of Welfare Services. The Public Services Department indicated that 538 people with disabilities were employed in the public sector, in 1997. In 1998 there were 3,309 people employed in the private sector according to the Labour Department. Totally, only 5.24% of people with disabilities are employed, in Malaysia. The rate of employment for people with disabilities in Malaysia is significantly lower than their non-disabled counterparts. It is expected that the rate of employment for women with disabilities, is less than that of men with disabilities.

The purpose of this study is to examine employment opportunities and barriers experienced by women with disabilities, in Malaysia. The issues examined include gender and disability discrimination, opportunities for promotion, further training and career advancement, as well as types of accommodations available at the workplace. The findings of this study will provide preliminary data for further investigation into employment problems faced by women with disabilities, in poorer communities.

METHODOLOGY

A semi-structured interview was designed to elicit information on employment opportunities and barriers from three presently employed women. The three respondents were professional women in managerial, administrative and teaching positions. The interview consisted of two parts. Part one requires the respondent to answer questions on their job title, number of years employed, number of dependents on their income and number of co-workers with disabilities in their workplace. Part two of the interview included the following questions:

- a) What types of facilities and accommodation are provided by the employer (housing, transportation, ramps, lifts, furniture and accessibility in the building)?
- b) Is the respondent given limited work assignment because of her disability?
- c) Does the respondent have to work harder than other able-bodied co-workers because of her disability?
- d) Has the respondent been overlooked or bypassed for promotion or further studies?
- e) Are the supervisors and co-workers helpful to the respondent?
- f) Does the respondent feel comfortable asking for help at work?

Each interview lasted between 45 to 60 minutes and the respondent was instructed to terminate the interview if they did not feel comfortable with the questions. Respondents were also informed about the confidentiality of their responses. Each interview was transcribed and coded for relevant data to answer the research questions.

RESULTS

Case 1

Respondent A is a 48-year-old librarian from a local university who has spinal cord injury due to a road accident. The road accident occurred on campus when the respondent was an undergraduate. After her graduation, the university made arrangements for an administrative job for her in the main library. She is provided with ramps, accessible toilet, stair-lift as well

as a separate entrance to the workplace. She is also given a couch in a rest area to lie down and to prevent bed sores. The furniture is assembled to facilitate easy movement in the work area. She is also given a covered car park that is spacious enough for her to move from her wheelchair into her car. The respondent would like to see further improvements such as accessible toilets on every floor of the library and an automatic door installed in the main entrance.

Respondent A has no regrets about her present work "I have no regrets but if I am not disabled I might try to find work somewhere else." She does not feel any discrimination at work and describes her employer and co-workers as "compassionate and empathetic." The only concern of her employer is that she may need to take frequent medical leave. However, in the 28 years of service she has taken less than 3 weeks per year for medical treatment. In the initial years of her employment, she was only given the day shift in the library, to ensure her safety whilst travelling to work. She did not feel that she needed to work harder than her non-disabled co-workers, but felt a need "inside to prove something better, although I am disabled." Her employer appreciates her efforts and she was recently recommended for promotion. She attributes her success to her positive attitude, her friendliness towards her clients and her ability to solve problems. She has a Masters degree and attends conferences regularly. She was voted "Employee of the Year" for 2001, and is considered a contributing member of the university.

Respondent A regards her co-workers as helpful and they accept her as a professional. In the first year of her employment, her co-workers were afraid to talk to her for fear "of asking the wrong questions." But now they help to put her wheelchair in her car, keep the fire door open and help take books from the higher shelves. She would like to advise other women with disabilities to keep looking for employment even though they have been rejected by potential employers. If given the opportunity, they "must prove themselves, give more than they can, have dedication, dignity, self-worth and have initiative." A major barrier for women with disabilities is overcoming lack of self-confidence. Her advice can be summed up as "have no fear, be adventurous, ask for the job and always believe you can do it."

Case 2

Respondent B became disabled at the age of 8 months because of polio. She is presently working as a remiser with a local stock broking firm. She lives with her family, drives to work and occasionally supports her mother financially. Respondent B feels very fortunate that her company takes the initiative to determine her needs at the workplace. Within her office structure she is given a special room with a gradient ramp, an automatic door and accessible toilets on every floor. She is very comfortable at work because she is given adjustable furniture and ample space to manoeuvre her wheelchair. She is given a larger car

park reserved for company directors in the building. Respondent B also indicated that she approached the building management to express her needs for facilities and accommodation. The ramp which was unsuitably constructed, was later modified to an appropriate gradient.

Respondent B's job requires her to meet and socialise with clients. She is not given limited work assignments because it is her primary responsibility to increase her income by increasing her clientele. She finds difficulty in securing clients from bigger corporations because her mobility problems limit her socialising to the cafeteria in the building. Restaurants located in luxury hotels are often not accessible for wheelchairs. She felt that her income could increase if "the outside world is more accessible." She describes her various clients as "some don't care if I am disabled but are friendly. Others feel discomfort and dare not recommend me to their friends." She has a "good reputation" with her clients and she has to prove her capability to them even though at times, it is inconvenient for her. An example she gave is, when she has to bank in a cheque in a building with no ramps or lifts.

Respondent B's present job does not involve a promotion, but more on-the-job training for licensing points. Her company provided her with the necessary training with the Securities Commission. She has not faced any discrimination in her present employment and is considering "staying on because the staff and management is good to me." Respondent B did relate her previous job seeking experience. A company employer wanted to hire her after hearing her qualification over the phone, but denied her an interview when he discovered her disability. She regarded the company's rejection as blatant discrimination, but persevered to look for other jobs. When she was interviewed for the present job her potential employer made no reference to her disability.

Respondent B attributes her success to the positive attitude of her company as well as her very supportive and helpful supervisor. Her supervisor and co-workers are helpful and she is not uncomfortable asking them for help. Examples of help that she requires, would be asking co-workers to manage her clients while she is on leave, search for files on high shelves and buy her favourite food in a non-accessible location. She would like to advance her career by securing a larger network of high investment clients.

Respondent B's advice to women with disabilities looking for employment is, "be proactive, be aware of your work rights, be confident, do not leave everything to fate and lose hope." She finds it necessary to have negotiating skills to request the management for necessary facilities and accommodations. Employers should not be overly concerned with the amount of medical leave taken yearly, because most people with disabilities do not require frequent medical attention.

Case 3

Respondent C has worked as a lecturer in Sports Psychology in a local public university, for the last 4 years. She is in her 30's and has a spinal cord injury due to a benign growth in the spinal column, diagnosed 12 years ago. She is self-supportive, lives with a friend and together with her siblings supports her mother financially. Respondent C's office is located in a partially accessible building. There is no lift and the ramp provided has a steep gradient unsuitable for wheelchair users, with limited upper body strength. She has to share accessible toilets with the students, since no accessible toilet is provided for the staff. No accessible showers are available in the building. The main entrance is inconvenient for Respondent C if it is locked on one side. She is able to move freely in the larger office but a sofa is not provided for her to take rest. She is eligible for staff housing, but did not apply because none of the buildings are accessible. She is driven to work by a friend and does not require a parking space.

Throughout the interview, Respondent C expressed her dissatisfaction with the gender and disability discrimination she faced from her supervisor. He is described as "unapproachable, favours work given to other men and would spend money to repair the porch but ignored the necessity of a suitable ramp." Her work assignments are limited to teaching and administrative responsibilities are shared among the male faculty members. When she received an achievement award given by the university, her employer did not give her recognition by sending a congratulatory note.

Her employer is described as, "lacks understanding about disability." He is also "condescending towards women." It took Respondent C 3 years to be confirmed for sabbatical leave but not for promotion. Her employer also did not allow her to teach final year courses. In contrast, her co-workers are "fine and I have a good relationship with them." She works very hard and loves teaching. She enjoys her close relationship with her students and her daily tennis games. She would have been a national netball player if she were not disabled. Her sports activities have been reduced due to her disability. She attributes her success to the collective encouragement from family and friends.. In addition, there is a lack of facilities for recreation for people with disabilities and mobility associated problems, in available facilities.

Respondent C is career oriented and would like to pursue her doctorate in Sports Psychology abroad, as well as be a certified Sports Psychologist. She advised other women with disabilities seeking jobs, to "not accept any job just because you need a job." Women should train themselves for the job they want, be confident during interviews, be firm and communicate their needs convincingly. They need to know their work rights, as well as government initiatives for hiring people with disabilities. Her final words speak for themselves, "be bold, be strong."

SUMMARY AND CONCLUSION

The findings reported in this paper are based on interviews of three employed women with disabilities. The women are gainfully employed because of their tertiary education and their positive self-image. The first respondent was given her present appointment because the accident that resulted in her disability, occurred on campus. The second respondent had her share of job rejections and experience taught her to demand for her work rights. The third respondent is still trying to overcome physical barriers at her workplace and at the same time, she has to deal with an unsupportive supervisor. All three cases provide useful insights into the employment history of women with disabilities in Malaysia. However, a more in-depth study is required to gather information on employment opportunities for women with disabilities in more marginalised situations such as those who are poor, uneducated, dependent on governmental welfare programmes and living in rural communities.

Employment means social equality and social freedom. Participation and access to employment is not a privilege but a basic right for women with disabilities. Employment for women with disabilities is important for three main reasons: (a) for economic independence and successful living, (b) for a sense of self-worth, dignity, and contribution to society, and (c) for integration into the mainstream non-disabled community.

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**STUTTERING IN THE VISUALLY IMPAIRED:
AN ATYPICAL GROUP**

Prakash B*, Dheepa D, Smitha R

ABSTRACT

The study investigated the speech of 10 adult males who were visually normal stutterers and 10 visually impaired stutterers with the intention to compare and contrast the dysfluency profile of the groups. The results revealed comparable type and frequency of blocks in both the groups. The incidence of stuttering in visually impaired persons was found to be more in the sample surveyed. The theoretical and practical issues in the management of visually impaired stutterers are indicated and discussed.

INTRODUCTION

"I'd rather be blind or deaf, or have a huge birth mark on my face, or be bald than stutter..." (1).

Research on stuttering in the past, have at least had three intentions namely (i) defining and explaining the symptomatology of stuttering (1,2, 3, 4, 5, 6). (ii) finding the cause (2,7, 8, 9) (iii) and cure for stuttering (1, 10, 11, 12, 13,). This has resulted in grouping and sub grouping stuttering (1, 14, 15, 16). The criteria for selection of subgroups were based on cultural influences, gender, severity, psychological adjustment, cognitive ability and neurogenic etiology. Yet another way to view this multidimensional communication disorder is as "atypical forms of stuttering". Among the subgroups that constitute obvious and uncontested minorities are the female stutterers, psychologically maladjusted stutterers and clutterers - the atypical forms of stuttering (17). The indisputable fact is that regardless of the theoretical views of causation and other issues - stuttering is in a sense atypical (17). However stuttering in the blind population had received little attention until Weinberg's research in 1964 (18).

Thyllefors (19) study shows the incidence of blindness in the world as 45 million (total blindness) and 135 million (low vision). WHO - PBD data bank (20) statistics show the incidence of blindness in India as 8.9 million. Prevalence of stuttering in the general population was estimated to be 2% in America (21). Incidence of stuttering in India is speculated to be 1 in 100 people (approximately). Weinberg's (18) research on the prevalence of stuttering among persons who are blind and partially sighted, reveals that the prevalence of stuttering is the

same as that in the general population. However, there are no such controlled statistics available in India. In this regard, the present study aimed to

- i. profile the symptomatology of stuttering in people who are visually impaired,
- ii. find out if differences existed in these profiles when compared with profiles of visually normal stutterers and finally,
- iii. to assess how do the visually impaired view the problem of stuttering.

METHOD

Participants

The participants in this study included twenty adult males in the age range of 22 and 30 years. They were divided into two groups, viz. group A and B comprising ten visually normal stutterers and ten visually impaired stutterers respectively. Participants in group 'A' were identified at the Department of Speech Language and Hearing Sciences of Sri Ramachandra Medical College and Research Institute, Chennai, during the camp conducted to commemorate International Stuttering Awareness Day (ISAD) 2001. Participants in group 'B' were identified at the Regional Centre of the National Institute for Visually Handicapped, Poonamallee, Chennai and Government Higher Secondary School for the Blind, Poonamallee, Chennai. They were selected from the ninety students screened at the school. All of them reported dysfluent speech since childhood. None of the subjects had hearing and cognitive deficits.

Procedure

The subjects were comfortably seated in a noise free environment and involved in the following experimental tasks: (i) conversational speech (revolving around daily routine, work place, time management and family), (ii) counting numbers one to twenty and (iii) narrating an incident or a story. Each speech sample lasted for a duration of four to five minutes, which was recorded on to a high quality audio cassette using a portable audio recording system.

Analysis of data

The recorded speech samples were transcribed verbatim and were analysed for sound syllable repetitions, part word repetitions, whole word repetitions, phrase repetitions, prolongations, filled pause, unfilled pause, false starts, parenthetical remarks and any other atypical dysfluency (if present). In addition, the percentage of dysfluency, number

of iterations and the rate of speech in words per minute (WPM) were also calculated. The data were tabulated and compared descriptively for the types of dysfluencies. The subjects' self perception of the stuttering problem were also analysed.

RESULTS

The dysfluency profiles of group A and group B are shown in tables 1 and 2 respectively and in figure 1.

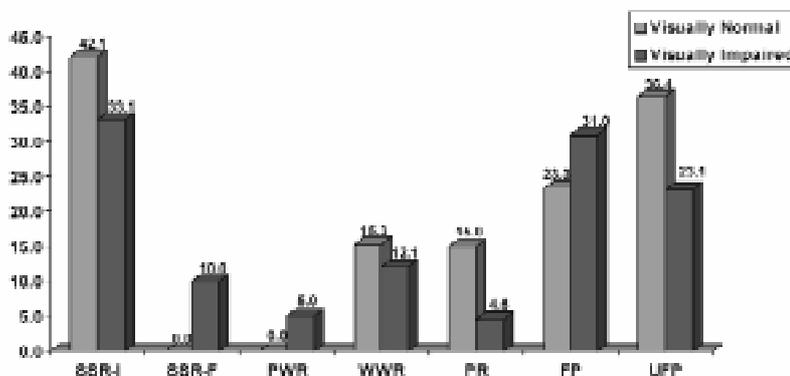
Table 1 : Dysfluency profile in group A (Visually normal stutterers)

Sub. No	Age in yrs	% dys fluency	No. of dys fluencies	No. of utterances	% Sound Syllable Repetition			No of iterations	% Whole Word Repetition	% Phrase Repetition	% Pauses			Mean duration of pauses in seconds	Rate of Speech in WPM
					Initial	Final	Total				Initial	Final	Total		
VN1	33	36.9	24	065	70.8	-	70.8	1-3	-	-	29.2	-	29.2	2.0	100
VN2	21	45.7	48	105	39.5	-	39.5	1-3	-	-	16.7	20.8	37.5	3.0	081
VN3	17	43.1	22	051	27.2	-	27.2	1-2	-	-	09.1	63.6	72.7	4.0	043
VN4	14	11.2	14	125	28.6	-	28.6	1-2	-	-	35.7	35.7	71.4	3.0	130
VN5	15	22.3	19	085	21.0	-	21.0	1-2	-	-	21.0	51.9	79.0	3.5	076
VN6	24	07.7	05	065	40.0	-	40.0	1-2	-	20.0	-	40.0	40.0	2.0	091
VN7	22	14.6	18	120	22.2	-	22.2	1	-	-	38.9	38.9	77.8	2.0	128
VN8	21	40.0	30	075	40.0	-	40.0	1-3	-	10.0	16.7	33.3	50.0	1.5	088
VN9	29	14.0	14	100	57.1	-	57.1	1-2	-	-	35.7	07.1	42.8	3.0	129
VN10	33	34.7	26	075	76.9	-	76.9	1-3	15.3	-	07.6	-	07.6	1.5	126
Mean	22.9	27.0	22	86.6	42.3	-	42.3	2	15.3	15.0	23.3	36.4	50.7	2.4	099

Table 2 : Dysfluency profile in group B (Visually impaired stutterers)

Sub. No	Age in yrs	% dys fluency	No. of dys fluencies	No. of utterances	% Sound Syllable Repetition			No of iterations	% part Word Repetition	% Whole Word Repetition	% Phrase Repetition	% Pauses			Mean duration of pauses in sec.	Rate of Speech in WPM
					Initial	Final	Total					Initial	Final	Total		
V11	19	16.4	21	128	14.3	-	14.3	1-3	-	09.5	-	66.7	09.5	76.2	1.5	091
V12	19	24.5	60	245	33.3	10	43.3	1-5	05	03.3	3.3	38.3	06.7	44.9	2.5	086
V13	21	17.7	25	141	32.0	-	32.0	1-3	-	36.0	-	12.0	20.0	32.0	1.5	109
V14	18	24.0	46	191	17.3	-	17.3	1-3	-	13.0	6.5	41.3	21.7	63.0	3.0	108
V15	20	18.2	53	290	18.9	-	18.9	1-3	-	03.8	-	49.0	28.3	77.3	2.5	089
V16	20	18.5	69	371	27.5	-	27.5	1-3	-	13.0	-	18.8	40.6	59.4	2.0	111
V17	20	14.3	24	167	33.3	-	33.3	1-2	-	12.5	4.1	12.5	37.5	50.0	2.0	099
V18	20	16.9	20	118	35.0	-	35.0	1-3	-	15.0	-	15.0	35.0	50.0	2.0	100
V19	13	08.7	69	191	73.9	-	73.9	1-4	-	05.8	-	11.6	08.7	20.3	2.0	088
V110	33	17.2	22	128	45.5	-	45.5	1-3	-	09.1	-	45.4	-	45.4	3.5	117
Mean	20.3	17.6	40.9	197	33.1	10	34.1	2.5	05	12.1	4.6	31.0	23.1	51.8	2.2	099

Figure 1: Dysfluency profile in groups A & B



SSR-I : Sound Syllable Repetition - Initial
 SSR-F : Sound Syllable Repetition - Final
 PWR : Part Word Repetition
 WWR : Whole Word Repetition
 PR : Phrase Repetition
 FP : Filled Pause
 UFP : Unfilled Pause

Analysis of data reveal that both the groups A and B exhibited similar types of dysfluencies. They included:

- i. sound syllable repetitions (mean : 42.3% in group A and mean : 33.1% in group B)
- ii. final syllable repetitions (10%) in one subject in group B whereas no such dysfluencies were identified in group A
- iii. part word repetitions were not found in group A
- iv. whole word repetitions (one subject in group A and all subjects in group B)
- v. phrase repetitions (two subjects in group A and three subjects in group B)
- vi. mean number of iterations (one to three in group A and one to five in group B)
- vii. pauses i.e. both filled and unfilled (mean:50.8% in group A and 51.9% in group B)
- viii. mean duration of pauses ranged from 1.5 to 4 seconds in group A and 1.5 to 3.5 seconds in group B
- ix. prolongations, parenthetical remarks and false starts were not observed in both the groups.

Rate of speech ranged between 43 WPM and 128 WPM in group A while subjects in group B had their rates of speech between 86 WPM and 117 WPM.

All visually impaired stutterers were aware of their speech problem. None of them knew of management options for the same. However, none felt that speech was a major impediment in their life, unlike the visually normal stutterers.

DISCUSSION AND CONCLUSION

The study focused on deriving and comparing the dysfluency profile of visually normal and impaired stutterers speaking Tamil. In consonance with Weinberg's findings (18), the present findings show no variations in the types and percentage of dysfluencies between the groups.

However, of the ninety students surveyed in the two blind schools, ten exhibited considerable percentage of dysfluencies to be labelled as "Stuttering". This is higher than the perceived notion that the prevalence of stuttering among blind persons is the same as that in the general population. One may handle the present finding with caution, owing to the small sample of visually impaired persons surveyed. Lack of scientific data to support incidence and prevalence of stuttering in the general population in India, further complicates the issue.

The finding that visually impaired stutterers view their problem as less interfering in their day-to-day life, unlike visually normal stutterers, has theoretical and practical implications. Stuttering caused and perpetuated due to listeners' adverse reaction to the dysfluent speech may be questioned at least from a remote sense. Managing stuttering in the visually impaired raises a question of whether one should create awareness of the speech problem and then treat or apply other innovative ways to deal with the impediment. Further research should probe a larger sample and find other associated symptoms like fear, anxiety, physical concomitants etc. These would aid in deciding whether different treatment strategies or techniques are to be devised and used with visually impaired stutterers, who in principle could be considered as an atypical group.

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CBR WORKS BEST THE WAY LOCAL PEOPLE SEE IT AND BUILD IT

M. Miles*

ABSTRACT

The growth in availability of practical information by which people may manage disability in home and local community, and some problems of transmission and cultural adaptation, are reviewed. There is a growing menace of simplistic globalised packages, promoted by deeply confused 'flying experts', ignoring or dismissing the indigenous concepts, knowledge and skills that are essential to success in disability service innovation.

INTRODUCTION

'Though Gandhi saw nothing wrong in learning from Europe, his major worry was that since his countrymen had no clear idea of the central principles and weaknesses of their civilisation, they did not know what to borrow and remained vulnerable to passing fashions and crude or subtle pressures of the aid agencies (The author originally wrote 'colonial rulers'. The modern equivalent, i.e. 'aid agencies', is here substituted). Even the most conservative Indians indiscriminately borrowed institutions and values incompatible with the central principles and ideals of their civilisation' (1).

This paper probes some gaps between global ideologies of disability service provision and grass-roots realities. The prevailing imbalance of resource distribution across the world means that for the great majority of disabled children and adults in economically poor countries, most of the formal and informal services available during their lives are provided, and *will* be provided, by resources that already exist in their locality; that is, if anything is provided at all. Services are more effective when already existing resources are enlisted in plans based largely on local concepts, knowledge, skills and design; with a modest level of imports from other countries, suitably adapted. Plans that are well understood by their implementers will be more easily adaptable by them in local situations that are undergoing substantial changes. Such plans may be called CBR, or XYZ; the name is unimportant. What matters is that concerned people in any locality should work towards what they see as appropriate goals for disabled children, and should learn from their own successes and mistakes.

The term 'CBR' has had many uses, some more ludicrous than others. In a southern African country, I once declined to accompany a Nordic team on a trip (eight hours driving each way) to see the 'CBR project' for which their agency was paying. Very late that night the Nordics returned, almost speechless with dust and annoyance. They had been taken to see

some European nuns caring for a few disabled children in an institution. This was the 'CBR project'. Maybe some semantic confusion had arisen. The disabled children were not being cared for 'at home' by families; they were being cared for 'in the community' by the nuns. So it was 'Community Based Rehabilitation'. Some of this kind of confusion is inevitable. Global communication promotes the rapid spread of buzz words, but the meanings rapidly diverge as people with different languages hear them, make sense of them in their own conceptual worlds, and invest them with meaning. (It was also obvious through the 1990s that funding could not be had for work with disabled children unless it was called 'CBR', or 'Inclusion'; so that is what applicants called it, regardless of meaning).

People in impoverished Asian or African countries who must deal with Europeans in the aid game spend a lot of time smiling, nodding and seeming to agree with western plans, while thinking how to bridge the gap between words and realities. They are usually well aware that the westerners understand nothing of the conceptual worlds they are blundering across with their plans and targets. The people hoping to receive aid may be less aware of how confused many western aid 'experts' are about what is happening in Europe or North America, where service policies have lurched round several historical loops under successive ideological master-plans. Frequent looping brings intellectual paralysis, more 'spin' and less actual service provision. Emotive words like 'community', 'rights', 'empowerment' and 'inclusion' are randomly sprayed on every policy. The frontline workforce spends less time in contact with people needing help, and more time sitting in their cars (parked 'in the community') filling timesheets and case reports so that managers can 'prove' the delivery of 'community entitlements'. Those who end up giving 'expert advice' to countries several thousand miles away, have seldom directly participated in this shambles. More often they have lectured about it in departments of social policy or disability studies; or have given courses 'preparing' managers to surf the whirlpool without being punched in the eye (or at least, not too often) by services users who feel 'empowered' by the rhetoric, but find 'care in the community' insufficiently caring.

During the 1980s and perhaps as far as 1993, i.e. the period when CBR was sexy in the aid game, one could meet people who imagined they 'knew what CBR was' and were keen to correct anyone having a different idea. As CBR has slowly declined as an aid trend, it is now rare to find people who think they are the only enlightened ones. With one meaning or another, CBR will probably be around for decades yet. Many more people will try it the way someone tells them, or (perhaps) the way they think it should be. The more realistically they assess their situation, potential resources and the likely effects of socio-economic trends and changes, the more likely they are to produce results that count as positive within their own context. The more idealistic they are and the more slavishly they follow wondrous schemes devised by far distant planners having no personal, hands-on experience of managing disability service development, the less likely they are to see success. This should be so obvious as not

to be worth writing - but the past 25 years saw floods of misguided importing of hopelessly idealistic schemes, which might perhaps have succeeded in some other, kinder, happier, imaginary world, but hardly in the world of late 20th or early 21st century reality.

HINDSIGHT ON INFORMATION

Histories of medicine, therapeutics, special education and rehabilitation suggest that the discovery and refinement of treatment and management methods has always been far ahead of their distribution to the people at large. In every age some effective knowledge and skill was available to a few people in a few places; elsewhere much less was available and people suffered for lack of knowledge and skill. Some attempts to bridge the gap have been made by locally trained or untrained practitioners, by itinerant quacks, and by various information media. Over a thousand years ago the physician al-Razi (865-925) wrote a manual called 'He Who Has No Doctor to Attend Him' (Arabic: *Man la Yahduruhu Tabib*) to spread useful self-treatment knowledge for common conditions, including hemiplegia, epilepsy and depression. It was disseminated by hand copying, long before the European development of printing. When printed material began to have a larger impact in urban Europe during the 16th century, medical knowledge also became more widely available, though confined by the limits of literacy and weaknesses of communication skills in practitioners. Almost 500 years ago came the first printed vernacular self-help book for expectant mothers, *Rosengarten* by the German paediatrician Rösslin, with advice also on treating children with epilepsy, eye defects or impaired motor abilities. Delegation of responsibility to rural practitioners with briefer training also has a long history. For example, urban British physicians in the Punjab linked up with rural Indian healers in the mid-19th century to provide a wider coverage. A century back, radio communication was born. Fifty years ago television was going public. Ten years back the Internet began its boom. The latest 'Where There Is No Doctor' (by David Werner and colleagues) has over 3 million copies in print in 80 languages. Werner's follow-up manual, 'Disabled Village Children' can be accessed on web pages by 500 million Internet users, and in any small town that boasts a cybercafe. Any page of it can be machine-translated with about 70% accuracy into 30 or more languages at low cost.

Technologies exist that can communicate tested, low-cost, practical knowledge and skill as fully illustrated screen text or video, concerning disability prevention, treatment and management in home and neighbourhood, to populations worldwide during the next 20 years. (If the world decided to forego one small war and do this instead, it could be achieved in two years, while offering polite regrets to the arms dealers for their loss of business). The global population, as far as remote villages, has already been reached by alluring messages and images about Coca Cola, McBurgers and various Hollywood goddesses. Admittedly, the world was not

expected to do much with these commodities apart from buying and consuming them or their pictures. Junk food sales show how far modern messages can penetrate when people have strong economic motivation to communicate across barriers of distance, literacy and culture.

In the disability service game, the drive for effective mass communication is comparatively weak. Several hundred thousand people earn their bread selling small pieces of disability-related knowledge and skill in clinics and schools in cities and small towns worldwide, in several hundred languages. If more and better information were already available and understood in every household, many of those people could be out of a job. More likely, they would upgrade their knowledge and skills to stay ahead and to facilitate the use of the information by each household needing it. But the information is not disseminated, made available in many languages and conceptual forms, facilitated, monitored, recycled, improved. The technical means exist, but the motivation is not there, especially for the difficult part which consists of blending small inputs of exterior knowledge with larger amounts of local concepts and cultural heritage. Much of the energy that should go into disability service and information development is dissipated in management and structures and buildings and politics and mutual throat cutting and conferences. Few of these activities seriously contribute to making the necessary knowledge and skills available in local languages and cultural / conceptual forms so that people could - if so minded -- competently prevent, treat or manage most of their disability by their own resources. What proportion would be so minded, if suitable information were available in appropriate and attractive forms, is not known. Intransigence and non-compliance with disability-related information is a worldwide problem, and the huge rise in availability of advice in info-rich populations leads to many contradictions and uncertainties that are hardly health-generating (2).

'GLOBOTOMISED' MENTALITIES

The need to be able to defend local choices and differences is becoming urgent as delusions of grandeur and omniscience spread among a growing class of 'globocrats', or (g)lobotomised bureaucrats. The totalising and globalising mentality has existed in the past among some rulers and administrators; yet it was limited by the comparatively weak availability of mass media for disseminating standardised knowledge, and the fact that nobody ever ruled more than a third of the world, nor did they seriously believe that they knew what was going on at the far ends of their empire (or even the other side of town). Now, after 50 years of growing globalisation of knowledge and of economic power, some officials in UN agencies and big INGOs suffer from the delusion that they hold in their hands the health and welfare of billions of little people 'out there', and that the responsibility has been given to them to lead, persuade or coerce the billions into living according to the decrees of Those Who Know Best.

Something of this delusion has entered the disability game. Medical knowledge generated during the 20th century in the Western Europe and North America civilisation achieved urban dominance worldwide through its combination of a strong experimental base, its system of refereed publication of material designed to extend and challenge the system, and the growth of media designed for rapid urban dissemination and feedback, at first nationwide, more recently worldwide. Techniques and therapies for *medical and physical aspects* of disability also got aboard the globalising trend from early in the 20th century. If it worked in London or Paris it was considered workable in rural Lesotho or Peru. With no natural predators, the globalising or McDonaldising medical mentality is able to flourish. (On the ground, however, implementation of grand medical plans does not work on scientific lines but with political expediency, economic chicanery, and a deep mistrust in the population for schemes foisted on them by urban technocrats and foreign dreamers).

Techniques and teaching methods concerned with *learning and socio-cultural aspects* of disability have met greater difficulties of global transmission and replication. The educational field has not seen a body of knowledge that achieved a global spread and urban acceptance equivalent to that of modern 'western' medicine. Learning and teaching processes and outcomes have been much less susceptible to scientific investigation. The nearest approach to global dominance in special education was the spread of 'oral' education of deaf children after 1880; yet that dominance was less than total in practice, however much lip service it received. In pedagogy for children with mental retardation or intellectual disabilities, no single method predominated. Techniques such as the Montessori approach, and behaviour modification, have had a vogue and been partially adopted in the general repertoire; but such fashions often generate exaggerated claims based on anecdotal evidence, which eventually attracts the sceptical gaze of researchers, as has happened with the claims of 'Portage' (3).

Braille's code of dots, for blind people to read, also has an appearance of complete domination as the 'solution' for blind people, and exemplifies an earlier globalising mania and narrow focus. The first schemes for blind reading that achieved international dissemination, i.e. the Lucas method, soon overtaken by William Moon's embossed script, were adapted for use in parts of India in the 1840s and 1850s, China in the 1850s, and Africa in the 1860s, enabling some blind children to be integrated in ordinary schools. The international spread of Braille came later. It was harder to learn but much cheaper to print, and could be produced by blind people independently. By about 1910, it had eclipsed Moon; yet battles raged through the 20th century over attempts to standardise Braille, against local innovations and adaptations. All these efforts now seem problematic because they focused blind education on literacy and were confined to a small proportion of the world's blind population. The majority would probably have benefited more from an earlier focus on orientation and mobility training and activities of daily living and skills for economic gain. (Or perhaps the majority, if ever they could have been consulted, might have had completely different priorities).

The 'triumph' of modern science-based medicine and the increasing complexity of knowledge in every social field might have led to a recognition of the need for a range of complex, flexible, locally-adjustable solutions. Yet such recognition is weak, partly because of the rising politicisation and mechanical 'package-delivery' mentality of service supply. Complexity of demands has tended to stimulate and reinforce a belief or delusion that *there must be a global 'best way'*, an evidence-based global 'best way' across the range of disability services, and this 'best way' can be discovered in a synthesis of the latest western methods and experiments, and then can be launched aggressively across the world, regardless of cultural and conceptual differences.

'We didn't get rid of smallpox by listening to their guddam cultural whoosits and witch-doctors and whatever. We went out there and jabbed good clean western vaccine into them and that's how we stopped smallpox. We gudda do it again with their blind and deaf and epileptic and mentally retarded and whatever other kids they got hidden away in the back room - because We Know How To Do It, and those kids have Gudda Have Their Rights! We-all are one Global Village now so those kids are Our Kids. And all Our Kids gudda have the best we can givvem'. [Slight paraphrase of the apparent sentiments of some globotomised (mis)planners c. 1995-2005].

This kind of simplistic, neo-imperial baloney seems to have become the default position in some (not all) UN and INGO agencies dealing with health, welfare, mothers and children. The fiasco of the so-called International Classification of Functioning (tested as ICIDH-2) indicates both the delusions of grandeur that may afflict a team working 'globally', and the additional problems of classification and terminology in the disability field, as against the purely medical field (4).

CONFORMIST AND U.N.-CONFUSED

UN and INGO staff are an odd mixture. Some come up through a privileged urban modernist English-language education, in countries where the modernising urban elite is a small minority battling against the colossal weight of a pre-scientific, traditionalist majority. Modernism and 'scientific progress' have been their guiding light and life-identity. Many are conformist and opportunist, climbing the career ladder by working hard within the current paradigm and never challenging the conventional wisdom. Others have shown some initiative and independent thinking back home, but are dumbed down by being 'called upward' to international working groups and advisory positions, before finally achieving brain-death while cocooned in UN or INGO billets, well paid and well insulated against the realities of life experienced by the majorities still living in rural poverty and urban slum squalor. There are also some who know that 'modern, scientific' solutions have had their day. They feel the chill winds of postmodernism, they know that there is a growing loss of confidence in the ability of the

dominant euro-american civilisation to solve global problems, or even to contain (let alone solve) its own huge social problems. They are also frustrated by their own helplessness amidst the stifling globobureaucracy. Yet they know that there is no comfortable living to be made as prophets of doom -- so they continue churning out the platitudes and hypocritical baloney, at least until their own pension is secured. In retirement some of these worms turn and hiss quietly at the organisations they once served.

Many more international aid people are deeply confused, so are motivated to read the global evidence optimistically. Certainly, much economic and social progress took place across the world during the 20th century. Hundreds of millions of people in Asia and Africa have a higher material standard of living than their grandparents and great-grandparents. Child mortality has been halved or quartered in more than 90% of countries, primary education has doubled or tripled, far more girls can expect a life with some education and paid employment as well as raising comparatively healthy children; more disabled people have access to mainstream services and benefits. **Why not be happy about it all?** The problem is that all 'development' (of the sort sponsored by large-scale euro-american aid) seems to *extend the range* of living standards within target countries, rather than shrinking the range by moving poorer people upward. Extending the range means that the optimists can find plenty of evidence that tens of millions of people have benefited from 'development'. Yet across sub-Saharan Africa and large areas of Asia the population is rising rapidly at the poorer end, so the number of people in desperate poverty hugely overfills the gap left by those who have shifted along the quality of life spectrum.

Earlier gains, e.g. in reducing child mortality, mean that millions of children survive for whom little or no health and educational services are available. In Pakistan for example, school provision tripled since Independence, which was a major achievement by the government; but the population also tripled. The optimist celebrates the greatly increased number of children getting some education. The realist notes that there are now vastly more children growing up illiterate and in absolute poverty than there were 50 years ago; and that with each passing year the 'education' offered in ordinary government schools sinks further below what is needed for economic productivity in the 21st century. If that is so for basic health and education services, the picture for childhood disability services is equally dismal; but it is also more complicated, and UN/INGO data are even further from reality. Many of the 1990s gains in child health and school access are disappearing as AIDS increasingly kills teachers, nurses and community workers across Africa and Asia.

UNEXPECTEDLY LUNATIC

How should one deal with aid people who seem fairly rational in everyday life, but who transfer ludicrously inappropriate policies from their home country to regions with very different

cultures and economies? Should one tell them they are behaving stupidly? That is unlikely to move things forward. One European agency, full of goodwill, asked me to advise a national disability organisation in southern Africa. The Europeans had paid for a UN disability statement, based on the concerns of wealthy countries with advanced social services, to be translated and printed in local languages. (In this particular country all formal education is in English. Anyone who can read at all can read English; but the European agency did not know this). My report highlighted quotations from reports of two rural branches of the disability organisation. One reported translating the UN document - full of 'rights' rhetoric - into a local language. The other branch reported that they had baked cakes, collected firewood and sold these items at the roadside so that their disabled children could afford to go to school.

This is the gap, or a tiny part of it. It appears wherever one looks, if one's eyes are open when looking. Another long-lived lunacy is, for example, the assertion that services are available to 'only 2%' of disabled people in developing countries - ignoring the reality of disabled children and adults using existing ordinary services (Medline provides ample research evidence). This parallels the belief among many Europeans that everyone in Africa 'lives in a mud hut'. There is often an amateurish reliance on experiences in projects in tiny countries. The aid equivalent of hugging a warm puppy is to visit one of those pocket-sized, pat-on-the-head nations, where the aid advisor can strut about as someone of importance. I once met a UN rehabilitation advisor who flew to Pakistan, an Asian Islamic nation having then 82 million people, direct from Barbados, a Caribbean island of 250,000 people. To address a national meeting the day after he arrived, he used his Barbados master plan, simply multiplying everything by 328 and substituting 'Pakistan' wherever 'Barbados' appeared. (His paper was distributed with the changes fully visible). Such stories are perhaps hard to believe - but there is a well-documented collection and analysis of the ludicrous world of 'flying experts' in agricultural and infrastructural development, where local knowledge, experience and cultural heritage is routinely dismissed in favour of some imported wondrous scheme (5). Some flying experts do retain their personal critical faculties. They continue offering the ridiculous 'package' they are paid to promote, but if challenged will admit that it is merely a gesture toward some distant, ideal future. Provided the rhetoric and ritual are respected, something more realistic can be planned on the ground.

Another blunder is to force CBR into 'Community Development' - as if all these activities require elementary skills that can be learnt from a textbook while cycling between villages. It is often associated with 'Rights' jargon, regardless of the practical constraints on poor people's access to legal rights in the countries concerned, and the questionable relevance of 'rights' ideologies based in western urban (male) individualism as compared with family and group identities in rural areas of developing countries. The effects of aid blunders continue long after the perpetrators have returned to the comforts, certainties and insurance policies

of their home countries. Paper-based 'rights' and 'inclusion' slogans, backed (naturally) by a fraction of the structural and attitudinal changes and resource provisions needed to give them substance, increase the gulf between rhetoric and reality while relieving families and communities of even the 'charitable duty' they may earlier have felt, however half-heartedly, to give disabled children some assistance. For many have-nots, even what little they once had is thus snatched away and replaced by fine-sounding slogans. They would have done better selling firewood and cakes.

CONSTRAINTS ON GROWTH OF CBR KNOWLEDGE

One reason why disability service planning associated with the CBR term (with spray-on 'rights', 'empowerment', 'inclusion' etc) has lost its way is that CBR knowledge is still thin, scattered, mostly unsifted, unreliable, unrecorded or unpublished. There are very few carefully observed descriptions of what actually happens at the front line, e.g. daily lives and activities of children and adults with disabilities in developing countries, whether told by themselves or an observer; daily care, treatment or management activities by relatives and others; ordinary activities of CBR workers with health, education and community development animators; activities of other people in the community, that have some impact, or could have impact, on disabled people (e.g. shopkeepers, builders, police, religious teachers, neighbours). Where such description is lacking, because nobody has bothered to observe and record and circulate it for feedback and collect further descriptions from different viewpoints, 'CBR' remains merely a set of disparate notions in different people's minds with little grounding in lived realities. The lack of observation and description leaves it open for any fool sitting in a distant aid office to dictate what CBR should be, without meeting any contrary evidence. The modest amount published about CBR continues to be mostly on 'What A Great Job We Did', i.e. the heroic struggle to get things going, urgent pleas for funds to expand, anecdotes from grateful clients, etc. No doubt this literature has its place, but the genre seldom contains any serious, critical thinking.

Some constraints on the growth of CBR knowledge are obvious:

1. Different meanings of 'CBR', as noted above. Through three decades CBR activities have been planned and run by individuals and groups usually knowing very little about what has occurred elsewhere. The tendency to work in ignorance continues because CBR involvement leaves little time for reading and information seeking. CBR knowledge and experience is seldom recorded in a careful, evaluative way. When carefully recorded, it is seldom widely disseminated.
2. Major differences exist in cultural and conceptual underpinnings, e.g. meanings of 'disability', 'health', 'community', and in patterns of interventions, expectations of health and healing.

3. The field is non-commercial and money can hardly be made from it. With no profits, there is little incentive for investment, no infrastructure, no information systems. CBR lives in borrowed space and temporary budget. Behind the Rights rhetoric, it is charity in practice.
4. Language barriers and lack of web access hinder communities from exchanging their experiences. Barriers between professional disciplines and fears of encroachment make professional exchange harder in most parts of the world.
5. Very few people in CBR have enough independence to look critically at what is going on, without the fear that they may lose their job, or fail to get the next consultancy contract.
6. The longstanding gap between the world of services for disabled *children* and that for disabled *adults* flourishes in the CBR field. This contributes to fragmentation of knowledge. Issues debated between families, children and professionals are separated from debates between disabled adults and another set of professionals.
7. Formal CBR research has been weak or non-existent in most developing countries. There have been probably 20 non-medical doctoral theses directly on CBR plus 20-30 linked with CBR and allied activities, during the past 15 years, and three times that number of theses at a lower academic level. (Estimates are based on a collection of large bibliographies on disability in South Asia, Middle East and sub-Saharan Africa). This is better than nothing, yet the great majority have not been published or made easily accessible. Most have a restricted focus, e.g. measuring effects of one aspect of CBR on specific members of a small population in a given location, sometimes with controls. Taken together with the modest amount of CBR research in refereed journals, they might add up to a body of knowledge; but no serious, critical appraisal has yet been made of even a quarter of this material. (Rather more review has been made of 'CBR' experiences in economically developed countries -- there is money available for doing so, and researchers eager for the money).

Possibilities do exist to set up collaborative recording of experience, stronger critical appraisal and evaluation, with wider dissemination, regular low-cost electronic meetings for exchange, at least in some countries, on the model of a 'Cochrane collaboration for Evidence-Based CBR'. The present *Asia Pacific Disability Rehabilitation Journal*, and the CBR website run by Jönsson, Helander and Herda at: <http://dag.virtualave.net/cbrforum.htm>, carry a slowly growing number of field reports and critical material from various viewpoints.

'BAKING CAKES' AGAIN?

Considering the narrowness and limited quality of 'CBR knowledge', it is easy to focus down to a minimal level of rehabilitation, and miss or dismiss the vast euro-american growth of technical and human knowledge applicable to rehabilitation procedures, which will increasingly be applied, as euro-american disabled people demand it. I noticed this gap recently, reading two doctoral theses. In one, a Dutch specialist in rehabilitation medicine observes and describes some of the paths through assessment and rehabilitation procedures in the Netherlands, from the differing viewpoints of individuals whose daily life and world has been disrupted by serious disease or injury, and of rehabilitation professionals engaging in assessments, therapies and rehabilitation. Van Dijk (2001) gives a detailed, sensitive and far-reaching analysis, bridging across communication gaps that disabled people have long complained about and of which the more perceptive professionals have long been aware (6). The second thesis, from a Belgian physical therapist in francophone Africa, discusses the origins of CBR and describes efforts to develop CBR in Benin and Ghana, with a field survey to assess the inputs and outcomes for over 500 participants aged 0-33 years and to distinguish factors contributing to the success or failure of the CBR work (7). This is a significant contribution to knowledge about the feasibility, planning, costs and outcomes of particular types of CBR in West Africa, in a context where few formal services were available compared with the Netherlands, and where it is probably correct for the main emphasis to be placed on extending at least a basic level of resources to far more of the population.

Would it then be foolish to hope that some attention might also be given to incorporating African service-user perspectives into CBR planning, in terms of both cultural-historical resources and personal knowledge and individual preference and feedback during the rehabilitation processes? Or is this again the contrast between translating some ridiculous UN Declaration, and baking cakes to sell at the roadside so that disabled children can pay school fees? The decision of course lies with people in the countries concerned. Fortunately another form of research has given a remarkable balance between these opposite poles of knowledge: the detailed account by David Werner of 'personalisation' of rehabilitation processes in a remote Mexican village, where disabled children and adults were encouraged to take charge of their environment, mobility aids and gadgets, and to rebuild their lives by their own initiative and mutual help, with intermittent advice from professionals who came to assist rather than to direct (8). This sort of 'CBR knowledge' has been underestimated, whether in Europe or the developing world.

Disempowering knowledge

One constraint is that the CBR field is plagued by high-level baloney and spin, lies, distortions and unsifted data, e.g. that grossly inflate numbers of disabled people and dismiss from the reckoning most of the informal local resources. Certainly, even those disabled children in

developing countries who have access to some formal services still don't have a lot going for them. For the majority, life is nasty, brutish and short, even in their own terms. Yet when one studies the social histories of how services develop, attitudes slowly change, things get done, chances open up, in Asian and African societies across centuries, it becomes apparent that the complex and multi-layered truths are indivisible. This means that the simple slogans and half-truths, i.e. the stock-in-trade of advocacy organisations, politicians and UN agencies, in the long run obscure the truth and do not serve those disabled children well. They affect people's behaviour adversely. If people know that on the ground some services are used by 20 to 30 per cent, but the globocrats, politicians, foreign academics and other fools in big cars continue to insist that it is only 2 per cent, this inevitably diminishes people's confidence in their capacity to change their lives and make their communities and societies less brutal. When high-level baloney overrides hard-won experience, it is very disempowering.

THE INFORMATION APPROACH AND CBR

CBR can usefully be viewed as an information system (9). Knowledge, skills and design are obviously needed in CBR, whether we think of a disabled baby, a politician drafting a law about access to public transport, or an elderly deaf person learning new income-generating skills along with others at the local mosque. Underlying the necessary knowledge and skills there are many deep local concepts of how life is lived, how family members relate to one another, the behaviour expected of children, how disabilities affect living, differences in gender roles, etc. These underlying concepts vary from area to area, and between regions, and between one religion or philosophy and another. Therefore it is impossible to define CBR and the aims and objectives of CBR on a global basis, once and for all. To some extent, CBR has to be discovered and practised by people for themselves, in each country, each town, each neighbourhood.

Scaffolding

Discovery for oneself does not mean that the knowledge, skills and design developed in one place cannot be used in another. Of course some imported knowledge and skills can be useful, mainly as scaffolding, to a lesser extent as building material, to enable people to construct CBR to their own design, based on their own conceptual foundations, rooted in their own country, their own histories, their own ways of living and being. Such a construction cannot be imported en bloc from one country to another. It can seldom be imported from city institution to rural village, or urban slum. On the other hand, it is rare to find it successfully constructed by villagers or slum dwellers entirely by their own efforts. Partnership is needed. Mutual listening and learning is needed. Some of those with one sort of knowledge and skill (maybe modern, urban, biomedical) may need to listen and learn from people with another sort (e.g. rural, survival-based, with religious elements) and vice versa. People with a traditional

heritage of concepts may need to delve into their folklore, art and drama, to uncover the positive and the ambivalent views of disability and assistance, and decide which are the authentic and valuable parts on which they will build. They are likely to do this only if they find that the offer of help from the city or foreign CBR advocate includes a genuine respect for different cultures and concepts.

CONCLUSION

CBR works best the way local people see it and build it.

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