

EDITOR'S COMMENT

The development sector has always been a dynamic one, witness to continuous change, innovation and reinvention. This includes changes in terminology for different facets of development over different time frames, for example, from 'rural development' to 'community development' to 'poverty alleviation' to 'poverty reduction.' In the disability sector, an example of changes in terminology is from 'vocational rehabilitation' to 'economic rehabilitation' to 'income generation' to 'livelihoods'. Some of these changes in terminology reflect the change in underlying ideology or principles, while some others are influenced by what is considered 'politically correct' at that point in time.

The one term that has stood the test of time in the disability sector is community-based rehabilitation (CBR). CBR is considered as the most significant innovation over the last quarter century for people with disabilities, especially for those in rural areas in developing countries. The positive benefits of CBR are documented in evaluation studies from different countries. The term 'CBR' is now a strong brand in itself, recognised all over the world. It is arguably the only 'brand' that has survived for such a long time in the development sector. That is why it seems unfortunate that there are moves today to change the name of community-based rehabilitation, because some groups in the disability sector do not consider it 'politically correct' to include the word 'rehabilitation' in the term.

Regardless of what is 'politically correct', CBR today is understood by most stakeholders in the disability sector as a strategy to promote inclusion, rights and equal opportunities for people with disabilities. Measures for 'rehabilitation' and 'impairment correction' are an equally important part of CBR, especially from a developing country perspective where there are still areas with minimal services for people with disabilities. Apart from vertical CBR programmes, the twin track approach, which promotes inclusive development while addressing particular needs of people with disabilities, is also an increasingly accepted strategy. This approach is becoming evident in current CBR trends, where CBR projects address the special needs of people with disabilities, and promote their inclusion in all mainstream development processes and activities.

No doubt there are CBR practitioners in some parts of the developing world who still see it as only a service delivery, 'impairment correction' approach, but this is not reason enough to

discard the term. Besides, changing the name of CBR into anything else will only lead to confusion, and in the long run, deprive people with disabilities in developing countries of the positive outcomes they get through CBR projects.

What is needed is education - for older CBR practitioners and for groups that are agitating for a name change - on the developments, current understanding and practice related to the term CBR, and to retain the same term that is well recognised and accepted in the disability sector in developing countries. Otherwise we are in danger of losing the only approach that is still seen as the most appropriate one for these countries and the only significant brand that the disability sector from developing countries can be proud of at present.

The APDRJ team wishes its readers a Happy New Year!

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GUEST EDITORIAL

**PERSPECTIVES ON DISABILITY, POVERTY AND
DEVELOPMENT IN THE ASIAN REGION**

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ABSTRACT

This study addresses the vital link between disability, poverty and development in developing Asian countries.

The social model of disability defines "disability" as the consequence of institutional and social discrimination, as well as exclusion of persons with impairments. It is possible that a comprehensive social model of disability can provide a new framework for explaining the complexity of disability, poverty and development, exposing disability as a cross-cutting developmental issue. Furthermore, adopting such a model will shift policy focus towards improving the social-economic conditions that currently restrict disabled people from full participation in life. However, it is still a valid fact that in developing countries, poverty is not only a dependent variable of social processes and social barriers, but also a root cause of many forms of impairment and disability. Thus, best practice is most likely to be ensured through an integrated approach, using best practice of both social and developmental terms.

This study aims at identifying priority areas for immediate action. Also, the empirical part of this study reviews and analyses the collective opinions and perceptions of those who took part in the questionnaire survey and focus group discussions, regarding disability rights, twin-track approach and priority areas, and targets for action by development agencies.

INTRODUCTION

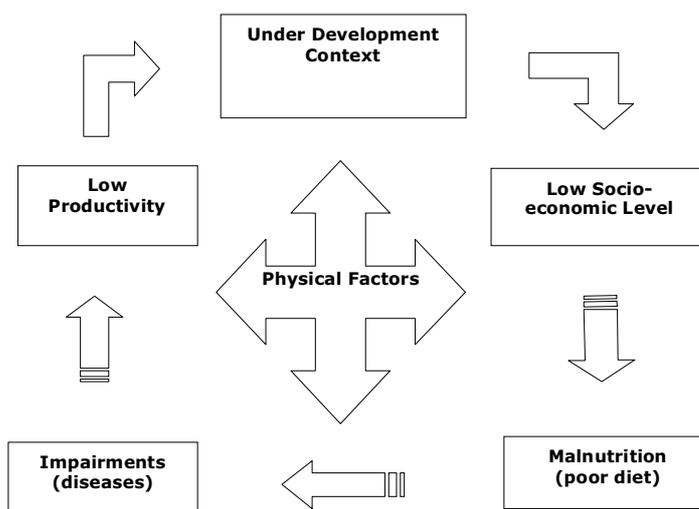
Increasing the linkage between disability and poverty is gaining global recognition. The United Nations, the World Bank, the Asian Development Bank, USAID, DFID, JICA and other

bilateral and multilateral aid agencies, have recently turned their attention towards disability mainstreaming and empowerment of persons with disabilities, adopting a so-called "twin track approach" --- an approach similar to the one advocated by the gender wing of some developmental agencies. This twin-track approach could be an effective tool to provide an enabling environment for disabled people to achieve greater livelihood security, equality, full participation in community life, and more independence and self-determination.

PERSPECTIVES ON DISABILITY: WHY DISABILITY IS A DEVELOPMENT ISSUE

The mutual relationship between poverty and disability in the context of developing countries is shown in Figure 1. This demonstrates that the vicious cycle of underdevelopment starts as a result of economic poverty, leading to malnutrition and disease, which in turn will lead to impairment and disability, contributing to a low level of human development and low productivity in the community (1). As a result, there will be a need for huge investment in medical care and rehabilitation at the expense of prevention and early intervention, and often such investment does not materialise due to lack of funding. With this model, poverty alleviation and sustainable, equitable economic development may be considered a pre-requisite for prevention of impairment (2).

Figure 1: Disabled People and Economic Needs in the Developing World



Poverty is closely linked to impairment, and impairment to social exclusion. Another perspective about the relationship between poverty and disability mainly concerns the fact that disabled people are more likely to experience financial difficulties, as well as social and economic deprivation and discrimination, especially in developing countries of Asia. For instance, in Sri Lanka, 98% of deaf people who are employed earn less than US\$ 2 a day, and 81 per cent earn less than US\$ 1 a day (3). In this sense, poverty, like other consequences of institutional discrimination, restricts disabled people's rights and undermines their ability to fulfill their socio-economic obligations. The social model of disability is the foundation for this perspective. The social model achieved much progress in the disability movement through representation of disabled people's experience and proved a forceful pressure for enacting anti-discrimination laws and disability policy changes. It provided an aggressive challenge to the old paradigm associated with the medical model of disability.

The social model of disability defines "disability" as the consequence of institutional and social discrimination and exclusion of persons with impairments. Recently, disabled people in both developed and developing countries have increasingly challenged the traditional view that disability should be the same as impairment. The new International Classification of Functioning, Disability and Health (4) attempts to measure impairment and disability from a new perspective that is much closer to the social model, while striking a balance of the need for empowerment and improving the capacities of the individual and the need for eliminating the barriers and constraints of his/her social and physical environment (4).

DISABILITY, POVERTY AND DEVELOPMENT IN THE REGION

Acton (5) identified several factors in developing countries that may hinder attempts to empower disabled people, but also argued that the developed world must assume a part of the responsibility in confronting disability-related issues globally. There are several indigenous developmental obstacles hindering the efforts of achieving improved quality of life for persons with disabilities in developing countries, such as poverty, income disparity, cultural factors (e.g. kinship marriage), illiteracy and ignorance, misconception, armed conflict, faulty priorities, corruption, and so on. All of these are the elements of overall socio-economic and cultural development. For instance, in Jordan where a persistent social pressure in favor of consanguineous marriage still exists, a clear correlation between parental consanguinity and

the incidence of severe mental retardation among children is frequently reported. The findings of the study conducted in Jordan by Staffan Janson (6), indicated a much higher kinship marriage rate of some 68% in the experimental group of parents of severely mentally retarded children, in contrast with the equivalent rate of 50% for the general population at the national level. Also, in Jordan, meningitis during infancy was found to be a major cause of childhood cerebral palsy in a sample survey conducted in the country (7).

While little is known in detail about the nature, scope and extent of disability in developing countries of Asia, not much more is known about how precisely disability and social discrimination are related to other forms of social exclusion. It is true that other forms of discrimination and social constraints, according to gender, social class, religion, ethnicity, caste, and so on, also affect the nature and problem of disability among people with the same level of impairments. Rural women with no income and no education are more severely disabled than wealthy, highly educated, urban men with the same physical and mental impairment. Therefore, in the discourse of disability and development, the concept of disability and the disability model must be re-defined, taking into consideration the complex fabric of a given society.

Poverty and disability share some similarity. Disability is often conceived as “a negative and static state” which requires intervention, rehabilitation and reduction. Interestingly, poverty used to be characterised in a very similar manner, as a negative endowment to be intervened and eradicated. Thus, by using the proposed comprehensive social model of disability, poverty per se can be understood more broadly as an outcome of social processes, including social exclusion, injustice and discrimination.

However, regarding the current modality of developmental interventions, some disability activists argue that development agencies still perceive disability in the developing world as primarily an individual problem and not part of the social and environmental context. In this sense, one can say that the persisting medical model approach which revolves around building capacity of individuals (disabled people) and individual coping skills for economic independence, has often ignored the importance of building up institutional capacity (social capacity) through removing social barriers, and changing the society itself.

A comprehensive social model can provide a new framework for explaining the complexity of disability, poverty and development, as it will reveal disability as a cross-cutting and interactive developmental issue. Furthermore, adopting such a model will shift the policy focus towards improving the social-economic conditions in which disabled people are currently positioned and restricted from full participation in life, and it will allow the creation of an inclusive, barrier-free, and rights-based society, a society for all.

Twin track approach

Over the last decades, and regardless of the large number of disabled people living in poverty in developing countries, disability has not been an important issue in developmental work, and rarely mentioned in any of the policy documents of international development agencies or international mainstream NGOs. Recently, however, there has been a growing interest in and concern about disability and rights of people with disabilities. The United Nations, the World Bank, USAID, JICA, and international NGOs have turned their attention towards disability and disability mainstreaming issues. Some of these agencies even began to formulate an official policy to mainstream disability into their work. This approach, which is similar to gender mainstreaming, means that the policies and projects should include disabled people's concerns as a key developmental issue. It also demands the active participation of disabled people in the design, monitoring and evaluation of developmental projects, including participatory planning and disability impact assessments. This approach of mainstreaming disability into generic development work is very similar to the proposed comprehensive social model of disability in principle, as both emphasise the cross-cutting and comprehensive nature of disability. The approach is also integrated and balanced, as it covers the need for empowerment of disabled people through networking, participation, CBR, capacity building, leadership training, etc.

The guiding principles of the twin-track approach to disability are reflected by a few policy papers of development agencies, such as "Disability, Poverty and Development" produced by the British Department of International Development (8) and more recently a paper by JICA on "Thematic Guidelines on Disability" (9). Some other development agencies, including a few UN agencies and the World Bank, are following this direction, and aiming at disability mainstreaming. They are increasingly seeing disability as a cross-cutting development issue. One important method of its implementation is to create a disability focal point, and/or introducing

disability sensitising (equality) training for development agency staff, so that they can recognise the vital link between poverty reduction, other development priorities (e.g. education for all, and combating illiteracy) and “disability”.

The 2005 World Summit outcome adopted in September 2005, recognised the need to guarantee the full enjoyment of the rights of disabled persons without discrimination (10). Therefore, incorporating the disability perspective into the international agenda is a mandate for all. In particular, action aimed at further implementing the Millennium Declaration and the MDG goals would result in effective fulfillment of the goals to realise improved standards of living, well-being, and human security on the basis of equality and inclusion of all.

This study incorporated the social model perspective, looking at poverty as an outcome of disability within the discourse of disability, poverty and development. However, the author argues that in most Asian developing countries, poverty is still among the most important causes of impairment, thus demanding a better balanced approach and broader perspective, such as a comprehensive social model approach to disability.

PURPOSE OF THE STUDY

The study aimed to explore available information on policies and guidelines of development agencies on disability, poverty and development. The empirical part of this study reveals the collective views and perceptions about disability rights, twin-track approach, empowerment of disabled persons, and priorities for action, of three groups who participated in the survey and focus group discussions in Hong Kong-China, Japan, Thailand, Indonesia and several other countries of the Asian region.

These groups are:

- (1) Official Development Assistance (ODA) workers,
- (2) Experts on disability issues,
- (3) Social workers/social work students

INSTRUMENT

Based on the findings of the preparatory focus groups in Thailand, a 27 item self-report questionnaire was constructed. Most questions were given as a bi-nominal choice of yes/no, while multiple choice questions of the 4-scale of (1) “not so important”, (2) “important but

not a priority”, (3) “very important”, (4) “top priority for immediate action” were used for substantive questions for priorities and action.

SAMPLE AND DATA COLLECTION

Data collection was based on convenience sampling, i.e., respondents (by group) were invited to complete the questionnaire on a voluntary basis. Overall, approximately 60 per cent of each group completed the questionnaire. Over a period of 7 months (June – December 2005), a total of 195 questionnaire forms (15 ODA workers, 56 experts on disability, and 124 social workers/social work students) were collected. 15 of these collected questionnaires were considered invalid due to the lack of consistence and unreliability of the data. This left a total of 180 completed and valid questionnaires for analysis, of 15 ODA workers, 51 experts on disability, and 114 social workers/social work students. 10% of the respondents have some form of disability.

DATA ANALYSIS

The valid questionnaire data were verified and processed using the SPSS software package for windows as frequency, percentages, chi-square test, and ANOVA (to examine the differences among the occupational groups and analyse the patterns). The qualitative data from the focus group discussions, available documented information, and field visits to two good practice projects were also analysed for comparison and analytic induction.

RESULTS

Table 1 shows the demographic characteristics of the total of 180 respondents of three occupational categories, ODA workers (n=15, 8.3%), experts on disability (n=51, 28.3%) and social workers/social work students (n=114, 63.3%).

Of the total (180 respondents), 111 (61.7%) were female and 69 (38.3%) were male. A much higher proportion of social workers/social work students (76.3%, n=87) were female compared to ODA workers (53.3%, n=8) and experts on disability (31.4%, n=16) ($\chi^2=30.589$, $p<.01$). The mean age of social workers/social work students (Mean=23.84, SD=8.006) was significantly lower than that of ODA workers (Mean=40.93, SD=10.720) and experts on disability (Mean=41.94, SD=11.564) ($F=76.091$, $p<.01$).

Table 1. Sociodemographic profile of respondents and their relationship with disabled persons

	ODA Worker (n=15,8.30%)		Expert on Disability (n=51,28.30%)		Social worker* (n=114,63.30%)		Chi Square	
	%	n	%	n	%	n	χ^2	p
Sociodemographic characteristics								
<u>Gender</u>								
Male	46.70%	7	68.60%	35	23.70%	27	30.589	.000 (a)
Female	53.30%	8	31.40%	16	76.30%	87		
<u>Age (years)</u>								
Range	26-63		24-71		18-56		$F=76.091$.000 (b)	
Mean (SD)	40.93 (10.720)		41.94 (11.564)		23.84 (8.006)			
<u>Contact with disabled persons</u>								
Yes	60.00%	9	98.00%	50	49.10%	56	36.653	.000 (a)
No	40.00%	6	2.00%	1	50.90%	58		
Relationship with disabled person(s) as:								
<u>Family member</u>								
Yes	13.30%	2	31.40%	16	3.50%	4	25.519	.000 (a)
No	86.70%	13	68.60%	35	96.50%	110		
<u>Service target</u>								
Yes	46.70%	7	54.90%	28	28.90%	33	10.648	.005 (a)
No	53.30%	8	45.10%	23	71.10%	81		

* Including social work students

(a) Chi-square test

(b) One-way ANOVA test ($F=76.091$)

Concerning previous contact with disabled persons, experts on disability reported a wider variety of exposure to and interaction with disabled people. Also, there was a significantly different pattern of interaction for each of the three groups. For instance, a much higher proportion of experts on disability had previous contact with disabled persons as family member (31.4%, n=16) than that of ODA workers (13.3%, n=2) and that of social workers/social workers students (3.5%, n=4) ($\chi^2=21.519$, $p<.01$). The overall exposure of social workers to disabled persons was rather limited; only to their contact with disabled persons as service target.

The knowledge about various human rights instruments of disability and basic national disability law was rather limited for social workers, but ODA workers and experts on disability had a better understanding of those instruments (Table 2). For instance, 82.4% of experts on disability knew about the ongoing process towards a new international convention on the rights and dignity of disabled persons, compared to that of 53.3% for ODA workers and 32.5% for social workers ($\chi^2=35.294$, $p<.01$).

Table 2. Knowledge of respondents regarding the guiding human rights principle on disability

Respondents know the process towards an International Convention	ODA Worker		Expert on Disability		Social worker		Chi Square	
	%	n	%	n	%	n	χ^2	p
Yes	53.30%	8	82.40%	42	32.50%	37	35.294	.000
No	46.70%	7	17.60%	9	67.50%	77		

Table 3 shows that the majority of the total respondents (55.0%) supported the twin-track approach to disability and development, rather than focus merely on empowerment of disabled persons (16.1%) or mainstreaming into development work (28.9%). However, social workers or social work students, whose primary role is delivery of direct social services to disabled end-users, showed a tendency to support disability specific

empowerment projects more than other categories. 21.1% of social workers/social work students chose “empowerment of disabled persons” as more important, compared to none for ODA workers and 9.80% for experts on disability ($\chi^2=9.632$, $p<.05$). Regarding the knowledge of ODA policy in their own countries, there was significant difference among ODA workers (91.70%), experts (38.50%) and social workers/social work students (8.0%) ($\chi^2=54.559$, $p<.01$).

Table 3. What aspect of the “twin track approach” should be emphasised?

	Total		ODA Worker Disability		Expert on worker		Social		Chi Square	
	%	n	%	n	%	n	%	n	χ^2	p
More emphasis on disability mainstreaming into overall development projects	28.90%	52	40.00%	6	39.20%	20	22.80%	26	9.63	.047
More emphasis on special projects on empowerment of disabled persons	16.10%	29	0.00%	0	9.80%	5	21.10%	24		
Equal balance	55.00%	99	60.00%	9	51.00%	26	56.10%	64		

About questions concerning empowerment and mainstreaming, as indicated in Tables 4 and 5, overall there was a wide difference among the three occupational categories of respondents. On the empowerment side, training and capacity building of disabled persons and their representative organisations was rated as the top priority for immediate action, by 66.7% of ODA workers, and 66.7% of experts on disability, compared to only 28.9% of social workers/social work students, who noted that this is considered a significant variation among the groups ($\chi^2=33.887$, $p<.01$).

Table 4. Importance of the projects on disability empowerment rated by the respondents

Importance of empowerment projects	ODA Worker		Expert on Disability		Social worker		Chi Square	
	%	n	%	n	%	n	χ^2	p
Training and capacity building of persons with disabilities and their organisations								
Not so important	0.00%	0	3.90%	2	0.00%	0	33.887	.000
Important, but not a priority	0.00%	0	0.00%	0	11.40%	13		
Very important	33.30%	5	29.40%	15	59.60%	68		
Top priority for immediate action	66.70%	10	66.70%	34	28.90%	33		
Advocacy related activities								
Not so important	13.30%	2	3.90%	2	0.90%	1	29.084	.000
Important, but not a priority	53.30%	8	21.60%	11	28.10%	32		
Very important	13.30%	2	37.30%	19	57.90%	66		
Top priority for immediate action	20.00%	3	37.30%	19	13.20%	15		

Furthermore, on the mainstreaming side, there is a statistically significant difference among the three occupational categories. For instance, concerning the introduction of universal design, 60.0% of ODA workers and 47.1% of experts on disability rated this as the top priority, compared to the equivalent of 27.2% for social workers/ social work students ($\chi^2=19.132$, $p<.01$). However, ODA workers were much more hesitant to support the establishment of a quota for disabled people in general training projects, as 33.3% of ODA workers regard this as “not so important”, compared to 5.9% for experts, and 3.5% for social workers ($\chi^2=29.331$, $p<.01$). This may be related to ODA workers’ worry and concern about an evidence-based accountability that may be imposed on them, for their follow-up action.

In mainstreaming of participation of disabled persons in decision making, only 28.1% of social workers considered this the top priority, compared to that of 93.3% for ODA workers and 62.7% for experts on disability ($\chi^2=38.619$, $p<.01$). One can say that ODA workers and experts were more supportive to participation of disabled persons in decision making than social workers/social work students.

On the contrary, ODA workers tend to show reservation towards pro-active and positive measures such as priority recruitment of disabled employees, and/or introduction of disability budgeting. 40% of ODA workers considered disability budgeting not so important, compared to none for experts and only 2.6% for social workers ($\chi^2=46.863$, $p<.01$). Also, priority recruitment of disabled employees was considered “not so important” by 33.3% of ODA workers, compared to that of 3.9% for experts, and 5.3% for social workers ($\chi^2=46.863$, $p<.01$). In contrast, ODA workers tend to support more gradual mainstreaming mechanisms such as disability sensitising training for development workers, and 80.0% of them considered sensitising training as the top priority for immediate action, compared to that of 49.0% for experts, and 14.9% for social workers/social work students ($\chi^2=40.501$, $p<.01$).

Table 5. Importance of the projects on disability mainstreaming rated by the respondents

Importance of disability mainstreaming activities	ODA Worker		Expert on Disability		Social worker		Chi Square	
	%	n	%	n	%	n	χ^2	p
Introduction of “universal design and physical accessibility” into infrastructure projects								
Not so important	0.00%	0	3.90%	2	0.00%	0	19.132	.004
Important, but not a priority	0.00%	0	15.70%	8	28.90%	33		
Very important	40.00%	6	33.30%	17	43.90%	50		
Top priority for immediate action	60.00%	9	47.10%	24	27.20%	31		
Promotion of "inclusive education" in education projects								
Not so important	0.00%	0	0.00%	0	0.00%	0	10.146	.038
Important, but not a priority	13.30%	2	7.80%	4	17.50%	20		
Very important	60.00%	9	39.20%	20	53.50%	61		
Top priority for immediate action	26.70%	4	52.90%	27	28.90%	33		
Establishing a quota for disabled beneficiaries in general training projects								
Not so important	33.30%	5	5.90%	3	3.50%	4	29.331	.000
Important, but not a priority	33.30%	5	31.40%	16	24.60%	28		
Very important	13.30%	2	37.30%	19	58.80%	67		
Top priority for immediate action	20.00%	3	25.50%	13	13.20%	15		

Different measures were rated on a scale of 1-4, with 1 as the lowest (not so important) and 4 as the highest (very important). Measures such as supporting the training and capacity building of disabled persons (Mean=3.33), network of disabled persons (Mean=3.14), CBR (Mean=3.16), introducing universal design (Mean=3.11), inclusive education (Mean=3.21), promoting the participation of disabled persons in decision making (Mean=3.27), establishing a disability focal point (Mean=3.02), introducing disability sensitising programmes for ODA workers (Mean=3.07), and formulation of a set of accessibility guidelines for infrastructure projects (Mean=3.18), are rated relatively high by all the groups combined. Measures such as support to advocacy activities (Mean=2.87), establishing a quota for disabled beneficiaries (Mean=2.77), introducing disability impact assessments (Mean=2.96), disability budgeting and priority recruitment of disabled employees in development agencies (Mean=2.84) are rated relatively low by the all groups combined.

Discussion from focus groups

Overall, there was strong recognition of the importance of disability as a development issue, rather than a social welfare issue, and an issue closely linked to the priorities of bilateral and multilateral development agencies and generic international development NGOs.

However, the link between poverty and disability was better understood by ODA workers and experts on disabilities, than service providers (i.e., social workers and social work students). This may be due to their limited exposure to developing countries and development work, and the pedagogical emphasis on the needs-based service delivery of social work. Perhaps, due to the very basic nature of social work, and their strong commitment to it, social workers/social work students may see “empowerment of disabled persons” (through vocational training, CBR, leadership training, etc.) as a very important target area. Social workers/social work students are also less supportive of advocacy related activities and networking of self-help groups of disabled people. This may be a reflection of their professional and patronising attitudes to a certain degree.

The twin-track approach to disability was appraised highly by all occupational groups, as a development and project initiative. Only a few experts on disability (including those with disabilities), expressed some caution towards this approach, as they think that this approach may make accountability less clear and more diffuse.

There is a need for the development of a set of good indicators for success and failure of mainstreaming initiatives. Imposing very strict reporting obligations by the local missions of development agencies, and introduction of more participatory and interactive techniques for evaluation of development projects (both generic projects and disability specific projects) were among the proposals made by all three groups.

There was a strong feeling about an urgent need to increase knowledge about disability and development, both in theory, and practice, and to identify good practice projects in the region, implemented by various development partners.

A few experts on disability proposed the adoption of more participatory appraisal such as participatory rural appraisal (PRA), in the production of a comprehensive study on disability and development, which includes an extensive review of literature and analysis of successful project initiatives in each country of the region.

The lack of funding in promoting the twin-track approach was raised by both ODA workers (Japan, Thailand) and experts on disability (Indonesia, Thailand). A few senior ODA workers confirmed that budgetary allocation would be required for mainstreaming disability as well, contradicting the myth of “mainstreaming of disability not requiring any extra budgetary allocation”.

The majority of experts on disability (particularly those with disabilities) thought that a clear definition of disability and approach would be central to designing a disability policy or strategy. The proposed model, a “comprehensive social model” was highly rated by the majority of ODA workers and social workers/social worker students; however, some experts on disability advocate the more radical social model of disability, which sees disability purely as discrimination and inclusion. They are concerned that an emphasis on the developmental aspect of disability (including poverty and disability) may reverse the perspective and attention towards the old medical or individual model.

Some experts on disability proposed that development agencies make a more concerted effort for removing the institutional and social barriers in a recipient country, through enhancing their technical support in formulating appropriate policy such as dispatching an expert on disability legislation and policy.

The majority of ODA workers had reservations concerning introducing proactive and affirmative action to promote inclusion of disabled persons, such as priority hiring of disabled employees, introducing a disability budget or establishing a quota for disabled beneficiaries in generic training. They seem to prefer a less drastic approach, such as a disability sensitising programme for staff.

CONCLUSION

Development agencies should integrate disability concerns into the mainstream of their development work, policy and practice by adopting a well-balanced, comprehensive social model approach to disability, which is well reflected by WHO-ICF and the twin-track approach. To achieve this end, the twin-track strategy advocated by some international development agencies such as DFID and JICA (along lines similar to gender issues) should be utilised.

All stakeholders, including ODA workers, experts on disability, and professionals for service delivery (such as social workers) should recognise the importance of disability as a development issue, rather than a mere social welfare issue. The introduction of disability sensitising training and the mandatory obligation of reporting of disability impact of all generic projects may be an effective initial step towards this goal. More action-oriented research is required to identify and compile examples of best practice for the empowerment of persons with disabilities, mainstreaming and the twin-track approach in developing countries of the Asian region.

In designing, monitoring and evaluation of development projects (including generic projects), disabled persons and/or their representative organisations should be invited and involved in assessment and evaluation within their local or national contexts.

Also, a more participatory research modality, such as PRA, action-oriented research and participatory learning and action (PLA) should be introduced in the process of research production on disability, poverty and development.

More elaborate discussions and debates may be required to consider positive and proactive measures, such as setting up a quota scheme for disabled people in training courses, disability budgeting, and affirmative action on hiring disabled ODA staff.

Sufficient budgetary allocation should be made available to support delivery of the twin-track approach. It is important to recognise the budgetary need, to implement disability mainstreaming into development work.

Parallel to the process towards an international convention on promotion and protection of the rights and dignity of disabled persons, development agencies should promote the paradigm shift from a charity-based approach to a rights-based approach. In this context, knowledge by development workers and others, of the existing human rights instruments such as the Biwako Millennium Framework (BMF), the Standard Rules and the International Convention should be upgraded.

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DEVELOPMENTAL ARTICLES

**CONVERGENCE BETWEEN THE INTERNATIONAL CONVENTION
ON THE RIGHTS OF PERSONS WITH DISABILITIES AND THE
BIWAKO MILLENNIUM FRAMEWORK FOR ACTION**

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ABSTRACT

The adoption of the International Convention on the Rights of Persons with Disabilities is a historic event for people in the disability sector from all over the world. In the Asian and Pacific Region, the United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP) has promoted the full participation and equality of persons with disabilities for the last 15 years, through two successive initiatives of decade framework. This article describes the salient characteristics of the Convention and discusses the convergence between the Convention and the Biwako Millennium Framework for Action.

INTRODUCTION

At 1050 hours on 13th December 2006 in New York, H.E. Sheikha Haya Rashed Al Khalifa, president of the sixty-first session of the General Assembly of the United Nations, struck the hammer against the rostrum, and history was made. The “International Convention on the Rights of Persons with Disabilities” was adopted by consensus. In many parts of the world, members of civil society and of disabled people’s organisations, who had made significant contributions to the drafting process, witnessed the historic event.

Though the rights enshrined in the Universal Declaration of Human Rights (1948) and the seven “core” United Nations International Human Rights Treaties, cover in theory, all people, including persons with disabilities, in practice, their rights were not duly protected and promoted (1). Though there are disability-specific global instruments such as the World Programme of Action (1982) and the later Standard Rules on Equalisation of Opportunities for Persons with Disabilities (1993), which are based on the principles of full participation and equality, they are not legally-binding. Attempts both in 1987 and 1989 to introduce a disability-specific convention did not succeed due to the lack of consensus among countries (2).

Thus, the adoption of the Convention of the Rights of Persons with Disabilities in December 2006, is the culmination of nearly twenty years of efforts in the United Nations, unequivocally establishing disability as a definite part of human rights instruments.

In Asia and the Pacific, the United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP) has promoted the full participation and equality of persons with disabilities for the last 15 years, through two successive initiatives of decade framework. From 2003, the second Asian and Pacific Decade of Disabled Persons started with the theme of “inclusive, barrier-free and rights-based society” along with the policy guidelines, the “Biwako Millennium Framework for Action towards an Inclusive, Barrier-free and Rights-based Society for Persons with Disabilities in Asia and the Pacific” (BMF).

From the onset of the second Decade of Disabled Persons, UNESCAP had promoted the work towards the Convention through many workshops and seminars. Most notably, in 2003, concerted efforts of participants from disabled people’s organisations, human rights institutions, legal professionals and governments produced the “Bangkok Draft,” a draft convention (3), which was used as one of the most useful references for the drafters of the Convention. Therefore, the adoption of the Convention is very significant for UNESCAP, both in terms of its relationship to the mandate of the Biwako Millennium Framework for Action, and in terms of acknowledging the UNESCAP contribution to the drafting process.

Against this background, this article has two aims: to describe the salient characteristics of the Convention and to discuss the convergence between the Convention and the Biwako Millennium Framework for Action.

SALIENT CHARACTERISTICS OF THE CONVENTION

The Convention is composed of 50 articles (4). It is comprehensive, encompassing civil, political, social, economic and cultural rights of persons with disabilities, covering such areas as equal recognition before the law, access to justice, education, health, work and employment, adequate standard of living and social protection and participation in cultural life, recreation, leisure and sport. The Convention not only prohibits discrimination but also calls for positive action and development activities to realise the rights of persons with disabilities. It is both reactive and proactive.

One of the salient characteristics of the Convention, is the inclusion of the concept that disability results from the interaction between individuals with impairments and attitudinal and environmental barriers. Though it is included in the Preamble and the Article 1 (Purpose) and not in the Article 2 (Definitions), the idea clearly negates the concept of disability as an individual pathology and draws attention to another dimension, in which the onus is on society (Governments and other stakeholders) to remove barriers for persons with disabilities.

Another distinctive characteristic is the inclusion of a concept, “reasonable accommodation.” Originally being a part of the civil rights law of the United States (1964) to respect practices of different religions at the work place (5), it refers to necessary and appropriate modification and adjustment needed to ensure the enjoyment of all rights by persons with disabilities on equal basis with others. It should be provided in response to individual needs. In practical terms, this can be the provision of sign language interpreters for hearing impaired persons, changing facilities or equipment to make them more accessible for visually impaired persons and physically disabled persons, or restructuring job scheduling for persons with psychosocial disabilities or persons with intellectual disabilities. In implementing this concept, “reasonableness” of the accommodation will have to be judged in an individual context with the consideration of not imposing too much burden on companies or government institutions. In this regard, having to deal with the complexities of these judgments and negotiations will be a challenge. Nonetheless, the significance of this concept lies in the fact that the Convention states that the failure to provide reasonable accommodations constitutes discrimination (Article 2). The Convention clearly states that actions should be taken in order not to discriminate against people with disabilities. In this respect, one might say that reasonable accommodation is a pre-emptive action and closely linked to the removal of barriers, which can cause disability and discrimination. Through this concept, pro-active nature of the Convention is strengthened.

The rights delineated in the Convention are not newly created rights: they are rights which already exist in the core human rights treaties, but are tailored and articulated in response to specific needs and circumstances of people with disabilities. Some of these rights are stated as independent articles, namely, Accessibility (Article 9), Living independently and being included in the community (Article 19), Personal Mobility (Article 20) Habilitation and rehabilitation (Article 26). An article on accessibility is unique in establishing the rights of people with disabilities to have access to not only the physical environment, transportation,

information and communications and other facilities, but also to services. Defining sign language as an example of language (Article 2) is also a significant step forward.

For many resource-deprived countries, the Convention might imply much greater expenditure and use of resources. However, the inclusion of the article on “International cooperation” (Article 32) responds to those concerns. Though each party fundamentally has to fulfil obligations under the Convention, the importance of partnership with international and regional organisations and civil society in the realisation of the rights of persons with disabilities is stressed in this article. In operational terms, the article calls for making general development activities more disability-inclusive, with emphasis on capacity-building, cooperation in research and technology transfer, and economic assistance as appropriate. The governments of the Philippines and Indonesia emphasised the importance of this article in their statement made immediately after the adoption of the Convention on 13 December 2006.

The Convention is a legally binding international instrument. Thus, it will have to go through the signature and ratification process. For this particular Convention, it will be open for the signature at the United Nations Headquarters from 30 March 2007, after which the ratification process starts. Once twenty countries ratify the Convention, it will take effect. In the ratification processes, in many countries such as Japan, domestic laws have to be aligned with the principles and contents of the Convention. Those laws which are discriminatory against persons with disabilities have to be either revised or nullified, and the laws which would proactively implement the Convention have to be developed. In some countries of the UNESCAP region, such as Japan, Republic of Korea and Thailand, leaders of the disability sector are already working on establishing an anti-discrimination law on disability for the effective implementation of the Convention. The alignment of domestic laws would be crucial in translating the spirit and the content of the Convention to the national context.

CONVERGENCE WITH THE BIWAKO MILLENNIUM FRAMEWORK FOR ACTION

The Biwako Millennium Framework for Action, the regional policy guidelines for the Asian and Pacific Decade of Disabled Persons, is not a legal document, and it is only effective until 2012. Thus, it does not have the same kind of legal power that the Convention has. Also,

there are differences in issues raised and concepts emphasised between the two instruments. However, the implementation of the BMF can reinforce the implementation of the Convention in the region and vice versa. They can be linked in a mutually beneficial way, and together used effectively in the Asian and Pacific region. The following description substantiates this claim.

First, both the Convention and the BMF are based on the concept of human rights. The BMF clearly states its primary vision of promoting a paradigm shift from a charity-based approach to a rights-based approach in disability issues, and it is reflected in the Decade's defining theme, "towards an inclusive, barrier-free and rights-based society" (6). It also contains an independent strategic section entitled "promotion of a rights-based approach to disability issues," in which it supports the disability-specific convention and development of domestic rights-based legislation. As the domestic rights-based legislation is an indispensable component of the Convention implementation, the BMF can reinforce the implementation. The concept of "reasonable accommodation" is not included in the BMF.

Though BMF's concept, "inclusive" is not delineated in the Convention, the idea is ingrained. In the BMF, "an inclusive society" is defined as "a society for all." This means that persons with disability or their perspectives and concerns should not be excluded from any activities of society, and that society should respect diversity and differences of people. This principle is included in the Convention in Article 3 on General Principles. "Barrier-free" is not a distinctive concept in the Convention, either. But the recognition of barriers is mentioned in the preamble and the article on the purpose.

Third, both the Convention and the BMF have development perspectives, but the latter fortifies the perspective. As discussed in the previous section, the Convention promotes development action for the realisations of rights, and that spirit is reflected in many articles such as the one on the international cooperation. The BMF does it by emphasising the development aspect in its definition of a rights-based society. It says that such society is "a society based on the concept of human rights, including the right to development." The BMF also incorporates two of the Millennium Development Goals (MDGs), universal primary education and eradication of extreme poverty and hunger, as applicable to the disability sector and expresses them as its policy and programme targets. This draws attentions to the need to include disability concerns in the attainment of the MDGs. In this regard, the BMF establishes itself

as a linkage between the global development mandate and the global disability-specific human rights instrument.

The BMF has more detailed description of issues, recommended policy and programme actions than the Convention. It provides 21 detailed time-bound policy and programme targets under the seven priority areas, namely 1) Self-help organizations of persons with disabilities and related family and parent associations; 2) Women with disabilities; 3) Early detection, early intervention and education; 4) Training and employment, including self-employment; 5) Access to built environments and public transport; 6) Access to information and communications, including information, communication and assistive technologies and 7) Poverty alleviation through capacity-building, social security and sustainable livelihood programmes. More than 100 actions are recommended under these. In addition, it has four strategic areas: (1) national plan of action on disability, 2) promotion of rights-based approach to disability issues, 3) disability statistics and common definitions of disability for planning and 4) strengthened community-based approaches to the prevention of causes of disability, rehabilitation and empowerment of persons with disabilities. It also has sub-regional, and interregional mechanisms for its implementation, under which 17 strategies are recommended. Each of these can be used as a useful point of reference in the implementation of the Convention. For example, in a strategy 15 under the section of “access to built environment and public transport,” the BMF recommends that the universal design concept be a part of loan/grant criteria of the funding agencies. This is clearly a strategy of disability-inclusive international cooperation that is in Article 32 (International cooperation) of the Convention.

Six of the BMF seven priority areas are covered in the Convention. These cover issues on accessibility. However, accessibility in the BMF does not mention access to services which is mentioned in the Convention. Though the one priority area, “Self-help organisations of persons with disabilities and related family and parent associations” is not included as an independent article in the Convention, the significance of the priority area, the participation of persons with disabilities in any-decision making processes, is included in the Convention. By comparison, the Convention covers more issue areas. It has independent articles on Children with disabilities, (Article 7), Awareness-raising (Article 8) and Article 10 to 18, which are conventionally described as civil and political rights.

For the disability statistics and data collection, the Convention calls for appropriate data collection, that is ethical and respects the privacy of persons with disabilities (Article 31). It also calls for dissemination of the statistics and data to be made accessible for persons with different disabilities. The BMF, on the other hand, provides a situation analysis in which the lack of data on disability prevalence, economic, social indicators of people with disabilities, and under-reporting of the prevalence were raised as issues. It encourages Governments to take more action on the data collection, applying the international standard. In this regard, the Convention can provide the ethical perspective in the operation of the BMF's recommendations.

CONCLUSION - TOWARDS THE SECOND HALF OF THE DECADE

The comparison between the Convention and the BMF in the previous section are not exhaustive, but it shows that two documents are complementary to each other.

2007 marks the mid-point of the current Asian and Pacific Decade of Disabled Persons, and in September, UNESCAP will organise a high-level intergovernmental meeting to complete the mid-point review of the BMF implementation and to agree on a document that would supplement the current BMF. The supplementary BMF would be developed in the light of current achievements and challenges emerging during the last five years. The document would be used as the guide for the second half of the Decade from 2008 to 2012.

The adoption of the Convention in 2006 is timely and the above-mentioned differences and similarities between the Convention and the BMF, would serve as a useful point for further examination of two documents and for creating a meaningful Biwako supplementary document.

At the same time, UNESCAP will promote the ratification and effective implementation of the Convention at the national level, including the development and implementation of anti-discrimination laws. This will go hand-in-hand with its efforts to promote further implementation of the Biwako Millennium Framework for Action.

UN Secretary-General Kofi Annan in his statement said that the adoption of the Convention "promises to be the dawn of a new era- an era in which disabled people will no longer have to endure the discriminatory practices and attitudes that have been permitted to prevail for all too long" (7). As the Asian and Pacific region ushers in the new era, the two formidable documents, the Convention on the Rights of Persons with Disabilities and the Biwako

Millennium Framework for Action would support the work on the region towards an inclusive, barrier-free and rights-based society.

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**A REVIEW OF COMMUNITY BASED REHABILITATION
EVALUATIONS: QUALITY OF LIFE AS AN OUTCOME MEASURE
FOR FUTURE EVALUATIONS**

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ABSTRACT

This review examines key articles in evaluation of community-based rehabilitation carried out in developing countries and proposes family quality of life as an outcome measure of community-based rehabilitation. The concept of community-based rehabilitation is reviewed, quality of life and family quality of life measurement scale is presented. It presents a practical approach to future evaluations of community-based rehabilitation programmes. This review presents the features of community-based rehabilitation evaluation (i.e., service delivery system, technology transfer, community involvement, and organisation and management), methodology, and findings. Implications are defined for the enhancement of community-based rehabilitation through practical suggestions for programme coordinators involved in community development for rehabilitation, equalisation of opportunities, and social inclusion of people with disabilities.

INTRODUCTION

The World Health Organisation (WHO) introduced the Community-Based Rehabilitation (CBR) strategy as part of its goal to accomplish health for all by the year 2000. The Alma-Ata Conference and Declaration of 1978 on Primary Health Care (PHC) creates a new vision for providing promotive, preventive, curative and rehabilitative services for the main health problems in the community (1). The Declaration of Alma-Ata states that people have the right and duty to participate individually and collectively in planning and implementation of their health care. This concept led to development of the first CBR models.

This paper examines relevant literature and research concerning evaluation of CBR and is divided into five sections: (a) CBR foundation, (b) past and current evaluation, (c) review of CBR evaluation, (d) summary of evaluation results, and (e) quality of life as an outcome evaluation for CBR. This paper proposes family quality of life (FQOL) as a CBR outcome measure and presents a practical approach to future evaluations using the only existing FQOL measure. The practical approach is based on the premise that CBR aims at enhancing opportunities of people with disabilities and their families to live their lives as they choose (2) and is rooted in quality of life (QOL).

Community-Based Rehabilitation: Foundation

In 1950, the World Health Assembly (WHA) called for development of rehabilitation programmes for people with disabilities. It was not until 1966 that the WHA adopted a resolution stressing the importance of rehabilitation, whereby it urged member states to develop their rehabilitation services as an integral part of the national health system. This review of CBR focuses on (a) conceptualisation, (b) components, and (c) principles.

Conceptualisation

CBR is a strategy within general community development for rehabilitation, equalisation of opportunities, and social inclusion of all children and adults with disabilities (3). The CBR concept is both simple and complex in nature (4). The simplicity has to do with its origins, i.e., delivery of rehabilitative services to people with disabilities in their communities. CBR's complexity is the result of the current concept of CBR programmes as multi-disciplinary, i.e., visiting people with disabilities and their families in their homes; providing appropriate information, therapy and/or training; and facilitating rights and duties of people with disabilities, family, and community members (5).

Components

The primary component of CBR as a concept and ideology is that community members are willing and able to mobilise local resources and provide appropriate services to people with disabilities. Other components of a multi-disciplinary CBR programme include: (a) creating positive attitudes towards people with disabilities, (b) providing functional rehabilitation services (e.g., physical therapy, occupational therapy, orientation and mobility training, speech therapy,

counselling, orthotics and prosthetics), (c) providing education and training opportunities (e.g., early childhood intervention and referral especially to medical rehabilitation services, special education in mainstream or special schools, sign language, Braille training, training in activities of daily living skills), (d) creating micro and macro income generation, (e) providing care facilities (e.g., respite care), (f) preventing causes of disabilities, and (g) managing, monitoring, and evaluation of CBR programmes (4).

Principles

The five basic CBR principles include: (a) utilisation of available resources in the community, (b) transfer of knowledge about disabilities and skills in rehabilitation to people with disabilities, families, and communities, (c) community involvement in planning, decision making, and evaluation, (d) utilisation and strengthening of referral services at the district, provincial, and national levels that are able to perform skilled assessments with increasing sophistication, make rehabilitation plans, and participate in training and supervision, and (e) utilisation of a coordinated approach among education, health, and social systems (6). Despite the identification of fundamental CBR principles, there are significant variations in implementation across countries. It should be acknowledged that since CBR's inception two decades ago, complexities arising from these initiatives in diverse communities with their unique cultural, social, and economic conditions, make it difficult for CBR to meet all needs of people with disabilities.

EVALUATION OF CBR: PAST AND CURRENT

CBR has been the focus of some form of evaluation since the first field-testing of the manual *Training in the Community for People with Disabilities* (7). Early reports state that only two of the 43 countries represented by the six regional zones in which the WHO operates mentioned any evaluation and research on CBR (8). Earlier country reports are limited to issues such as initial consultant visits, training workshops held, and number of stakeholders involved in training (8). Subsequent evaluation studies presented extensive sets of data on the number of people identified with disabilities, the number of people with disabilities who received assistance, and the type of assistance (9). This review highlights (a) four features of evaluation, (b) individual and programme evaluation, and (c) process and impact evaluation.

Four Features of Evaluation

CBR evaluation refers to a standard to make objective judgements of activities and outcomes of a CBR programme. There are significant variations in implementation of CBR, and it is widely acknowledged that the CBR concept is highly adaptable to meet specific needs in the developing world. The challenge here is the need to provide a method of CBR evaluation that allows each significant variation of the CBR programme to encapsulate components, principles, features, and core evaluation criteria. Four features of CBR on which evaluation might focus are service delivery system, technology transfer, community involvement, and organisation and management (7).

First, service delivery system relates to how services and training are provided to people with disabilities and their family members at the community level. Specific issues include, among others, utilisation of the primary CBR worker; training family members to teach people with disabilities; and partnerships among the CBR worker, people with disabilities, and family members of people with disabilities.

Second, technology transfer relates to technical skills that the primary health-care worker/local supervisor of the CBR programme should possess. Specific issues include, among others, teaching technical skills to CBR workers at low cost and in the shortest possible time; the nature and extent of skill the CBR worker should have; early identification of disabilities; and use of appropriate technology.

Third, community involvement relates to training people with disabilities to ensure that training is not the sole concern of the family members and the CBR worker, but also of the community where the person lives. Examples include assessing change in community attitudes towards people with disabilities and mobilising community resources to support and assist people with disabilities.

Fourth, organisation and management is a feature of CBR that ensures effectiveness of a programme. Specific issues related to this CBR feature include linkages within the referral network to the primary health-care worker, person with disability, family member, and the community; identification of appropriately trained personnel; and importance of people with disabilities as key personnel in the management of CBR programmes. In this paper, the summary of evaluations are classified according to the four features of CBR, and some of the evaluations cover more than one feature of CBR.

Individual and Programme Evaluation

Jonsson (10) provides a framework for CBR evaluation consisting of individual and programme evaluation. The individual evaluation involved (a) functional aspects with components such as daily living skills, communication skills, mobility, and behaviour; (b) educational aspects with components such as school attendance, school involvement, and educational achievement; (c) vocational aspects with components such as vocational training, placement, and income generation; and (d) social aspects with components such as participation in family life and participation in community life. Programme evaluation consists of the overall aspects, with components such as effectiveness, efficiency, relevance, impact, and sustainability.

Process and Impact Evaluation

Campfens (11) identifies process and impact as two principal types of CBR evaluation. Process evaluation is an ongoing, systematic collection of information to keep pace with what is happening, ensuring that a programme is in accordance with objectives, and assessing how activities are carried out and how inputs are used (11). Impact evaluation involves assessment of the programme or a component of it at a point in time (11). Its purpose is to determine the extent to which the goals and objectives of the programme have been achieved as a result of planned outcomes and to identify what changes (i.e., environmental and contextual) have occurred because of the programme.

Campfens (11) states that it is important to view both process and impact evaluation as part of a continuous programming process. Viewing evaluation as a continuous process provides a framework, whereby problem identification, planning, implementation, and process/impact evaluation are integral to evaluation. Furthermore, it enables information from each component to merge and provides an opportunity for each component to be revisited continuously.

SUMMARY OF CBR EVALUATION

A complete review of CBR evaluations remains difficult, because most of them remain unpublished and furthermore, little quality research on CBR has been published. In unpublished reports aimed at an internal audience, effectiveness and impact have often been approached through subjective views of parents of children with disabilities and, more rarely, people with disabilities themselves, in terms of the programme's usefulness (12). This review is based on

journal articles published during the period 1987 to 2002. The criteria for inclusion was that they featured one of the four features of evaluation. These 30 evaluations were published in the following journals: (a) Disability and Rehabilitation, (b) Child: Care, Health and Development, (c) International Disability Studies, (d) Actionaid Disability News, (e) International Journal of Rehabilitation Research, and (f) publications of United Nations Development Programme. The review's focus is four features of evaluation: (a) service delivery system, (b) transfer technology, (c) community involvement, and (d) organisation and management. CBR programmes evaluated in these articles are from the 15 following countries: Afghanistan, Bangladesh, China, India, Indonesia, Jamaica, Lao, Nepal, Palestine, Pakistan, Philippines, South Korea, Ukraine, Vietnam, and Zimbabwe.

Service Delivery System

Service delivery system evaluation has focused on three broad areas: (a) utilisation of primary health-care worker/community based rehabilitation worker (13, 14, 15, 16); (b) benefits of community-based rehabilitation workers versus outside personnel coming in to provide training (13, 17, 18, 19); and (c) training family members to teach people with disabilities with a broader goal of integration and peace-building (20, 21).

Methodologies used in the evaluations varied in nature, ranging from practical methods to examine the quality of medical rehabilitation (12) to using reliable scales such as a 10-item questionnaire adapted from the international pilot study on childhood disabilities (14). Other evaluations used individually-tailored assessments to record changes in status for different types of disabilities (21), as well as using interview schedules and focus group discussions (16). Researchers indicate that CBR enhances successful integration, service delivery to persons with disabilities in their home environment, efficient utilisation of resources, and cost savings in tertiary care (22).

Technology Transfer

Most of the technology transfer evaluations reviewed focus on the nature and extent of skills CBR workers should have (11, 23, 24), as well as on identifying disabilities through application of simple detection techniques (25, 26, 27). Another evaluation area within technology transfer relates to a model for training personnel at various levels in the CBR programme (28, 20, 29). Methodologies used in these evaluations varied in nature ranging from Strengths, Weaknesses,

Opportunities and Threats (SWOT) analysis (27) to the use of International Classification of Impairment, Disability and Handicap (25), as well as questionnaires adapted from the draft United Nations Development Programme (UNDP) Guide on Evaluation of Rehabilitation Programmes for Disabled People.

Community Involvement

Most community involvement evaluations assessed attitudes of the community towards people with disabilities (30, 31, 32, 24, 19) and particularly attitudes of CBR workers towards people with disabilities (33). Other areas of focus include identifying and utilising community resources in the CBR programme (34, 27) and community participation through mobilising support for the social rights of people with disabilities (20, 35, 16). Methodologies used in these evaluations varied in nature ranging from asking caregivers to tell life stories of children with disabilities in their own words, followed by guideline interviews on subjective determinants of neighbourhood support (30), to an attitude measurement developed specifically for the Indian context (33).

Organisation and Management

Organisation and management evaluations reviewed focus on organisational models in implementing CBR programmes (36, 20, 14, 37, 22, 24, 38, 39) and personnel in CBR programmes (40, 27). Furthermore, applied research has proved CBR to be effective and acceptable as an approach to delivering basic rehabilitation services (41). Case study was the methodology frequently used in these evaluations (36, 40, 37, 22, 38, 39). Other methodologies include use of a questionnaire to assess knowledge, attitude, and practice levels (24) and interviews with standardised, open-ended questions (20).

SUMMARY OF EVALUATION RESULTS

By and large, findings of the evaluations reviewed provide encouragement and hope to pursue CBR as a strategy within general community development for rehabilitation, equalisation of opportunities, and social inclusion of people with disabilities. Most notable among the findings are:

1. CBR is highly effective and valuable for people with disabilities in the community (20, 40, 21).

2. CBR makes it easier to integrate people with disabilities through education programmes (38).
3. CBR makes it possible to train generic community workers in delivery of rehabilitation and prevention services to people with disabilities and their families (25, 28, 27, 29).

Findings also revealed areas that needed to be strengthened for CBR to be an effective strategy for achieving objectives of WHO's health for all initiative. Most notable among them are:

1. CBR programmes failed to teach activities of daily living skills to persons with disabilities in a successful manner (e.g., aids and appliances were provided without an impact on functional ability) (12).
2. CBR personnel acknowledge benefits of the programme but point to several problems including lack of rehabilitation education for them (23).
3. Voluntary care entailed in CBR conception and practice further contributes to exclusion of women not only from the labour force but from most other aspects of life (35).
4. An effective training curriculum for CBR workers should contain a multi-disability training approach (24).

Both quantitative and qualitative methods were used in the evaluations reviewed. It is evident that very few evaluation studies involve assessment of the programme or a component of it at a point in time (a) to determine the extent to which the goals and objectives of the programme have been achieved as a result of planned outcomes, (b) to identify what changes have occurred in functional ability as a result of the programme, and/or (c) to identify what environmental and contextual changes have occurred. Only two evaluations (42, 43) reviewed are impact evaluations; and the rest are process evaluations.

Based on close review of evaluations, policy makers in international developmental agencies and bi-lateral donor agencies are likely to ask "So what"? Policy makers are interested in evidence from both process and impact evaluations in order to recommend CBR as a strategy for rehabilitation, equalisation of opportunities, and social inclusion of persons with disabilities throughout the world. The next section of this paper proposes an outcome measure that could provide impetus towards research benefiting advancement of CBR.

QUALITY OF LIFE: OUTCOME EVALUATION FOR COMMUNITY BASED REHABILITATION EVALUATION

This section focuses on (a) individual quality of life as an outcome for CBR evaluation and (b) family quality of life as an outcome for CBR evaluation. Quality of life (QOL) is defined as individuals' perception of their position in life in context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns (44). QOL has emerged as a potentially unifying concept in setting goals for services and for assessing their impact on people's everyday lives (45). The unifying concept of quality of life enables service providers to reorganise resources around individuals rather than rearrange people in programme slots (46, 47).

Individual Quality of Life: Outcome for CBR Evaluation

Measurement tools that have been developed to measure QOL for individuals with disabilities have multiple domains with multiple items in each domain. Various measurement methods have been used to assess QOL for people with disabilities, including surveys and questionnaires (48, 49), interviews (50), and open interviews and surveys (51, 52). Few tools have considered separate versions for people with disabilities in different life stages (48, 53, 54).

Individual QOL measures may be used for various purposes, including programme evaluation, research analysis, policy development, and meeting individualised needs (55). First, these measures could guide programme development as well as evaluate effectiveness of services in enhancing quality of life. Second, they enable evaluators to aggregate, compare, and contrast findings related to quality of life across evaluations. Third, they can also be instrumental in guiding policy by identifying unmet needs that may be used to influence resource allocation decisions. Finally, they could be tailored to meet individual needs, environments, and preferences, which would then allow prioritizing and focusing on domains of QOL that are most relevant to a particular individual within a particular context.

Among the evaluations featuring QOL, one (42) used Comprehensive-QOL Scale. Another (48) suggests that QOL was substantially lower among people with physical disabilities who received no rehabilitation services compared to those who did receive physical rehabilitation, community-based rehabilitation, and labour market assistance. QOL scores tended to be highest, however, among those who received a combination of all three services. This study

suggests that an integrated approach may be the best way for maximising impact of individual rehabilitation services.

With regard to individual quality of life, an outcome measure that can be used in CBR evaluation is the World Health Organisation Quality of Life Assessment (44). The WHOQOL was developed simultaneously across fifteen international field centers and includes hundred items and twenty four facets relating to quality of life, which are grouped into four larger domains: physical, psychological, social relationships and environment. It also includes one facet examining overall quality of life and general health perceptions. Psychometric analyses of the WHOQOL showed that facets' Cronbach's alphas ranged from .65 (for the physical environment facet) to .93 (for the work capacity facet) (56).

Family Quality of Life: Outcome for Community-Based Rehabilitation Evaluation

An equivalent outcome for families with respect to support for families is enhancement of family quality of life (47, 57). Researchers have proposed FQOL as an outcome measure for early intervention services (58), and it has been suggested that FQOL for individuals and their families may be the only acceptable outcome of services and policies (47). Researchers in Canada and the United States have each provided a framework for ascertaining perceived quality of life in families. Canadian researchers developed a theoretical framework and an accompanying survey for gathering information about family quality of life (59).

Brown et al. (59) developed the Family Quality of Life Survey that measures four concepts quantitatively: attainment, satisfaction, opportunities for improvement, and initiative by family members to take advantage of opportunities. Brown et al. (59) defined opportunity operationally as "options available to families that are relevant to their needs" (p 210). Also, the concept "initiative" was referred to as, "families taking advantage of available opportunities" (p. 210). These four concepts were measured in nine key areas of family quality of life: health, leisure, financial well-being, family relationships, support from other people, support from services, careers and career preparation, spiritual and cultural life, and community and civic involvement. The Family Quality of Life Survey also encouraged participants to provide a considerable amount of qualitative information. The psychometric properties of the Family Quality of Life Survey is not yet established.

A group of researchers from the United States (60) created the foundation for a family quality of life research programme through qualitative inquiry in order to develop grounded theory for conceptualising family quality of life domains and indicators. FQOL has been defined as conditions where the family's needs are met, family members enjoy their life together as a family, and family members have the chance to do things that are important to them (60). This concept focuses on the individual with disability and other family members from their positions within the family and community (61). The investigators of family quality of life, based on extensive qualitative (60) and quantitative (59) analyses, have identified five domains of FQOL. These findings were the basis for a pilot version of a Beach Center Family Quality of Life Scale. Park et al. (62) conducted initial development and psychometric evaluation of the pilot scale. After further evaluation of the factor structure of the scale, Park et al., (62) reported that family quality of life consists of five unidimensional factors: Family Interaction, Parenting, Emotional Well-being, Physical and Material Well-Being, and Disability-Related Supports.

The Beach Center Family Quality of Life Scale measures levels of family perceptions of the importance of different domains of family quality of life, and their satisfaction with those domains. The scale contains twenty five items and five subscales: Family Interaction (six items), Parenting (six items), Emotional Well-being (four items), Physical/Material Well-being (five items), and Disability-Related Support (four items). The psychometric properties are very good. The Cronbach's alpha for the total instrument is .94 (63). Each of the five subscales display unidimensionality and internal consistency: Family Interaction (alpha=.92), Parenting (alpha=.88), Emotional Well-being (alpha=.80), Physical/Material Well-being (alpha=.88), and Disability-Related Support (alpha=.92).

IMPLICATIONS FOR PRACTICE

The ILO, UNESCO, UNICEF and WHO Joint Position Paper on CBR with and for People with Disabilities (2004) states that through CBR, families of individuals with disabilities and members of the community can work towards equalisation of opportunities for all community members with disabilities. The position paper promotes increased participation of people with disabilities including family members of individuals with disabilities. Furthermore, Rule 13 (3) of the Standard Rules specifies that "states should initiate and support programmes of research on social, economic, and participation issues that affect the lives of persons with

disabilities and their families”(p. 31). Hence, CBR evaluation must encompass all family members in QOL measures, and this can be achieved by using a family quality of life measure.

The Beach Center FQOL Scale can be a starting point in addressing impact evaluation, as it is the only available quantitative tool on FQOL. It applies to families with children from birth to early adulthood. It can be used with multiple family members in gaining their perspective (using a 5-point Likert-type format) on the extent to which they believe each indicator is important and the extent to which they are satisfied the indicator is realised in their family. The Beach Center FQOL scale can be administered through a paper and pencil format or through an interview with family members individually, or in a group. The salient feature of the scale is that results are mapped so that the dimensions of importance and satisfaction are compared. This enables users to “assign” particular indicators to one of the following quadrants:

1. High importance/Low satisfaction (priority indicators for more support).
2. High importance/High satisfaction (indicators representing family strengths).
3. Low importance/Low satisfaction (indicators that are not priority areas for more support).
4. Low importance/High satisfaction (indicators that are not priority areas for more support).

Upon completion of the FQOL Scale, the CBR programme coordinators can identify perspectives of the entire group of families served, as well as those of individuals within the total group and within family units. Through the information gathered, CBR programmes will focus on indicators that families report are of high importance and low satisfaction. These indicators will be the place to begin when planning provision of family support. Group activities can also be planned for those indicators that all, or most families believe are of high importance and low satisfaction. Additionally, individual activities can be planned to support those indicators where individual families or individual members within families need support.

Once domains of family quality of life are understood and their correlates assessed, it is possible for service and support providers to implement a number of programme-based quality enhancement, thus enabling CBR programmes to focus on the correlates and predictors of a life of quality for people with disabilities and their families. Upon identifying significant predictors, CBR programmes can make programmatic changes to enhance quality of life (64, 65).

CBR plays a significant role in the lives of individuals with disabilities and their families. Hence, it is imperative that future CBR evaluations provide empirical evidence on whether

or not it enhances quality of life. The tools such as the WHOQOL and the Beach Center FQOL scale can be used to gather evidence, that CBR programmes indeed do enhance individual quality of life and family quality of life. This evidence will enable policy makers to continue to advocate inclusion of CBR in public policies, as an effective strategy within general community development for rehabilitation, equalisation of opportunities, and social inclusion of all children and adults with disabilities.

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EVALUATION IN COMMUNITY BASED REHABILITATION PROGRAMMES: A STRENGTHS, WEAKNESSES, OPPORTUNITIES AND THREATS ANALYSIS

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ABSTRACT

The purpose of this article was to qualitatively analyse the extent to which community based rehabilitation programmes have been evaluated over the past thirty years. A framework of strengths, weaknesses, opportunities and threats analysis was used in conducting this analysis. Using an extensive search of MEDLINE, 22 articles were located that described and evaluated one or more dimensions of CBR. Three studies each from Australia, India, Zimbabwe and two studies each from England, Philippines, Vietnam and one each from Finland, Guyana, Jamaica, Japan, Pakistan, Papua New Guinea, Thailand, and United States were included in the analysis. A variety of methods used, most evaluations conducted in community settings, focus on mobility related evaluations by most programmes, and development of new instruments were the strengths of CBR evaluations. Some of the weaknesses were lack of consistency in outcome measures, lack of cost benefit and cost effectiveness studies, small sample size of many studies, and lack of focus on other than mobility related disabilities by most projects. The opportunities for CBR evaluations pertain to training assessments, use of mixed models, using indicators from a standard taxonomy, and focusing on medical rehabilitation. The threats to CBR evaluations are a need to prioritise from multifarious activities and having limited resources for evaluation.

INTRODUCTION

Three decades have elapsed since the World Health Organisation (WHO) introduced the community-based rehabilitation (CBR) strategy as part of its goal to accomplish “Health for All by the year 2000”(1). A training manual was produced in 1980 (2) that was revised in

1989 (3) and has now been translated in several languages for use at the village level. In essence, the primary tenet of CBR is to provide primary care and rehabilitative assistance to persons with disabilities, by using human and other resources already available in their communities. The five basic principles of CBR strategy include:

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

The purpose of this article is to qualitatively analyse the extent to which the CBR approach and programmes have been evaluated over the past thirty years. A framework of strengths, weaknesses, opportunities and threats analysis has been used in conducting this analysis (4).

METHODOLOGY

In order to collect the materials for the study a search of MEDLINE database was done. A search of the terms “community based rehabilitation” and “evaluation” in MEDLINE revealed forty four articles of which twenty two met the inclusion criteria. The inclusion criteria were publications: (1) in English language; (2) that dealt with community-based rehabilitation as opposed to institutional based rehabilitation; (3) publications that described any aspect of either a qualitative or quantitative evaluation of a CBR programme and (4) published after 1980. Foreign language publications or publications that did not describe CBR evaluation were excluded. Also excluded were publications not in MEDLINE database, professional reports, or other forms of publication.

RESULTS

The studies have been arranged in the order of the year that these have been published. The studies are summarised in Table 1.

Table 1. Summary of evaluation-related studies in community-based rehabilitation

Year of Publication	Country	Design	Outcome Measures	Salient findings
1985 ⁵	Finland	Experimental	<ul style="list-style-type: none"> · Self perceived health status · Functional capacity · Independence in household tasks · Social participation · Leisure activities · Costs 	<ul style="list-style-type: none"> · Self perceived health status improved in experimental group · No change in other variables
1987 ⁶	Zimbabwe	Post-test only design	<ul style="list-style-type: none"> · Etiology · Learning targets · Ratings of clients' progress · Participants' reactions to the programme 	<ul style="list-style-type: none"> · 41% undiagnosed, followed by 22% with cerebral palsy · 16% showed outstanding progress with 79% steady progress
1988 ⁷	Guyana	Multiple baseline design & qualitative assessments	<ul style="list-style-type: none"> · Griffiths test of development · Portage assessment · Emotional disturbance of mothers · Attitude of mothers · Child rating · Initial reactions 	<ul style="list-style-type: none"> · 33 children (1.85%) were identified as disabled · Portage and Griffiths assessments showed significant improvement after training. · Parental attitudes also changed significantly
1988 ^{8,9}	Pakistan	Pre-test Post-test design	<ul style="list-style-type: none"> · 23 item questionnaire from WHO manual² that includes information about type of disability and improvement in disablement 	<ul style="list-style-type: none"> · Difficulty in seeing and moving most common · 80% persons with disability showed improvement in one or more areas

1992 ¹⁰	Philippines & Zimbabwe	Pre-test Post-test design	<ul style="list-style-type: none"> · Status for six types of disabilities in terms of ability scores · Starting school · Percent employed 	<ul style="list-style-type: none"> · 78% persons with disability in Philippines and 93% in Zimbabwe showed improvement in ability scores · 26% children with disability in Philippines and 69% in Zimbabwe started school · 61% in Philippines employed and 50% in Zimbabwe
1992 ¹¹	Jamaica	Post-test only design	<ul style="list-style-type: none"> · Views on CBR worker's visit · Knowledge · Attitudes · Practices 	<ul style="list-style-type: none"> · 25% commented on CBR visit and of these half were positive · Positive changes in knowledge · 67% showed changes in attitudes · 70% said their practices had changed
1992 ¹²	India	Post-test only design	<ul style="list-style-type: none"> · Disease acceptance · Respect in the family · Occupation after rehabilitation 	<ul style="list-style-type: none"> · Acceptance about Leprosy had increased in patients · Respect in the family increased for 95% of the leprosy patients · All patients had some kind of occupation
1996 ¹³	Zimbabwe	Post-test only design	<ul style="list-style-type: none"> · Traditional beliefs · Impact of a child with disability on the caregiver · Community involvement · Perceived ability to teach the child · Attitude toward various health services 	<ul style="list-style-type: none"> · 72% respondents in one group were satisfied with CBR · Significant correlation was found between appreciation of CBR and attitude toward various health services · Significant correlation was also found between perceived ability to

			· Expectations for the future of a disabled child	teach and expectations for the future of the child
1998 ¹⁴	England	Post-test only design	· Community outcomes · Hospital anxiety and depression scale (HAD) · Functional Independence/ Assessment measure (FIM/FAM)	· Community outcome scale was developed and validated
1998 ¹⁵	India	Post-test only design	· Parental adjustment	· Development and validation of a parental adjustment scale for rural parents of disabled children
1998 ¹⁶	Vietnam	Qualitative	· Training content · Training methods · Training evaluation	· Assessment of CBR training needs, content, methods, and evaluation
1998 ¹⁷	United States	Factorial mixed model design	· Examination of CBR related knowledge	· CBR continuing education programme with administrators and professionals, revealed higher gains than in paraprofessionals
1998 ¹⁸	Thailand	Pre-test post-test design	· Walking velocity · Pain levels · Costs	· Statistically significant improvement in pain levels and walking velocity · Costs much cheaper than institution based care
2000 ¹⁹	Philippines	Qualitative audit methodology	· Access · Effectiveness of referral · Satisfaction · Training · Collaboration	· Using personal interviews, focus groups, and records review it was found that the CBR programme was received as important & accessible

				<ul style="list-style-type: none"> · Satisfaction was high · Referral systems were functioning well but could be improved · WHO training manual was useful but training could be improved
2000 ²⁰ & 2003 ²¹	Australia	Qualitative SWOT analysis	<ol style="list-style-type: none"> 1. Network partnerships 2. Balance of product and process 3. Knowledge transfer 4. Problem solving 5. Financial and resource infrastructure 6. Human investments 7. Community focus 8. Social cohesion 9. Participation 10. Government partnerships 11. Communication 12. Community building skills 13. Leadership 14. Community control over decision making 15. Trust 	<ul style="list-style-type: none"> · Strengths: 1, 2, 4, 6, 7, 8, 15 · Weaknesses: 5, 10 · Opportunities: 3, 9, 12, 13, 14 · Threats: 5, 11
2001 ²²	Vietnam	Qualitative SWOT analysis	<ul style="list-style-type: none"> · Five tenets of WHO model 	<ul style="list-style-type: none"> · Strengths with regard to utilization of available resources, knowledge transfer, & referral · Weaknesses regarding community involvement & multi-sectoral approach
2002 ²³	Japan	Case control design	<ul style="list-style-type: none"> · 12 Functional fitness tests 	<ul style="list-style-type: none"> · All test items revealed performance deficits in

				stroke survivors · Need to subgroup CBR clients according to functional fitness
2002 ²⁴	England	Randomized control trial	· Barthel index (BI) · Brain injury community rehabilitation outcome-39 (BICRO-39) · Functional independence measure (FIM) · Functional assessment measure (FAM) · Hospital anxiety and depression scale (HAD)	· Improvements on BI and BICRO-39 · No changes on HAD · No change in FIM+FAM scores · No changes on socializing or productive employment subscales of BICRO-39 · Benefits can continue years after TBI
2003 ²⁵	Australia	Qualitative thematic analysis	· Goal statements of Brain injury survivors	· Taxonomy of 21 categories within 5 domains utilizing 125 descriptors was developed
2003 ²⁶	Papua & New Guinea	Survey and qualitative	· Screen for childhood disability · Perceptions of disabled	· More sensitive tool · Qualitative methods good for eliciting perceptions
2003 ²⁷	India	Prospective treatment and comparison group design	· Positive and negative syndrome scale (PANSS) · Disability Assessment Schedule (DAS)	· CBR model was more effective in reducing disability · Within the CBR group the compliant group had better outcomes than partially or non compliant individuals
2005 ²⁸	Australia	Prospective repeated measures design	· Skill development following an outdoor adventure course · Goal-based learning	· Over 80% stated goals were achieved · Approach showed promise for CBR

The first study was done in Posio, Finland (5). Using an experimental design, it was found that self-perceived health of the elderly and disabled persons improved for the experimental group. No changes were found for functional capacity, independence in household tasks, social participation, and leisure activities. The primary costs of rehabilitation were lower for the experimental group, but the secondary costs were the same. The author of the study recommended better training of CBR functionaries in evaluation, involvement of outside experts, planning for evaluation at the beginning, and having an interdisciplinary supervisory team.

The second study was done in four areas of Zimbabwe (6). Using a post-test only design, it was found that a large number of persons with disability (41%) were undiagnosed. Based upon the coordinator's rating of a client's progress, it was noted that 16% demonstrated outstanding progress, 79% steady progress, and 5% showed little, or no progress. Except for one, all the 136 participants found the programme to be helpful. Three aspects were found to be important in programme success: partnerships with agencies, training in mental handicap, and culturally relevant resource materials.

The third study was done in Guyana (7). The study used a multiple baseline design where three data points were taken over a two month period in the baseline and data was collected using the Portage checklist and Griffiths test of development. The study also collected qualitative data on emotional disturbance of mothers, attitude of mothers, parental rating of the child with most other children, and sentence completion to gauge initial responses. The study contacted 815 homes with 4,644 persons and found 33 children as disabled (1.85% of the sample of children). A repeated t-test Griffiths test revealed statistical significance ($p < 0.01$) and so also significance was found on Portage test. Parents also rated significant improvement in their children. Overall, the CBR approach was found to be successful.

The fourth study was done in a slum area (Kachi Abadi) and a village near Lahore in Pakistan (8,9). The questionnaire from the WHO manual (2) in a house-to-house survey was used to gauge the prevalence of disability and identifying persons in need of intervention. Eighty two persons were trained and reevaluated after 1-2 years using the WHO questionnaire and it was found that 66 (80%) had made improvement in one or more areas of the programme such as looking after self, moving around the house, attending school etc.

The fifth study was an evaluation done in Philippines and Zimbabwe in 1992 (10). The study used a pre-test post-test design and found that ability scores after CBR training increased by 78% in Philippines and 93% in Zimbabwe. Likewise, 26% children with disability in Philippines and 69% in Zimbabwe started school and 61% persons with disabilities were employed in Philippines and 50% in Zimbabwe.

The sixth study has been done in Jamaica (11). The study utilised a post-test only design and found that knowledge, attitudes and practices improved in approximately two third of the persons with disability. The seventh study is about Greater Madras Leprosy Treatment and Health Education Scheme (GREMALTES) project done in India (12). The study utilised a post-test only design and found that acceptance about disease had increased in patients. Also respect in the family increased for 95% of the leprosy patients. After rehabilitation, all patients had some kind of occupation.

The eighth study was done in Zimbabwe (13) and interviewed CBR beneficiaries on six variables: (1) traditional beliefs about children with disabilities, (2) impact of a child with disability on the caregiver, (3) community involvement, (4) caregiver's perceived ability to teach the child, (5) attitude toward various health services, and (6) expectations for the future of a disabled child. A significant correlation between appreciation of CBR and attitude toward various health services was found. Also, it was found that perceived ability to teach and expectations for the future of the child had significant correlation. The ninth study was done in England (14) and aimed at developing and validating a community outcomes scale for persons with traumatic brain injury. The tenth study developed and validated a parental attitude scale for parents of disabled children in rural India (15). The eleventh study is a qualitative account of training methods and their evaluation developed in Vietnam for community based rehabilitation (16). The twelfth study was physically based in The United States but entailed a 4-day continuing education training for 308 administrators, professionals and para-professionals from several countries (17). The training showed improvement in the knowledge of the participants – more in administrators and professionals as compared to para-professionals.

The thirteenth study done in Thailand (18) aimed at examining effectiveness and cost of the CBR programme in a slum after a period of three years. Using a pre-test post-test design, effectiveness of the programme was assessed by measuring walking velocity, pain levels,

and reasons for discontinuing the use of the CBR programme. Statistically significant changes in walking velocity and pain levels were found. Only nine out of 178 patients stopped using CBR because their condition did not improve. The cost per patient per day, was found to be approximately Bt 111, which was much cheaper than institution based rehabilitation.

The fourteenth study was done in Philippines (19) after seven years of operation and used qualitative approach of audit where records were reviewed, in-depth personal interviews were conducted with key informants and focus groups discussions were conducted. It was found that CBR programme was perceived as important and accessible. The referral systems were functioning well but there was scope for improvement. The clients and their families were satisfied with the services and they were willing to help in the continuation of the programme. The WHO Training Manual was rated as useful. However, there was scope for improvement in training methods, duration, follow-up, and translation into the local language.

The fifteenth study was done in Australia and published in 2001 (20) and 2003 (21). It utilised participatory rural appraisal in its planning and conducted qualitative SWOT (Strengths, Weaknesses, Opportunities and Threats) Analysis around 15 identified characteristics. It was found that network partnerships, balance of product and process, problem solving, human, intellectual and social investments, community focus, social cohesion and relationship of trust were strengths of the CBR programme. Financial and resource infrastructure and partnership with government and policy infrastructure, were identified weaknesses. There were greater opportunities for knowledge transfer, widespread participation, community building skills, leadership, and community control over decision making. The threats pertained to financial and resource infrastructure and communication system.

The sixteenth study was an evaluation done in 2001, in Vietnam (22). A participatory SWOT analysis method was utilised for evaluation. The data were examined against the WHO model. Strengths of the programme were found in three out of five areas, namely, utilisation of available resources, transfer of knowledge about disabilities, and utilisation and strengthening of referral systems. The weaknesses were in the areas of community involvement in planning and decision making and co-ordinated multi-sectoral approach. The seventeenth study was done in Japan (23) that compared stroke survivors with controls and found that functional fitness levels were less and varied in stroke survivors. The study recommended that CBR projects should group individuals according to functional fitness. The eighteenth study looked

at traumatic brain injury survivors in England and used a randomised controlled design (24). The study found that years after injury, the benefits continue in TBI survivors and must be harnessed by CBR programmes. The nineteenth study done in Australia looked at qualitatively classifying client goals in CBR programmes with acquired brain injury survivors (25). A taxonomy related to five categories of goals was developed : (1) me and my body, (2) looking after myself, (3) addressing psychosocial issues, (4) relating to others, and (5) services and information.

The twentieth study was done in Papua and New Guinea (26) and developed a ten question screening questionnaire for childhood disability and also collected qualitative data from persons with disabilities to understand their perceptions. The twenty first study was done in India with persons suffering from chronic schizophrenia (27). Using a prospective treatment and comparison group design, the study found that the CBR model was more effective in reducing disability and within this group the compliant group had better outcomes than partially, or non compliant individuals.

The final study is from Australia (28), in which a three stage programme was evaluated. In the first stage, practical activities were used to build social skills. In the second stage a 9-day outdoor adventure course was introduced with physically challenging tasks and in the third stage individuals worked on individual goals that they had set. This programme that emphasised goal setting was successful in achieving 80% of the goals and offers potential for CBR programmes.

DISCUSSION

The purpose of this study was to examine CBR programme evaluations and discuss the strengths, weaknesses, opportunities and threats from these analyses. In the analyses, three studies each from Australia, India, Zimbabwe; two studies each from England, Philippines, Vietnam; and one study each from Finland, Guyana, Jamaica, Japan, Pakistan, Papua and New Guinea, Thailand, and United States were included.

Strengths

One of the strengths of the evaluations is that they have been varied in their methodology. Two studies (5,24) used randomised control design, Six used quasi-experimental designs (8,10,18,23,27,28), six used post-test only designs (6,11,12,13,14,15) five used qualitative designs

(16,19,21,22,25), and three used mixed model designs (7,17,26). The use of a variety of methods provides an opportunity to both generate hypotheses and test hypotheses. It adds to the repertoire of potential evaluators an array of methods to pick and choose from.

Almost all the evaluations of CBR programmes have been based in community settings, which is another of its strengths. The approach of CBR is different from the institutional-based approaches in the fact that these are based in community settings. The perceptions of the community are central to planning and evaluation of CBR programmes and it is praiseworthy to find, that such is the case.

In terms of the types of disabilities focused upon, most of the evaluations have focused on mobility-related assessments. Rehabilitation of brain injured persons has also been the focus of many country CBR programmes, especially the ones in developed countries (24,25,28).

Many projects have used existing instruments and validated those to their populations, while other projects have developed new measures. Noteworthy among those are the community outcomes scale developed in England (14) and a parental adjustment scale developed in rural India (15).

Weaknesses

One of the weaknesses of the CBR evaluation that is evident, is that there is lack of consistency in outcome measures. Wirz and Thomas have also pointed out at this weakness in a seminal article on this issue (29). Many of the outcome measures describe the practice as opposed to effectiveness.

Only one study has measured the costs of the CBR programme (18) and only one study has assessed the progress on the WHO model (22). More studies that discuss cost benefit and cost effectiveness issues and also examine the effectiveness in terms of the WHO model are needed.

Another weakness about which not much can be done is the small sample size utilised by many of the evaluations. What can be done in such situations is that qualitative and mixed models be used instead of quantitative models. Another problem in some of the descriptions is that the writing style could be better and details of the methods used could be explicitly elaborated.

A final weakness pertains to the fact that other than mobility related assessments, other disabilities have not been adequately addressed. For example, only one evaluation (27) pertains to mental disability.

Opportunities

Assessment of training has been addressed in an evaluation of a few CBR projects. There is ample opportunity for systematic evaluation of training efforts. Such evaluation can be done in terms of content, methods, and impact in terms of changes in knowledge attitudes, and behaviours.

There is greater opportunity regarding use of mixed models in conducting evaluations. There is need for combining both qualitative and quantitative methods in conducting CBR evaluation. Both these differing methodologies have a lot to contribute to CBR evaluation. The use of participatory approaches is mandatory, given the nature of the CBR approach. However, this has not been utilised completely by all CBR evaluators.

There is also an opportunity to use a variety of methods such as case studies, focus groups, nominal groups, participatory techniques, content analysis, and key informant interviews (30).

In terms of indicators, Wirz and Thomas (29) have presented a taxonomy of indicators that is quite useful. They have identified three domains, namely maximising the potential of the person with disability, service delivery, and the environment where the person with disability lives. In the domain of maximising the potential the following are included: functional independence, education, economic independence, inclusion, community leadership roles and participation in/ownership of programmes. In the domain of service delivery programme planning and management, financial and people management, training and sustainability are included. In the third domain of environment, included are family attitudes and involvement and community attitudes and inclusion of PWD. Using a systematic framework like this one, by all CBR projects is an important opportunity. Inter-country consensus meetings that refine this classification and make it useful for adoption by all CBR projects are needed.

Some authors have talked about systematisation of evaluation of medical rehabilitation (31). Medical rehabilitation is an important component of CBR and must be evaluated. A tracer approach consisting of three aspects of medical rehabilitation offers potential opportunity for

bringing in systematisation. The three components of this approach are focus on technical quality based on minimum technical standards for each impairment; interpersonal quality that entails observation of service sessions; and management (structural) quality which involves comparing rehabilitation goals of service users and service providers.

Threats

A potential threat for CBR evaluations lies in the fact that these projects have multifarious activities and focusing on all activities in evaluation, is seldom possible. Mitchell (32) has suggested and categorised priority areas into four domains. The first is that of service delivery system where issues such as utilisation of CBR worker needs to be evaluated. The second domain is that of technology transfer where issues such as effectiveness of the WHO Manual needs to be evaluated. The third domain is that of community involvement, where issues such as assessing changes in attitude of community towards disabled people is evaluated. The final domain is that of organisation and management, where issues such as identification of the best organisational model for CBR is evaluated.

CBR, by its nature operates in resource-poor settings. In such settings, it is often difficult to find resources for conducting evaluation at the expense of programming. This is a real threat to CBR evaluations. Conscious efforts need to be made in the planning stage itself, to budget for evaluation.

SUMMARY AND CONCLUSIONS

The article examined twenty two CBR evaluations, to develop a list of strengths weaknesses, opportunities, and threats from these articles for future evaluators. The strengths included variety of methods used, most evaluations having been conducted in community settings, focus on mobility-related evaluations by most programmes, and development of new instruments. Some of the weaknesses of CBR evaluations were lack of consistency in outcome measures, lack of cost-benefit and cost-effectiveness studies, small sample size used in many studies, and lack of focus on other than mobility-related disabilities by most projects. The opportunities for CBR evaluations pertained to systematisation of training assessments, use of mixed models, using indicators from a standard taxonomy, and focusing on medical rehabilitation. The threats to CBR evaluations were the need to prioritise from multifarious activities and having limited resources for evaluation.

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ORIGINAL ARTICLES

VOCATIONAL REINTEGRATION OF PEOPLE WITH SPINAL CORD LESION IN BANGLADESH – AN OBSERVATIONAL STUDY BASED ON A VOCATIONAL TRAINING PROJECT AT CRP

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ABSTRACT

The employment situation for disabled people in Bangladesh has been demonstrated to be extremely poor. CRP (Centre for the Rehabilitation of the Paralysed) recently engaged in a new rehabilitation initiative, aiming at bringing people with spinal cord injury back to their previous occupations.

This article outlines the components of this initiative and assesses its success on the basis of an observational study completed at the end of the three-year programme. The study focuses in particular, on a number of critical issues surrounding disability, poverty and vocational rehabilitation in Bangladesh. An estimated 50% of the participants successfully reintegrated into paid employment, of which three quarters returned to occupations very similar to their previous ones. Serious financial struggles and inaccessible workplaces were reported as the most common obstacles. There is an urgent need for comprehensive rehabilitation programmes for all people with disabilities, particularly since the government fails to recognise its responsibilities in this regard.

INTRODUCTION

According to the most recent figures, the population of Bangladesh is fast approaching 150 million people out of which almost half currently live below the poverty line (1). Many studies, for example Department for International Development (DFID (2)) and Alam, Bari and Khan (3), have confirmed that a strong relationship exists between poverty and disability,

with each being both a cause and a consequence of the other. DFID (2) also estimates that “as many as 50% of impairments [in developing countries] are preventable and directly linked to poverty” and Elwan (4), suggests in a background paper for the World Development Report from the World Bank that as many as one in five of the world’s poorest people are disabled.

Presently, there are no reliable data from either the government or other agencies to establish the number of disabled people in Bangladesh (5), although current estimates from the WHO on the prevalence of disabled people in the world suggest around 10% (6). The UN suggests that disabled people constitute as many as 20% of people in some developing countries (7). The estimates with reference to Bangladesh, over the past twenty years have ranged from 0.5% to 10% (8, 3) highlighting the need for a comprehensive, accurate study about the size and nature of the disabled population in the country. Regardless of which estimate is closer to the truth, it is evident that the absolute number of people living with a disability is extremely large. Even if one were to adopt the rather conservative estimate of 5%, one is looking at a population in excess of 7 million people who are disabled and most of whom are presumed to live below the poverty line.

Numerous studies about the employment situation of disabled people in Bangladesh, have shown that many become jobless as a result of their disabilities and are thus further disadvantaged or disabled as a consequence (9, 10). The major barriers facing disabled people seeking to re-enter the workforce, reach far beyond the physical limitations imposed on them by their disabilities. Momin (10) identified 11 barriers facing disabled people who are in paid employment or, who are seeking to re-enter the workforce. These are barriers which are mostly attributable to a generally poor understanding of disability in the society. The Danish Bilharziasis Laboratory (11) similarly asserts that prejudice, ignorance and a lack of training and educational opportunities for disabled people have caused significant barriers for disabled people seeking employment. The government is not seen to be doing much to improve the situation despite the Disability Welfare Act of 2001 (12), which aims to protect the rights of disabled people and ensure equal opportunities. Although the passing of the Act itself is recognised as a milestone, its implementation has been poor (8) and parts of the Act remain in conflict with existing legislation on education and employment (13). In relation to the Asia-Pacific regional workshop on the National Plan of Action on Disability, Alam (5) stated that

'In the disability arena, the [Bangladeshi] government has not yet taken any large initiative to review its implementation, monitoring and/or evaluation of either the national policy or legislation as yet'.

Furthermore, the lack of a social security network means that disabled people receive no financial aid to assist them with the added expenses resulting from their impairments – either directly or through loss of employment. A study entitled 'Disability in Bangladesh' (DIB) cited in Alam, Bari and Khan (3) suggests that over 96% of people with disabilities in Bangladesh, receive no help. In addition, there is a distinct lack of government initiative to advance the employment situation for disabled people through vocational training, education, legislation on accessibility at work and so on (14, 15).

A small number of non-governmental organisations are involved in rehabilitation and vocational training for disabled people in Bangladesh. CRP (Centre for the Rehabilitation of the Paralysed) is a non-governmental organisation specialising in the rehabilitation of people with spinal cord lesion in Bangladesh. Great emphasis is placed upon vocational training at CRP. Given the difficult employment situation for disabled people, the organisation recognises work rehabilitation as vital to most rehabilitation programmes. Similarly, a return to paid employment is regarded as the most important outcome measure of successful reintegration into society. Momin (16) outlines a model for a comprehensive rehabilitation programme focusing on vocational training. As the person's medical condition improves, a strategic shift in priority will allow training in daily living activities, vocational training and education, to be given precedence. Once in the community, the person still enjoys the support of community based rehabilitation through home visits and mobile clinics. The model also aims to encourage family and the community to participate to some extent, while addressing issues of social inequity and discrimination towards disabled people.

In a recent study, comparing a CRP run rehabilitation programme with general hospital treatments offered to spinal cord injury patients in Bangladesh, Momin (10) offers the strongest evidence to prove that the rehabilitation approach is effective. General hospitals offer little care beyond acute medical treatment, with very few clients receiving services from occupational therapists or physiotherapists and with no focus on vocational training (16). In a study comparing 64 spinal cord injured persons from CRP and general hospitals Momin (10) further demonstrates that mobility aids are a rarity among discharged persons who

subsequently become very dependent on family members as they are unable to participate actively in the community. Of the 32 participating spinal cord injured persons who received treatment from general hospitals, 20 became unemployed, whereas only 3 people of the 32 who received treatment at CRP faced unemployment, afterwards. The results offer strong evidence of a statistical significant difference ($p < 0.0001$, $\chi^2 = 19.61$, $df=1$) in the unemployment rates of the two groups.

Nonetheless, CRP realised that persons with spinal injuries still face difficulties in returning to their previous occupations. In 2002, CRP engaged in a new work rehabilitation programme funded by the United States Department of Labour which aimed at bringing people back to the same sort of occupations they held, before sustaining their injuries. The rationale for the programme was that it often seems sensible to aim for a person to return to his or her previous occupation, since attaining new job skills is expected to pose more of a challenge, than retraining existing ones. Moreover, to see disabled people return to their former occupations and re-engage in society much as before, may help eliminate prejudice surrounding disabled people and their capabilities within the community. The primary objective of such a work rehabilitation programme then, is to retrain people physically until they are able to manage their vocational tasks. This will hopefully bring about positive changes in the attitudes of employers and colleagues, thereby achieving the secondary objective of targeting ignorance and raising awareness about disability.

This article outlines the components of this initiative and assesses its success on the basis of an observational study completed at the end of the three-year programme which ran from 2002 to 2005. The study focuses in particular, on a number of critical issues surrounding disability, poverty and vocational rehabilitation as raised by the participants, including their suggestions for improving the programme. Finally, the issues raised here are considered in a broader context with particular emphasis on the implications for policy makers and organisations working with disabled people.

METHODS

The ultimate aim of the work rehabilitation programme based at CRP's site in Savar, in the Dhaka district of Bangladesh, was to enable participants to return to their previous employment or a suitable alternative. Anyone admitted to CRP were offered a chance to enrol, although

priority was given to persons exhibiting a higher potential for rehabilitation because of the limited number of qualified occupational therapists at CRP's disposal. At the end of the allotted three-year period from August 2002 to June 2005 a total of 109 persons had completed the programme.

Participants were tested on initial assessments in seeking to identify their strong and weaker points, including their overall potential for successfully completing the rehabilitation process. In pre-work training, physical conditioning was given priority with the aim of building strength, endurance and motor function, while focusing on activities relevant to the individual participant's vocational training. The vocational training was then extended to a scheme involving simulated work practice through a strategy of graded activities. Furthermore, in seeking to provide a transition between institutional care and a return to work, issues of productivity, safety, physical tolerance and work behaviour were addressed at this stage. During the final phase of the vocational training scheme, the participants were sent on placements either on site at CRP, or in nearby workplaces. After being discharged from CRP, having completed the core modules of the rehabilitation and vocational training schemes, the participants were offered continuing support through an extended service in the community, entailing follow-up visits at the participants' new worksites.

Of the 109 individuals who completed the programme, 46 participants between the ages of 15 and 50 years were chosen conveniently from Dhaka's surrounding districts, to form the basis of an evaluation report completed at the end of the three-year programme. The participants were selected on the basis of their proximity in relation to the data collectors, to reduce time spent on transportation between CRP and the participants and to facilitate communication. In seeking to relax the interviews and reduce the inconvenience caused to the participants, all interviews were carried out in the homes of the respondents. It took a total of two months to complete the interviews.

RESULTS

Of the 46 respondents, only 6 were female, reflecting the general male to female ratio in spinal cord injury admittances at CRP. The participants mostly had little or no formal education. They were typically from poorer homes in rural environments, with a

disproportionately large number of very young adults among them, suggesting that people in this age group are at greater risk of sustaining serious injuries.

During the rehabilitation process whilst admitted to CRP, the participants would typically receive some level of care from a close relative additional to the hospital care. In seeking to gain a broader perspective on issues discussed with the respondents, the person who had been in charge of looking after their injured family member – and who had typically observed the events unfold from the time of the injury happening – was interviewed as well. Most commonly, the carers were the wives – often uneducated and not involved in income generating activities such that with the loss of their husband's income, the entire family would face severe economic difficulties.

At the time of the interviews, 18 of the 46 participants were engaged in employment completely similar to or much the same as their previous employment. A further five participants were engaged in occupations which bore some or no resemblance to their former occupations. Of the 23 individuals who returned to work only four out of the 15 wheelchair bound individuals were amongst them whereas five out of eight individuals on crutches were reemployed. There is some evidence therefore, that wheelchair users are finding re-employment more challenging compared to people who do not need mobility aids or, who only depend on crutches ($p < 0.028$, $\chi^2 = 4.847$, $df=1$). This finding is not entirely unexpected as the dependency on – and type of – mobility aid to some extent is indicative of the severity of injuries. However, there is also a possibility that mobility aids accentuate the user's disability making it more difficult for the jobseeker to convince a future employer of his or her capabilities. Moreover, there is a real issue concerning accessibility at work, including transportation to and from work. Problems such as these were identified by the participants in the interviews.

The participants were asked to identify a number of issues which they considered most important in influencing their ability to re-enter the workforce (Table-1).

Table 1. A ranking of the factors (listed in order of importance with the most influential at the top) which proved helpful to participants who were re-employed (on the left), and which were a hindrance to participants who did not regain employment (on the right)

Helpful factors identified by the reemployed participants	Hindering factors identified by the unemployed participants
Success of the WRP* Cooperation in the family Motivation Physical ability Attitudes in the community Accessibility at work Attitudes of colleagues and employers	Physical inability Inaccessibility at work Motivation Attitudes in the community Little effectiveness of the WRP* Lack of cooperation in the family
* Work rehabilitation programme	

The participants who were re-employed, considered the work rehabilitation programme the single most influential factor behind their return. The second most influential factor identified by this group, was co-operation in the family. The greatest hindrances to participants who did not return to work, were their physical inability and inaccessibility at work. Motivation was identified by both groups as a strong determining factor; indeed in the re-employed group motivation was placed before physical ability and accessibility at work. It is remarkable that the two top ranking factors amongst the re-employed participants are also the two bottom ranking factors in the unemployed group. Perhaps this is an indicator that when things go right, the immediate surroundings such as carers and the family get the credit, whereas when things go wrong, blame is put on the affected persons themselves (physical inability) or on the outside world (inaccessibility at work) both of which are difficult to change.

Financial struggles brought on by a low income, or lack of initial capital was reported as the single most problematic issue facing the re-employed participants in their new employment

(Table-2). An inaccessible work environment was also identified by the respondents as a critical issue along with their own physical disabilities. Finally a few persons reported negative attitudes from colleagues and employers. 18% of the re-employed participants reported that they faced no problems at work.

Table 2. A ranking of problems faced by the reemployed participants in their new employment

Financial struggles
Inaccessible work environments
Physical limitations
Unhelpful attitudes of colleagues and employers

When asked what they would like to improve about the work rehabilitation programme, a third of the participants suggested that pre-assessments of the individual worksites be introduced, so that the service providers at CRP gain a better impression of what awaits the participants once there are back at work (Table-3).

Table 3. Suggestions for improving the existing work rehabilitation programme, listed in order of priority

Introduce pre-assessments of worksites
Further focus on follow-up assessments
Introduce some measure of financial assistance
Further involvement of family, employers and the community
Increase the duration of the programme
Include suggestions for workplace modifications

Currently, the vocational training programme is designed on the basis of what the participants tell the programme coordinators about their previous work. Pre-assessments would allow

for the occupational therapists and other service providers to work closer with the participants in tailoring the individual programmes, to better suit the needs of each person. Furthermore, the limited number of qualified therapists available, meant that the occupational therapy department in charge of the programme was struggling to achieve the pre-arranged level of follow-up assessments and the programme was consequently somewhat compromised on this point. The issue of follow-up assessments was raised by almost a quarter of the participants, as critical for improving the programme. 13% of the participants suggested that some measure of financial assistance be introduced to help with initial set-up costs etc. and a further 13% suggested greater involvement of family, employers and the community in the programme.

DISCUSSION

It emerged from interviews with the participants, that individual motivation is seemingly a key factor behind successful work rehabilitation, suggesting that increased focus on post-traumatic depression perhaps through counselling, could be beneficial. It would quite possibly have a positive effect on motivation if, somehow, cooperation from employers and the local community was encouraged and families were more extensively involved in the rehabilitation programme. A further possibility for advancement of relations between the community and the rehabilitation programme, presents itself through the initiation of workplace assessments and follow-up visits when the participants have left the rehabilitation centre and returned to the community. The participants emphasised that the current programme would have benefited from more extensive pre and post-assessments. Follow-up field visits were seen as crucial in ensuring a continuing programme in the community, after the initial training phase at the rehabilitation centre had ceased.

The issue of poor accessibility for disabled people in the built environment, at work and on public transport, was raised several times by most participants and identified as a prime factor preventing disabled people from returning to work. The little efforts put towards building a more enabling environment, bear evidence of a view of disability where disability is apportioned to the physical limitations of disabled people only. This is in stark contrast to the social model of disability where society is seen as disabling people through a combination of social and environmental barriers. Physical limitations need not be disabling in an inclusive environment.

Given the extent of the problem, it is understood that ensuring proper access for disabled people in the community and at work, would almost certainly improve the success rate of reintegration of disabled people into working life and hopefully in the process create a better, safer work environment for all. It seems therefore, that comprehensive work rehabilitation programmes and other programmes involved with disability in societies like Bangladesh, where inaccessibility pose such a barrier, should raise this challenging issue and lobby for the government to do the same. The government needs to take seriously its responsibilities towards disabled people as outlined in the Disability Welfare Act of 2001, by ensuring stricter implementation of existing anti-discriminatory laws and imposing planning and building regulations that advance accessibility.

A remarkably small proportion of persons who are brought for rehabilitation at CRP are female (17) suggesting a reduced risk of spinal cord lesion amongst women. However, some of the discrepancies in the gender distribution of admittances may be attributable to the patriarchal nature of Bangladeshi society, where social and cultural restrictions confine women to the “protection” of men within their family (18). Injured women as a result may be less likely to be brought to the rehabilitation centres. Another consequence resulting from fully relying on the man to provide an income for the family is the serious economic hardship experienced by many families when the husband or father is physically disabled and has lost his ability to work. Alam, Bari and Khan (3) argue that, “For every person who has an impairment and/or disability, 4 to 5 other family members are [...] affected”. Vocational reintegration is understood to be fundamental in preventing the onset of these serious consequences.

The severe economic constraints imposed by the changed circumstances, may be the ultimate impediment hindering people with disabilities from regaining employment whether it is a question of building an access ramp, buying mobility aids, or raising initial capital for setting up a small business. Hoque, Grangeon and Reed (17), found that the majority of people with spinal cord injury, were labourers carrying heavy loads on their heads or tree-climbers employed in agriculture in rural Bangladesh. This finding is also in accordance with CRP’s records on client demographics and suggests that the vast majority of these peoples come from very poor economic backgrounds. Therefore, integral to vocational rehabilitation, is arguably some level of financial rehabilitation. Work rehabilitation programmes may find it worthwhile investing

in some means of initial financial support for its participants either directly, or in Bangladesh, via existing micro-credit schemes.

Despite the difficult issues outlined in this article the work rehabilitation programme described here, managed to successfully reintegrate an estimated 50% of the participating individuals, of whom three quarters returned to occupations very similar to their previous ones. To what extent these individuals would have reintegrated had they not participated in the programme is uncertain. However, previous studies suggest a remarkably low reintegration rate in disabled persons who receive either no treatment or conventional treatment from general hospitals around the country (9, 10). Hence, there is a desperate need for inclusive, non-profitable rehabilitation programmes for all people with disabilities, particularly since the government does little to improve the disability situation. A further point made at the Asia-Pacific regional workshop in 2005, was that “the government does not yet have the required capacity and/or personnel to do a situation analysis of persons with disabilities. Nor does it have the means to gather information on any other socio-economic indicator. Fortunately, the Government also recognises these limitations. So it is highly dependent on the NGOs [non-governmental organisations]” (5). Meanwhile, it is estimated that around 70% of people with disabilities in Bangladesh are still unable to seek medical or rehabilitation assistance because of economic hardship (DIB cited in Alam, Bari & Khan (3)). And this despite government promises (12) to, “undertake appropriate Schemes including Credit-Support programmes for rehabilitation of the persons with disabilities” and to ensure the “Establishment and maintenance of Rehabilitation Centres both at Government and Non-Government level” and to “supply supportive logistics/materials for curative treatment [...] to persons with disabilities from Hospitals, Health Complexes and Rehabilitative Centres either cost-free or at low-cost” as stated in the Disability Welfare Act of 2001. The APCD (8) notes that despite the passing of the act in 2001 “the Government has not enacted or amended laws and regulations that cover traffic and industrial/labor laws for promoting health and safety in the workplace in public places, in transport and in the home, as well as set safety standards for equipment used in industry”.

The majority of the sampled participants sustained their injuries at work. Hoque, Grangeon and Reed (17) also found that the majority of their study population had sustained their injuries in a work related context. These facts serve to demonstrate the neglected

responsibilities of employers, to protect their employees by adhering to health and safety laws. These are responsibilities that will continue to be neglected until the government recognises its equally important responsibility of enforcing those same laws.

The work rehabilitation programme under study aimed at re-integrating clients into the same sort of employment that they held prior to their injuries. Although specifically designed for people with spinal cord lesion, the programme would easily adapt to include people with a wider range of disabilities. Future projects of a similar nature can hopefully draw on the experiences and recommendations made here.

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**STRESS AMONG MOTHERS OF CHILDREN
WITH CEREBRAL PALSY ATTENDING
SPECIAL SCHOOLS**

P.V. Vijesh *, P.S. Sukumaran **

ABSTRACT

This paper draws attention to the stress experienced by mothers of children with cerebral palsy attending special schools in Kerala State, India. Stress level was assessed using the local language version of the Questionnaire on Resources and Stress and the data were analysed with respect to certain child related and mother related variables. The study reveals that stress experienced by mothers of these children is at a moderate level and the pessimism expressed regarding the child's ability towards achieving self sufficiency, is found to be most stress producing factor. Among the child related and mother related variables, only multiple disability along with cerebral palsy is a significant variable in deciding the difference in the severity of stress among the mothers. This article also gives suggestions on how the stress levels can be minimised among the mothers.

INTRODUCTION

Cerebral palsy is a term used to describe a broad spectrum of motor disability, which is non-progressive and is caused by damage to the brain, at or around birth. Although the damage is nonprogressive, the clinical picture changes as the nervous system develops and the child grows. There are usually associated disabilities like mental retardation or hearing impairment.

The birth of a child with cerebral palsy places the family in a dilemma. Society views parenthood positively, but it views the birth of a disabled child negatively. Awareness of society's ambivalence, adds to the stress the family feels within themselves.

The stress factors accompanying the birth of a normal child are intensified when the child is disabled. The marital relationship may suffer unduly from the added stresses of blame, guilt and anxiety. A child's disability attacks the fabric of marriage in different ways. It excites

powerful emotions in both parents. It reshapes the organisation of the family. It creates a fertile ground for conflict (1).

The economic stress may be multiplied by additional hospital and medical costs. The parents' social life may become non-existent. They may be fearful of rejection by their friends and relatives. Additional stress is likely to occur in families of disabled infants, depending on each family's unique characteristics, like number of members in the family, presence of other chronic illness, disabilities and so on. However, the psychological impact experienced by these families are common-shock, denial and grief.

Generally, parents of a disabled child progress through six emotional stages upon discovering their child's disability: disbelief, guilt, rejection, shame, denial and a feeling of helplessness. Though reactions to the birth or diagnosis of a disabled child may vary from parent to parent, or family to family, people seem to share common elements. Frequently, the parents' initial feelings are shock and numbness; parents may experience periods of panic, anxiety and helplessness, as well as periods of indifference and anger, at which time they face nearly overwhelming depression, apathy and bitterness (2).

As normal children progress from one developmental stage to the next, their parents observe them with pride, anxiety and alarm. Parents have expectations of them based on social, family and experimental standards. When the children's behaviour deviates from the established standards, family crisis may develop.

Every child affects his/her family in the process of growing up based on the characteristics of the child and characteristics of the family. Transitions from infancy to early childhood, to late childhood and to adolescence, affect the family and the child. Crises and triumphs present in every child's life affect the family too. In addition to the pressures and demands that all parents experience, parents of disabled children must learn to deal with the exceptionality of various natures, some times for a life time.

Parents become aware of their child's exceptionality at birth, or shortly thereafter during the pre-school years, or after the child enters school. If they recognise the child's exceptionality before school entry, they have time to adjust to the child's condition and can accept the need for special education and related services. If they become aware upon or after school entry, they may need time to adjust to the diagnosis, thereby delaying implementation of the needed interventions.

The prevalence of cerebral palsy is gauged by the number of cases present during a specific time and is usually calculated as age-specific prevalence rate (3). A reasonable estimate of the prevalence of cerebral palsy at school age is 3 to 4 per 1000 live births in industrialised nations (4). Unfortunately, in Kerala, special schools and rehabilitation centres exclusively for children with cerebral palsy are very few in number. Children with cerebral palsy are in most cases, clubbed along with mentally retarded children. Teachers' training institutes for the care of children with cerebral palsy are less in number in Kerala state and research work is also not undertaken in the field of cerebral palsy and related areas. Until now, no studies were reported on the stress of mothers of children with cerebral palsy from this southern state of India.

METHODOLOGY

A descriptive method was used to achieve the objectives of the study (5). The tools used included Case Sheet Record and Questionnaire on Resources and Stress.

The Case Sheet Record is prepared to collect general information about the child with cerebral palsy and his/her family from the mother of the child. This includes information such as the child's name, sex, age, birth order, type of cerebral palsy, religion, presence of multiple disability, name of the school that the child is attending, locality of residence. In addition, details of mother such as age, educational status, occupation, monthly income, type of family, are also collected.

The Questionnaire on Resources and Stress (QRS) is the local language version of the short form of the Questionnaire on Resources and Stress modified by Freidrich, Greenberg and Crnic in 1983 (5). It measures the impact of a developmentally delayed, or chronically ill child, on other family members. The tool measures the four broad categories (1) parent and family problems (2) pessimism (3) child characteristics and (4) physical incapacitation. The instrument requires respondents to provide 'true' or 'false' answers concerning their children and family. QRS-F gives a total stress score and separate scores on the four independent factors of stress. A total of higher value in the scale indicates severe stress and lower value indicates lower stress. A range of score 0-17 indicates minimum stress; 18-34 indicates moderate stress and 35-52 indicates severe stress.

This four category structure suggests that the problems facing the families of disabled children are clearly multi-dimensional and that the score on a given dimension cannot predict or be predicted from knowledge of the score of the remaining dimensional factors. The KR-20 reliability coefficient for this short form is determined to be 0.95. Validation study of QRS-F is determined to be 0.93 by its authors. Also, correlations between QRS-F factors and other independent measures of depression, problem checklist and social desirability are indicative of the concurrent validity of the QRS-F.

Since this tool was originally developed in English, a vernacular translation carried out by Mathew and Asha (6) was used for the study. The test retest coefficient of reliability of the whole test estimated by using Spearman-Brown Prophecy formula, was 0.92. The scores obtained from this version were correlated with the English version and it was 0.78.

The reliability and validity coefficients indicate that the vernacular version of QRS-F used, is reasonably dependable and can be used to assess the stress experienced by mothers of children with cerebral palsy.

Classification of Data

The data were classified according to the different variables studied viz., age, sex, birth order, type of cerebral palsy, mobility factor, multiple disability, religion, location of residence, age, education and occupation of mother, type of family and husband's stay and support. Instead of considering the socio-economic status as a single variable, education, occupational status of the mother and monthly income of the family were taken separately as it would specify more clearly the relation of the variables with the maternal stress.

The educational level of mothers was categorised into three groups as follows:-

- Low education group:- Up to class 9.
- Middle education group:- Class 10 to Bachelor Degree.
- High education group:- Post Graduation and Professional Degree.

Similarly, the occupational level of the mother was categorised into 4 groups as follows:

- Group I : Daily wages, fisher woman, agricultural labour, petty shop business.
- Group II : Clerk, accountant, retired people, laboratory assistant, junior nurse, health inspector
- Group III : Office superintendent, gazetted officer, teacher, engineer, doctor, senior nurse

- Group IV: Unemployed

Monthly income of family was categorised into three groups of low income group, middle income group and high income group; based on monthly incomes.

The birth order of the children with cerebral palsy were classified as first, middle and last born. If the child with cerebral palsy is the elder one in the family or if there is only one child, then he/she is considered as the first born. Those children with cerebral palsy who were born between the first and the last child are considered as middle born. If the child with cerebral palsy is the youngest one among two or more number of children, he/she is considered as the last born category.

Mobility of the children with cerebral palsy was classified as group I, II, III and IV. Children with cerebral palsy who are independent in mobility are referred to as group I. Children with cerebral palsy who are independent with devices, are referred to as group II. Those children with cerebral palsy who are dependent on wheelchairs, are considered as group III. Children with cerebral palsy who are dependent on caregivers, are considered as group IV.

The mothers of the children with cerebral palsy are grouped into the younger group in which the age is less than 35 years, middle group where the age ranges between 36-50 years and older group in which the age is more than 50 years.

The types of families of children with cerebral palsy are grouped into nuclear family and joint family. The status of husbands living with the family is classified under four groups I - husbands who are staying with the family a minimum of 5 days or more per week. Group II- husbands who are staying away from the family for 5 days or more per week. Group III indicates divorced cases, and Group IV are widows. The husbands' support in bringing up the children with cerebral palsy are categorised under Group I- physical support only, Group II-financial support only, Group III-both physical and financial support and Group IV-no support at all.

RESULTS

The mean stress experienced by 50 mothers of children with cerebral palsy is 22.8, which is at moderate level. Out of 50 mothers, 16 mothers expressed mild stress, 23 mothers showed moderate stress and 11 mothers expressed severe stress. A section-wise analysis showed that Factor II that concerns pessimism regarding the child's ability with cerebral palsy towards

self sufficiency; was found to be more stress producing. Factor I related to parent and family problems was found to be the least stress producing.

The mean stress experienced by mothers of cerebral palsied children aged between 3-6 years was 22.94 and that of 7-11 aged group was 22.46. Independent “t” test showed that there was no statistically significant difference in the severity of stress experienced by mothers of these two groups.

The mean stress experienced by mothers of boys with cerebral palsy was 23.4 and that of girls with cerebral palsy was 21.90. Independent “t” test showed that there was no significant difference in the severity of stress experienced by these mothers.

With respect to the birth order of the child with cerebral palsy the mean stress experienced by mothers of first born children was 25.78, that of middle born children was 19.0 and that of last born was 21.83. ANOVA indicated that there was no significant difference in the severity of stress experienced by these mothers.

The mean stress experienced by mothers of spastic children was 22.65, that of ataxic children was 23.42, that of choreo-athetoid was 19.44, that of floppy type was 23.33 and of mixed group was 28.75. ANOVA indicated that there was no significant difference in the severity of stress experienced by these mothers.

Mothers of children with cerebral palsy and multiple disability showed a mean stress of 25.37 and those of children without multiple disability had a score of 15.46. Independent “t” test revealed that there was significant difference in the severity of stress experienced by mothers of these two groups ($t= 10.32, df 48, p<0.01$). On comparison of mean values, it was found that mothers of children with multiple disability experienced significantly more stress.

With respect to the mobility of the children, mothers of children with cerebral palsy who were independent in mobility showed a mean stress of 18.90, those children who were independent with devices showed a mean stress of 18.00, those children who were dependent on wheel chair had a score of 25.78 and those of children who were dependent on care givers showed a mean stress of 25.56. ANOVA indicated that there was no significant difference in the severity of stress experienced by these mothers.

The mean stress experienced by mothers in the younger age group was 22.90 and that of the middle age group was 22.33. Independent “t” test indicated that there was no significant difference in the severity of stress experience by these mothers.

Hindu mothers showed a mean stress of 23.00, Christian mothers showed a mean stress of 22.42 and Muslim mothers showed a mean stress of 26.60. ANOVA indicated that there was no significant difference in the severity of stress experienced by these mothers.

Mothers from a low education group showed a mean stress of 27.75, those from the middle education group showed a mean stress of 21.62 and those from a high education group showed a mean stress of 26. ANOVA indicated that there was no significant difference in the severity of stress experienced by these mothers.

The mean stress experienced by mothers belonging to rural area was 22.05 and that of urban area was 23.30. Independent “t” test revealed that there was no significant difference in the severity of stress experienced by mothers of these two groups.

The mothers from a low monthly income group showed a mean stress of 23.11, those from a middle income family showed a mean stress of 21.73 and that of high family income showed a mean stress of 26.5. ANOVA revealed that there was no significant difference in the severity of stress experienced by mothers from different income groups.

The mean stress experienced by the unemployed mothers was 22.30, that of group I (daily wages etc) was 40.00, that of group II (clerks etc) was 23.50 and that of group III (gazetted officers etc) was 8.66. Since 88% of mothers belonged to the unemployed category, no further statistical analysis was done in determining the effect of occupation in difference in the severity of stress experienced by mothers.

Type of family was not found to be a significant variable in deciding the difference in the severity of maternal stress. The mean stress experienced by mothers from a nuclear family was 21.00 and that of other type of family (joint family etc). was 24.21. Independent “t” test showed that there was no significant difference in the severity of stress experienced by mothers from these two groups.

The mean stress experienced by those mothers whose husbands stayed with them was 22.43 and that of those mothers whose husbands stayed away from the family was 23.84. Independent “t” test showed that there was no significant difference in the severity of stress experienced by mothers of these two groups. All the 50 mothers reported that they were getting physical and financial support from their husbands in bringing up their children. All the 50 children were undergoing physiotherapy, regularly.

Table 1. Mean, standard deviation and percentage of total stress experienced by mothers of children with cerebral palsy attending special schools

Variable	Mean	SD
Total maternal stress	22.8	9.56

Table 2. Frequencies, percentages, means and standard deviations of different categories of stress experienced by mothers of children with cerebral palsy attending special schools

Category(stress score)	Number	Mean	SD
Mild (0-17)	16	11.25	3.98
Moderate (18-34)	23	23.34	3.58
Severe (35-52)	11	37.00	1.95

Table 3. Means, standard deviations and percentages of maternal stress with respect to factor I, II, III, and IV

Stress factors (max. Score)	Mean	S.D	% in relation to max. score
Factor I (20)	7.00	4.32	35.00
Factor II (11)	6.64	2.45	60.00
Factor III (15)	6.06	4.02	40.40
Factor IV (6)	3.18	1.61	53.00

Table 4. Means, standard deviations and t value of maternal stress with respect to age of the children with cerebral palsy

Age groups	N	Mean	SD	t value
3-6 yrs	35	22.94	10.54	<1
7-11 yrs	15	22.46	6.81	

Table 5. Means, standard deviations and t value of maternal stress with respect to the sex of the children with cerebral palsy

Groups	N	Mean	SD	t value
Male	30	23.40	10.14	<1
Female	20	21.90	8.59	

Table 6. Means and standard deviations of maternal stress with respect to birth order of the children with cerebral palsy

Birth Order	N	Mean	SD
First	23	25.78	9.41
Middle	15	19.00	9.84
Last	12	21.83	7.39

Table 7. Summary of ANOVA for the difference in maternal stress with respect to birth order of the children with cerebral palsy

Source	sum of squares	df	mean square	F ratio
Between groups	432.41	2	216.20	2.44
Within groups	4157.59	47	88.45	
Total	4590.00	49		

Table 8. Means and standard deviations of maternal stress with respect to the type of cerebral palsy

Type	N	Mean	SD
Spastic	20	22.65	8.99
Ataxic	7	23.42	11.00
Choreo-athetoid	9	19.44	5.43
Floppy	10	23.33	6.04
Mixed	4	28.75	8.55

Table 9. Summary of ANOVA for difference in maternal stress with respect to the type of cerebral palsy

Source	Sum of squares	df	Mean Square	F ratio
Between group	248.65	4	62.16	<1
Within group	4341.45	45	96.47	
Total	4590.10	49		

Table 10. Means, standard deviations and t value for maternal stress with respect to multiple disability of the children with cerebral palsy

Group	N	Mean	SD	t value
Multiply disabled	39	25.37	9.09	10.32**
Non-multiply disabled	11	15.46	6.69	

** Significant at 1% level

Table 11. Means and standard deviation of maternal stress with respect to the mobility factor of children with cerebral palsy

Group	N	Mean	SD
I (Independent)	11	18.90	10.37
II (Independent with crutches)	9	18.00	8.35
III (Dependent on wheelchairs)	14	25.78	8.76
IV (Dependent on care givers)	16	25.56	8.21

Table 12. Summary of ANOVA for maternal stress with respect to mobility factor of the children with cerebral palsy

Source	Sum of squares	df	Mean Square	F ratio
Between group	620.79	3	206.93	2.39
Within group	3969.21	46	86.28	
Total	4590.00	49		

Table 13. Means, standard deviations and t value of maternal stress with respect to the age of mothers

Group	N	Mean	SD	t value
Younger (below 35)	41	22.90	9.91	<1
Middle (36-50)	9	22.33	7.88	

Table 14. Means and Standard deviations of maternal stress with respect to religion

Religion	N	Mean	SD
Hindu	31	23.00	9.18
Christian	14	22.42	9.44
Muslim	5	26.60	11.35

Table 15. Summary of ANOVA for maternal stress with respect to religion

Source	Sum of squares	df	mean squares	F ratio
Between group	67.37	2	33.68	<1
Within group	3602.63	47	76.65	
Total	3670.00	49		

Table 16. Means and standard deviations of maternal stress with respect to the education of the mother

Group	N	Mean	SD
Low group (0-IX)	8	27.75	11.64
Middle (X-degree)	32	21.62	7.88
High (P.G./ Professional)	10	26.00	12.29

Table 17. Summary of ANOVA for maternal stress with respect to education of mother

Source	sum of squares	df	Mean Square	F ratio
Between group	319.48	2	159.74	2.78
Within group	2697.00	47	57.38	
Total	3016.48	49		

Table 18. Means, standard deviations and t value of maternal stress with respect to the location of residence

Group	N	Mean	SD	t value
Rural	20	22.05	10.74	<1
Urban	30	23.30	9.11	

Table 19. Means and standard deviations of maternal stress with respect to family income

Group	N	Mean	SD
Low (upto 3000/-)	18	23.11	10.01
Middle (3001 to 8000)	26	21.73	9.76
High (above 8001)	6	26.50	5.67

Table 20. Summary of ANOVA for maternal stress with respect to monthly income

Source	Sum of squares	df	mean square	F ratio
Between group	113.60	2	56.80	<1
Within group	4476.40	47	95.24	
Total	4590.00	49		

Table 21. Means, standard deviations and t value for maternal stress with respect to the type of family

Group	N	Mean	SD	t value
Nuclear	22	21.00	9.37	1.17
Others	28	24.21	9.50	

Table 22. Means, standard deviations and t value for maternal stress with respect to the husband's stay with family

Group	N	Mean	SD	t value
Stayed with the family	37	22.43	10.34	<1
Stayed away from family	13	23.84	6.95	

DISCUSSION

This study points towards the fact that irrespective of the differences in child related and mother related variables, the level of stress in mothers of children with cerebral palsy is almost the same, and is of a moderate level. This may be due to the non-progressive nature of the condition. Another reason for this can be that all the children studied attend special schools and the mothers think positively in the hope that their children will attain some level of independence. For any parent the maximum stress producing event in their life is that point in time when they realise that their child is disabled. For all the mothers who participated in this study, this realisation had happened long ago. It is striking that the study reveals a significant difference in the stress level between mothers of children with multiple disability. The presence of multiple disability is a significant variable that decides the level of stress experienced by mothers of children with cerebral palsy. Cerebral palsy in itself is adequate enough to create stress among mothers and it is worse if the children have other difficulties. The different categories of associated disabilities were mental retardation, learning problems, speech and hearing problems, visual problems, behavioural problems and epilepsy. 97% of multiply disabled children showed features of mental retardation and speech problems. The cumulative effect of these problems might have produced a significantly high amount of stress in mothers of multiply disabled children. This indicates a need for a more comprehensive assessment of children with cerebral palsy by which the severity of the associated problems as well as the possible impact on mothers could be predicted.

Analysis of stress experienced by mothers of children with cerebral palsy showed that Factor II which deals with the pessimism regarding the child's ability to reach self sufficiency was the most stress producing factor for the mothers. For any parent of a disabled child, the most stress producing factor is the child's dependence for daily living activities. Once the child attains independence in these activities, the dependence on the mother is reduced, and naturally it will reduce the stress level. This gives an important point in managing the disabled child, where the emphasis has to be on attaining independence in daily activities.

Factor IV which expresses the physical incapacities of a child is second to Factor II, in causing stress, while Factor III which assesses the behavioural and attitudinal problems is next. Interestingly Factor I, which assesses parent and family problems is the least stress producing factor for mothers. Generally, it is assumed that this factor would be the most

stressful for mothers as it can alter interpersonal and marital relationships. The present findings show these as least stress producing to mothers. The age of the children with cerebral palsy selected for this study is an important factor in determining this finding. All the children were in the range of 6-11 years. At this age level, the problems associated with giving birth to a disabled child would have been settled in the family and thus Factor I causes the least stress to mother.

Child related variables such as age, sex, birth order, type of cerebral palsy and mobility of the child with cerebral palsy are found to be non-significant variables in determining severity of stress among mothers of these children. Mother related variables such as age, religion, educational level, location of residence, monthly income, employment status, type of family, husband's stay with family etc were found to be non significant variables in determining stress levels of mothers.

CONCLUSION

The present study shows the extent of stress experienced by mothers of children with cerebral palsy attending special schools. Based upon the findings of this study, the following suggestions are made.

- A concerted effort must be made to prepare and train mothers of children with cerebral palsy in handling the needs of their children. This efforts should start from the stage of identification of the disability of the children.
- Formulation of small mothers' groups in the special schools, will provide the mothers a needed platform for expressing their difficulties, sharing their experiences, solving their problems and more importantly, to develop a mutual help system.
- The Parent Teacher Association (PTA) should be strengthened and function as a link between the special school and the community. PTAs should be the link to make the community aware about various aspects of cerebral palsy and should take necessary steps to promote proper education, vocational training and placement.
- Organisations of parents should be formed to fight for the rights of persons with cerebral palsy and their families and to persuade the government to take action for the implementation of various rehabilitative measures.
- Special teachers and school authorities should recognise the important role of mothers in the whole process of special education and should keep on motivating the parents for their active participation.

- The services of professionally qualified counselors should be available in the special schools so that active involvement of mothers could be enhanced.
- Siblings and other family members should be encouraged and equipped to participate in the training and educational process of children with cerebral palsy. This will help the mothers to relax and to reduce their anxiety about the future of the children. This will also help in developing optimism among the mothers.
- Steps should be taken to produce books and other reading materials regarding the causes, types of cerebral palsy, training and education of children with cerebral palsy at community level in regional languages and make them available to all mothers and family members, which will be of utmost utility to them.
- Special teacher training programmes should be given due importance to develop skills in the special teacher trainees, for effectively working with mothers. This will help the teachers to keep a healthy relationship with the mothers.
- Representatives of mothers should be included in all the administrative as well as academic committees of the school. This is very important for increasing mother participation and satisfaction.
- Physical therapists of the special schools should be given more role in explaining about the causes, features, types, prognosis of cerebral palsy to the mothers. This will help in the development of awareness and realistic outlook regarding cerebral palsy.
- The special schools should also conduct periodic orientation programs for parents and community.

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**BIOLOGICAL AND PSYCHOSOCIAL PREDICTORS OF
DEVELOPMENTAL DELAY IN PERSONS WITH INTELLECTUAL
DISABILITY: RETROSPECTIVE CASE-FILE STUDY**

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ABSTRACT

Intellectual disability is one of the commonest disabilities during the developmental period. It is often associated with several factors. The aim of the study was to identify the biological and psychosocial factors associated with developmental delay resulting in intellectual disability. The study team reviewed 438 case files of persons with intellectual disability. Results indicated that maternal age at conception, foetal presentation, neonatal seizures and infections were the best indicators of developmental delay characteristic of intellectual disability. Psychosocial variables such as emotional trauma during pregnancy, economic status and education of parents had no significant impact on development. It is concluded that developmental delay characteristic of intellectual disability could be predicted by specific biological factors, which will help in initiating appropriate intervention.

INTRODUCTION

Intellectual disability is associated with several biological and psychosocial factors. The biological factors are further divided into genetic and non-genetic factors (1). The risk factors may be singular or multiple. Several studies have documented the role of intrauterine environment, consanguinity, hazards of prematurity and birth process, and postnatal factors that could arrest development (2, 3, 4). Among the non-genetic biological factors, maternal age at conception, infections, neonatal seizures and dietary deficiencies were found to be detrimental to overall development (1, 4, 5, 6, 7, 8). Similarly, several psychosocial factors such as psychological trauma, impoverished environment, low socioeconomic status and certain cultural influences on child rearing were identified to be detrimental to development,

leading to intellectual disability (4, 9). Some recent surveys have identified few probable causes of intellectual disability such as illness during pregnancy, birth related factors and illness or head injury during childhood (10). The risk of developmental delay depends on the interaction between biological and psychosocial variables (4). Therefore, it is difficult to identify specific etiology (11). From the review of literature it appears that intellectual disability can have multiple causes and the more the number of risk factors, the greater the chance of significant developmental delay. Nevertheless it is notable that a majority of these factors are preventable.

Although there are several developmental scales to identify at-risk population, this approach is not always feasible due to lack of expertise and availability of tools. It also has limited predictive value. Therefore, identifying the probable causes will help in identifying children at risk and in initiating early intervention strategies to minimise the risk of developmental delay (4).

The aim of the study was to identify biological and psychosocial predictors of developmental delay in persons with intellectual disability.

METHODS

The study was conducted at the National Institute for Mentally Handicapped (NIMH) Regional Centre, Kolkata, India. Data were collected from the case files. The information from the case files is authentic as data were collected by clinical staff having at least a graduate degree in the field of intellectual disability and minimum of four years experience thereafter. The files recorded medical, psychosocial and educational information from parents, interviews and from other relevant anecdotal records. At the next level the information was verified and detailed assessment was conducted individually by a psychiatrist, a clinical psychologist and a special educator. Case files of individuals between one and 18 years with data reported by first degree relatives and with a development quotient (DQ) of below 70 on Developmental Screening Test (DST) (12) were included in the study. Age limit was decided on the premise that perceptible changes in various areas of development could be seen by the first year and that developmental assessment loses its relevance in diagnosing intellectual disability after 18 years. DQ cutoff was chosen corresponding to intelligence quotient in standard practice of diagnosing intellectual disability (13). Cases where

DST score did not match with other psychological tests of adaptive behaviour and intelligence were excluded from the study.

Though detailed psychological assessment was carried out in most of the cases, the present study has taken only the scores of DST, as it was not feasible to apply comprehensive intelligence scales in certain cases due to the nature of intellectual disability or associated disabilities. DST measures development from 0 to 15 years in the general population and is applicable to any age group of persons with intellectual disability. It yields developmental quotient (DQ). Despite criticism that DST is loaded with speech and language items, it is widely used in the Indian context to assess overall development and also as a screening tool of intellectual disability. DST shows good correlation with Vineland Social Maturity Scale and Indian adaptation of Binet's scales (14).

The analysis was carried out with Statistical Package for Social Sciences (SPSS Version 12.0) for Windows. Descriptive statistics and linear regression analysis were done as per their basic assumptions.

RESULTS

There were 712 new cases registered with the institute from August 2004 to July 2005 from which 204 files were excluded due to lack of sufficient data and another 70 that did not fit the age limit. The final sample was 438 of which the majority were males (64.1%) and the mean age was 8.17 (SD 4.80). Mild and moderate retardation had equal distribution (31.7%), which was followed by severe retardation (25.3%). Hundred percent of fathers had gainful occupation or employment though only 82.4% were literate. Among the mothers, 79.2% were literate and 96.8% were housewives. The mean age of conception of mothers was 24.86 years (range: 15-48 years; SD 5.54). The majority was from urban area (52.7%) followed by rural (25.6%) and semi-urban areas (21.7%).

Table 1. Frequency of risk factors¹

Variables	n (%)
Prenatal factors	
Emotional trauma	58 (13.2%)
Malnutrition	33 (7.5%)
Physical trauma	27 (6.2%)
History of abortion	12 (2.7%)
Infections	12 (2.7%)
Prescribed drugs	6 (1.4%)
Epilepsy	2 (.5%)
Natal and postnatal factors	
Delayed birth cry	224 (51.1%)
Neonatal seizures	141 (32.2%)
Low weight	123 (28%)
Premature birth	73 (16.7%)
No immunization	51 (11.6%)
Infections	32 (8.2%)
Head injury	29 (6.6%)
Overweight	22 (5.0%)
Abnormal colour	13 (3.0%)
Post-term birth	13 (3.0%)

¹Given in descending order

Table 2. Biological and psychosocial predictors of development

Independent variables	Unstandardised Coefficients (B)	Standard Error	Standardised Coefficients (B)	t
(Constant)	29.250	58.522		.500
Biological factors				
Maternal age at conception	.633	.206	.267	3.065**
History of abortion	2.686	7.392	.019	.363
Self-medication	-.742	6.786	-.006	.109
Malnutrition	-6.664	3.840	-.096	1.735
Maternal infections	-1.196	1.105	-.082	1.082
Prescribed drugs	-11.466	6.808	-.090	1.684
X-Ray	-2.928	11.574	-.013	.253
Gestation	.872	2.213	.022	.394
Type of delivery	-.554	.917	-.036	.604
Normal foetal presentation	38.018	16.601	.173	2.290*
Prolapsed Cord	-3.704	17.628	-.012	.210
Delayed birth cry	-1.411	1.707	-.051	.827
Abnormal birth weight	-.746	.923	-.050	.808
Colour	.167	.627	.016	.266
Neonatal seizures	-5.038	1.930	-.140	2.611**
Cerebral infections	-7.237	3.306	-.117	2.189*
Head Injury	1.115	.775	.078	1.438
Family History	.847	.818	.056	1.036
Psychosocial factors				
Psychological trauma	-1.268	.998	-.069	1.270
Fathers' Education	1.852	1.412	.110	1.312
Mothers' Education	.612	1.414	.035	.433
Socio Economic Status	.002	.000	.045	.679
Rural/urban	.655	.678	.052	.966

* P < .05

** P < .001

Dependent Variable: Developmental Quotient

Table 1 indicates the frequency of several prenatal and postnatal factors. Table 2 indicates that maternal age at conception, foetal presentation, neonatal seizures and cerebral infections were found to be detrimental to the overall development.

DISCUSSION

Intellectual disability is a condition associated with significant intellectual delay and deficits in adaptive behaviours. In general this condition is caused by interaction of several biological and psychosocial factors (4). Contrary to previous studies (3, 8), the present study revealed that higher the age the better the development of children. This finding could be understood from the fact that approximately 50% of the maternal population in this study had conceived between 20 to 28 years of age, a period which is biologically and psychologically conducive for gestation and child rearing. This finding indirectly supports few earlier studies in which older mothers were found to be more interactive and showed inventiveness and tolerance in child rearing thereby facilitating conducive environment for growth and development (15, 16). The psychosocial implication of this finding is that teenage couples should be given appropriate information on consequences of conception with reference to the age of the mother, need for regular antenatal checkup, nutrition and strategies to secure social support to guide them in child rearing.

Normal foetal presentation at the time of delivery was found to be indicative of normal development. The present study also revealed that high proportion of individuals had neonatal seizures (32.2%), which emerged a predictive factor. The incidence of neonatal seizures is much higher than earlier reports (17). However, this corroborates findings of earlier studies on general population that the incidence is high in developing countries (18). In the context of neonatal seizures a question may arise that the study population was developmentally delayed therefore possible neurological defects could have led to seizures rather than the other way. Though this is possibility, it can be noted that all neonatal epileptic seizures except typical absence seizures may themselves aggravate the brain injury responsible for the seizures (19). However, physicians should consider whether there were any neurological abnormalities in the first one year of life before the onset of seizures, as this combination may indicate poor prognosis of cognitive development (20).

In the present study 8.2% had cerebral infections including meningitis and encephalitis although

there were no data to suggest whether they were primary or secondary. Nevertheless, cerebral infections emerged as a predictor of developmental delay supporting earlier studies that these infections will cause wide range of impairments particularly related to cognitive development (5). As early detection is crucial in treating these infections effectively, young parents should be educated about the common signs while their childrens are under neonatal care so that they can utilise appropriate health facilities when emergency arises. Contrary to earlier studies, lack of significant effect of psychosocial variables in this study could be due to well matched subcategories.

Based on the above findings it is concluded that age of mother at the time of conception, abnormal foetal presentation, neonatal seizures and cerebral infections could be risk factors for development. Wherever appropriate health facilities are not available, this information could be imparted to families through grassroot professionals such as health workers, where available. These findings can be generalised with due consideration to certain limitations intricate to any retrospective study such as lack of anecdotal records in all cases and hence possibility of recall bias by the informants.

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BRIEF REPORTS

**BEYOND COMMUNITY BASED REHABILITATION:
CONSCIOUSNESS AND MEANING**

Tavee Cheausuwantavee*

ABSTRACT

This article seeks to explore CBR through different perspectives. Based on existing literature and research on CBR, the paradoxes between CBR as ideal and CBR in usual practice, are identified. The dual meaning of 'disability' through 'stigma' and 'empowerment' perspectives is explored, along with the dual understanding of 'community consciousness' as 'individualism' and 'collectivism'. The two dimensions of 'disability' and 'consciousness' together are characterised into four distinct paradigms. Most past rehabilitation services are placed in a stigma-collective paradigm. It implies that philanthropy, inter-subjective value, morality and public awareness of society have usually constructed and supported any help and services for people with disabilities, including CBR. This paper looks at limitations of the past perspectives on CBR, and also points out the need for 'consciousness' studies on CBR. To understand the discrepancies of CBR, people need to look "beyond" CBR as it is commonly understood.

INTRODUCTION

Since its inception about three decades ago, community based rehabilitation (CBR) has evolved as a social model approach (1) for enhancing quality of life for persons with disabilities (PWDs), particularly for those in developing countries. The evolution of CBR has spanned over three decades, the first during 1980-1989, the second during 1990-1999, and the third beginning in 2001 (2).

Based on a social model, the tenets of CBR have been defined by various authors (1,2,3).

- CBR focuses on empowerment, rights, equal opportunities and social inclusion of all PWDs.

- CBR is about collectivism and inclusive communities where PWDs, their families and community members participate fully for resource mobilisation and development of intervention plans and services for PWDs.
- CBR needs to be initiated and managed by insiders in the community, rather than outsiders, for its sustainability.

There have been many studies on CBR, particularly from the majority world (3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 17). Most studies point out that ideally, CBR could have provided developing countries with an approach to effectively reach all their disabled citizens. However, CBR as it developed has illustrated both positive and negative aspects and has also become somewhat controversial. Most of the studies have limited themselves to quantitative study or positivism (18), emphasising empirical study and objective reality. Studies of CBR have looked at dimensions such as attitudinal survey, quantitative assessment and evaluation, descriptions of CBR, explanations of concept of CBR and inferences from secondary data. Therefore, in the past CBR tended to be treated as a static variable or objective reality, focusing on the medical model or social model, rather than viewing it through the perspective of dynamic and pluralistic realities which naturally exist in the world.

CONTRIBUTIONS AND PROBLEMS OF CBR

Many studies have pointed out the positive and powerful aspects of CBR (4,5,6,11,12,16, 19). They have recorded contributions of CBR as a strategy for promoting positive attitudes of society toward PWDs, and in improving coverage of services for PWDs who otherwise would not have access to institution based services because of cost constraints, transportation problems, limited availability of professionals or services. These studies have stressed that CBR is a valid and crucial strategy for enhancing quality of lives of all PWDs in the community.

However, a large number of studies have also identified negative and paradoxical aspects of CBR (7,10,16,19,20,21). For instance, financial support for CBR projects has been inadequate, and available mainly from external donors, particularly international non-governmental organisations (NGOs) and other charity based organisations (16,20,22). Thus, CBR projects have found it difficult to sustain their activities on withdrawal of

external donors and funding. In addition, due to poverty and the influence of capitalism, CBR workers have become stakeholders who need salaries and benefits (23, 24) rather than volunteers and collectivists who could devote themselves to their work without wages or any benefits. While promoting positive attitudes toward PWDs has been one of the contributions of CBR, much of the community have continued with negative attitudes toward PWDs as incapable, sinful, or as people paying for sins of previous births (25, 26, 27, 28, 29, 30). As a result, PWDs tend to be discriminated against, stigmatised and labelled, without empowerment, equal opportunities or social inclusion. Some communities believe that it is difficult and even impossible to provide rehabilitation services for PWDs, while others believe that rehabilitation services must be managed by families or professionals (16, 31, 32). Many early CBR projects have adopted a top-down approach and are run by outsiders without adequate attention towards community concerns and participation. These problems and their complexities are a major challenge for the further development and progression of CBR.

Literature has thus identified three discrepancies or paradoxes between CBR as ideal and CBR in usual practice. First, although CBR is supposed to focus on empowerment, rights, equal opportunities and social inclusion of all PWDs, in practice much of the community have negative attitudes towards PWDs. Second, CBR is about collectivism and inclusive communities, while in practice CBR workers are stakeholders and individualists who need wages and benefits. Third, CBR is supposed to be managed by the community, while in practice, CBR projects often are top-down in approach and run by outsiders without consideration towards community concerns and participation.

If one looks at the dual meaning of disability in terms of stigma and empowerment, and the dual community consciousness in terms of individualism and collectivism, and if one takes the two dimensions of meaning of disability and consciousness together, one can arrive at four distinct paradigms. These are stigma-individualism, stigma - collectivism, empowerment - individualism and empowerment - collectivism (Figure 1). Traditional rehabilitation services, public assistance, institution based rehabilitation (IBR), outreach, CBR, self- help services or independent living (IL) movement can be placed within each paradigm (Figure 2). Although some services may not be strictly separate from each other, most of the past services for PWDs can be placed in the stigma-collective paradigm. It implies that philanthropic basis, inter-subjective value, morality and public awareness of society usually have supported help and services for PWDs, including CBR.

This underscores the fact that CBR as a social model as understood today, may be only an ideal. Alternative conceptualisation of CBR as a socio-medical model, along with other models should be recognised and accepted for more appropriate provision.

Figure 1. Concepts and experiences reflected by meaning of disability and community consciousness

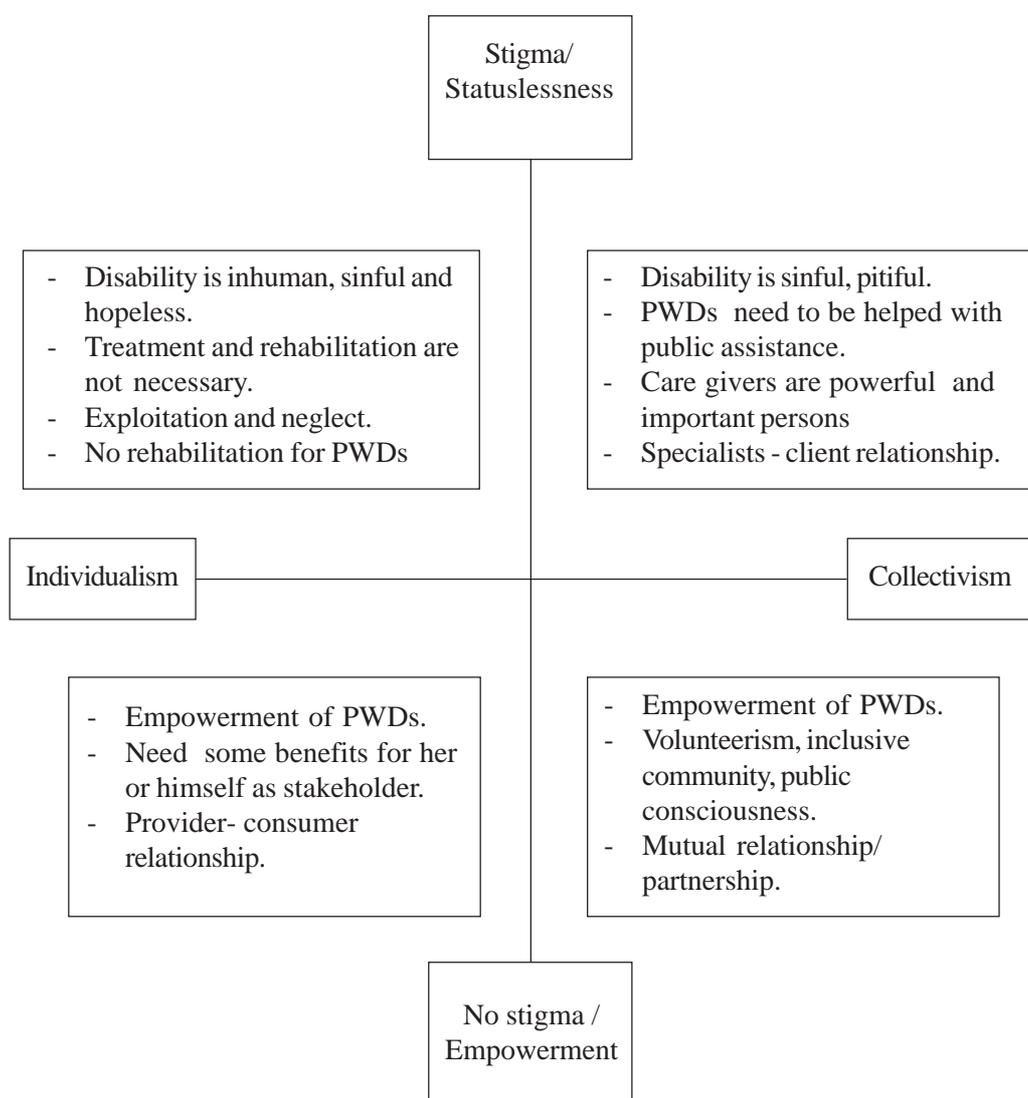
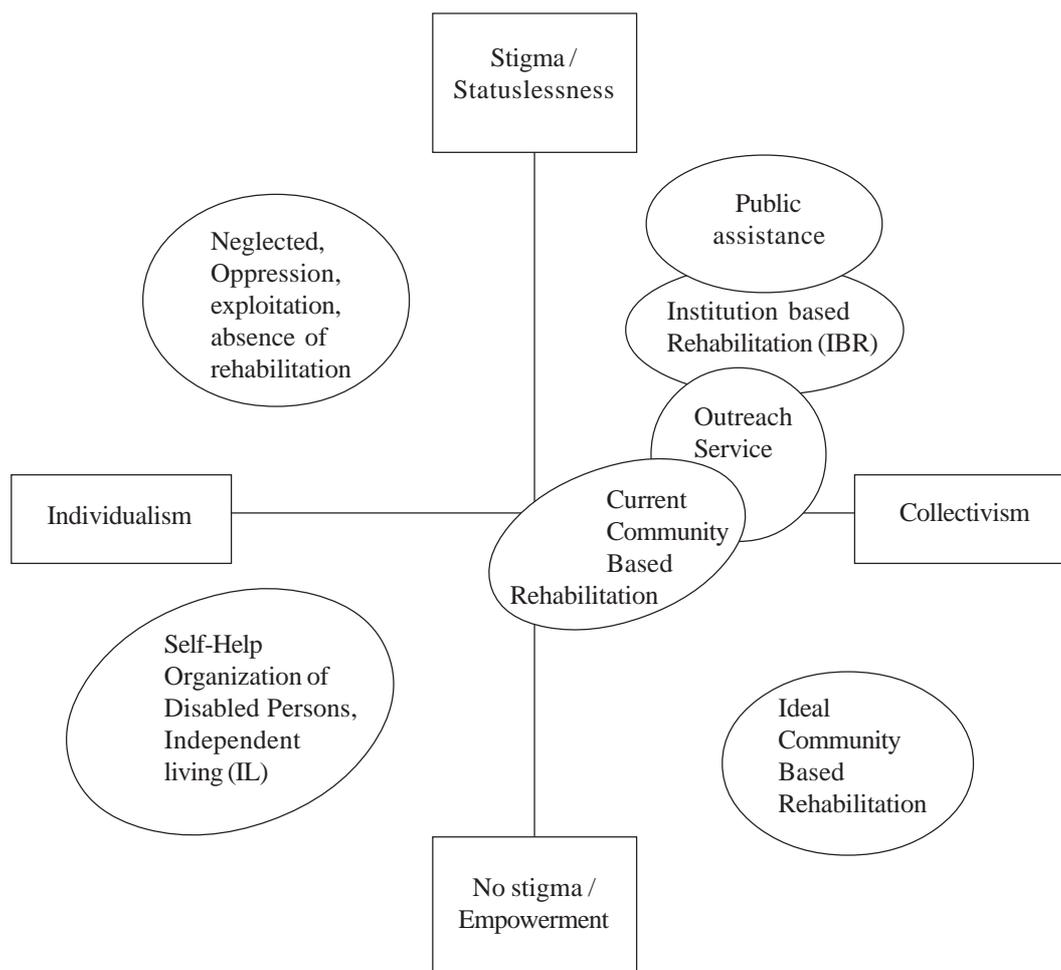


Figure 2. Services for PWDS placed by meaning of disability and community consciousness



TOWARD CONSCIOUSNESS AND MEANING OF CBR

To understand the discrepancies and interplays of CBR in terms of its holistic, dynamic nature in a meaningful manner, alternative inquiries besides traditional positivism or quantitative inquiry need to be undertaken. In recent years, there are a few qualitative studies and

discussions on the importance of qualitative research (33, 34, 35, 36). Qualitative research methods are usually employed in fields such as anthropology, ethnography, grounded study, critical study, hermeneutic study, discourse analysis and so on. Qualitative research also needs to be understood in terms of its philosophical background and paradigm including ontology, epistemology, theory, methodology and data source (37, 38). In response to viewing CBR through a collective perspective, research methodology also needs to be constructed appropriately, to look at issues such as motivation, feeling, awareness and intentionality of individuals involved in CBR. Consciousness study (39, 40) is likely to be appropriate for this purpose.

Phenomenology is one of methods of qualitative research, the study of structures of consciousness as experienced from the first-person point of view. The central structure of an experience is its intentionality, its being directed toward something, as it is an experience of or about, some object. An experience is directed toward an object by virtue of its content or meaning (which represents the object) together with appropriate enabling conditions. Thus, it tends to oppose positivism or objectivism. Phenomenology can be one of crucial disciplines to develop methodologies to address and understand the holistic and dynamic nature of CBR. It can also contribute towards transformative learning (41) for PWDs and their families, community members, professionals and researchers involved in CBR.

CONCLUSION

From the inception of CBR about three decades ago as a valid and worthwhile strategy for enhancing quality of life for all PWDs, it has been implemented in many countries, particularly developing countries. Many studies have reported problems of CBR in practice. The discrepancies between the tenets of CBR as an ideal and in practice, can be illustrated and studied with critical disciplines rather than positivism ones. These issues are "beyond" the traditional perspectives and inquiry. CBR can be viewed as the phenomenon of human consciousness and intentionality. The study of consciousness and human collective from a phenomenology perspective can be undertaken for better understanding of CBR. Although phenomenology has its own limitations, it can be an alternate perspective to help focus on the ways in which individuals construct in their own consciousness, the meaning of disability and CBR.

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