

COMMUNITY APPROACHES TO HANDICAP IN DEVELOPMENT (CAHD): THE NEXT GENERATION OF CBR PROGRAMMES

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ABSTRACT

This paper has presented the basis of one approach to addressing disability in developing countries. Community Approaches to Handicap in Development (CAHD) builds on the pioneering work done by others in the CBR field and presents a bridge between CBR and development. The brief rationale and examples included here represent only the skeleton of CAHD. More comprehensive descriptions and practical tools for implementation are available in the CAHD toolkit produced in 2001, developed by CBM International, Centre for Disability and Development and Handicap International.

INTRODUCTION

Community-based rehabilitation (CBR) was developed more than 20 years ago as a solution to the problems of disabled persons living in developing countries. Since that time, as several authors have noted, there have been many changes to the concept of CBR and how it is being implemented. However, it is still estimated that only about 2% of the disabled people living in developing countries are currently receiving assistance (1). Even more significant is the evidence that many disabled people are dying prematurely due to their exclusion from the development process and lack of adequate services. It is the authors' conclusion that as many as two out of every three people who become disabled "missing disabled people" are dying for reasons that are primarily related to poverty in their communities and negative attitudes about disability. These two major problems are just beginning to be addressed with some coherence by most existing CBR programmes. The new strategy for implementing CBR, Community Approaches to Handicap in Development (CAHD), that is outlined in this paper is a direct response to these problems.

A WORD ABOUT TERMINOLOGY

The terms used in this paper, *impairment, disability and handicap*, are not in the same way as those currently proposed in the new World Health Organisation (WHO) ICIDH-2 (2) nor those used in the past. There are several reasons for this non-conformity. First, it is the logical result of using language to describe a different understanding of the causes of impairment, disability, and handicap, and an expanded strategy for eliminating them. Second, describing impairment, disability, and handicap is a sensitive topic. Currently, disabled people are trying to take the terminology that describes both their condition and social status out of the realm of medicine. As a result, many words that were once commonly used are now considered derogatory by disabled people, and for this very valid reason are being changed. However, the changes being sought vary in different countries and, for the greater part, have not yet been widely understood, or accepted by the general population. Furthermore, the language of this debate about terminology is primarily English and little consideration has yet been given, to how the new terms translate into other languages. It is important to note that in most other languages, the terminology to describe any aspect of impairment, disability or handicap, has not yet been developed. In most developing countries the terms impairment, disability and handicap are just now starting to be understood. Significant changes to the meaning of these terms at this time will only create further confusion. Finally, both the old and the new terminologies were primarily developed by specialists, working in a developed rehabilitation service-delivery system, to deal with problems associated with the reaction of others to disabled persons in society. However, we are now in a situation where we need to talk about the absence of disabled persons in some societies. This means we need to talk more about causes of the problem, rather than only about the problem itself. We also need to be able to talk about this topic

in societies where there are either none, or at best, only a few specialists and no systematic approaches to providing assistance.

Developing new approaches for decreasing handicap means developing a new way of looking at problems and solutions. The new perspective, thinking of impairment, disability, and handicap as development issues that can be changed by specific activities rather than as treatable medical issues requires an adapted terminology. This adapted terminology must be readily understood by all those who will have a role in decreasing handicap: community members and development workers, as well as medical and rehabilitation professionals.

CAHD AND DEVELOPMENT

CAHD is not a new idea, rather, another step in the development of CBR. Because of over 25 years of successful disability advocacy and awareness by CBR programmes, development donors and programme implementers began to explore the idea of disability in the context of development. They started to realise that disabled people were being systematically excluded from their activities when they became aware of three major aspects of disability related problems.

1. The first is that medical rehabilitation interventions can only solve one aspect of the overall problems affecting the lives of disabled people. It minimises the effects of their impairment.
2. The second is that disabled people are part of every group, both vulnerable and non-vulnerable, and as such, face the same problems as everyone else.
3. The third is that the magnitude of the problems faced by disabled people in their normal lives is increased significantly by the social barriers that result from a lack of awareness about disability issues.

As awareness of the needs of disabled people increased among development organisations, policies began to change, for example, Britain's Department for International Development (DFID, 3) and several UN organisations (4) are now taking significant steps to ensure inclusion of the disabled people in all areas of development.

Changes in awareness about disability related problems in both CBR and development programmes resulted in a shift in programme focus. Most earlier CBR and development programmes had a vertical focus that resulted in activities that were primarily directed towards developing (changing) vulnerable people (including disabled people), by trying to rehabilitate them so that they would fit into the existing community. As programme planners became aware of these problems, they started to shift to a horizontal focus to include all aspects of the community. Even though this change in focus resulted in significant efforts to include activities designed to change attitudes towards vulnerable people, they remained the primary focus of programme activities. Completing the shift from a vertical to a horizontal focus means changing the entire community, it means changing to a horizontal, community-development focus that includes and addresses the needs of the entire community. The problem for programme planners then becomes much larger and requires consideration of all aspects of the disabling process from impairment to disability to handicap.

Once a programme's focus changes from vulnerable people and their needs, to communities and their needs, the scope of activities increases. Programmes need to consider new areas of activities and new ways of implementing their existing activities. For existing CBR and development programmes, this means:

1. Expanding existing areas of work, in disability and/or development, to deal with a broader understanding of handicap and development.

2. Changing the focus of programme activities from a telescopic-lens focus on disabled people, or other vulnerable groups and their problems, to a wide-angle lens focus which includes all aspects of a society.
3. Recognising that development of networks of organisations to share resources and responsibilities, is the most effective way to implement the broad range of activities necessary to create change.

CAHD's provides the necessary broad programme focus for planners and programme implementers. It is this process that is described in the following sections of this paper.

THE "MISSING DISABLED PEOPLE"

A comparison of the prevalence rates of disability between developed and developing countries indicates that there are many "missing people" in developing countries. In some developed countries (Australia, Britain, Canada, and USA), the prevalence rate of disability is about 18%⁹ of the total population. In developing countries, the WHO estimate that the prevalence rate of disability is about 5% (5) of the total population. This difference exists although disability incidence rates are the opposite: higher in developing countries, and much lower in developed countries. How can this difference of 13% be accounted for? Possible explanations include:

1. Different definitions of disability.
2. Inaccurate disability incidence/prevalence studies.
3. Different distribution of population by age group (A significant percentage of people in developed countries are older as more people live longer. Older people have more impairments and disability resulting in an increased percentage of the total population being reported as disabled).
4. Disabled persons are not reported because they are kept hidden.
5. Premature death of people who become impaired or disabled.

While each of the first four of these factors may account for part of the 13% difference, it is hard to conceive that they would account for the magnitude of the total difference. This leads to the conclusion that the last factor, premature death, is responsible for the largest part of this difference. Based on this analysis, it appears that approximately 10% of the total population is dying prematurely because they are disabled. While this conclusion is difficult to verify at this time, anecdotal and other evidence obtained from people experienced in working in the development of disability related projects, indicates that significant numbers of disabled people die prematurely.

There is a significant difference, in both financial and technical resources available for day-to-day living and service provision in developed and developing countries. It is also important to note, that this inequity in resources is not only evident between countries. In fact, it is often even more evident within countries in all sectors. This leads to the further conclusion that poverty is the main reason that there are so many "missing people" as many as two people missing for every surviving person with a disability.

THE CYCLES OF IMPAIRMENT, DISABILITY, AND HANDICAP

There are two different cycles of impairment, disability, and handicap shown below. The first, is the positive cycle of impairment and disability that will occur once handicap has been eliminated. This cycle is the ideal that we all work towards. The second, is the negative cycle of impairment, disability, and handicap that, is to a greater or lesser extent, the norm in most countries. The status of handicap in all countries will lie somewhere on the continuum that exists between these two cycles. Generally, developed countries will lie somewhere closer to the ideal positive cycle and

developing countries will lie somewhere closer to the negative cycles. The objective of all programmes should be to make the transition towards the positive cycle.

The complex negative cycle, which is driven into a downward negative cycle by people's negative attitudes, is described in the following sequence.

1. The cycle starts at the top, with organisations. In CAHD, organisations are described as formal and/or informal groups of people, working together outside the family home, to achieve specific objectives. Some examples of objectives of organisations are to provide governance, or goods, or services, or to create social change. They include formal and non-formal organisations and businesses, both governmental (GO) and non-governmental (NGO). Organisations create the circumstances that govern the lives of others.

An example of organisations creating negative economic circumstances is the World Bank and International Monetary Fund (IMF) debt restructuring policy imposed on developing countries.

2. After organisations, continuing clockwise around the cycle comes the negative, social, political, economic, and environmental circumstances that are created by organisations.

World Bank and IMF structural readjustment policies, as imposed on developing countries, have resulted in a marked increase in the main indicators of the presence and impact of poverty. It has affected all aspects of life, from a decreased average life expectancy to a decline in health care services and an increase in illiteracy rates.

3. Next, come the negative circumstances, poverty (the inequitable sharing of the world's resources: locally, regionally, nationally and internationally), that are the result from the policies of organisations.

DFID (3) estimate that more than 50% of the impairments that result in people being included in current disability prevalence rates, "are preventable and directly linked to poverty."

4. Impairment enters the cycle through external or natural causes such as genetics, disease, ageing, accidents, etc. It comes immediately after poverty because poverty is a major cause of impairment. Impairment also increases the impact of the cycle by creating short-term poverty when it disables people who are then unable to engage in productive activities.

An estimate from Nepal from the personal communications of a physiotherapist working in Nepa indicates that more than 30% of the disability that results from trauma could have been prevented if adequate rehabilitation services were available¹⁴.

5. Often, services and assistance for disabled persons are not provided because of the barriers created by people and their organisations. Most often, these barriers are the result of attitudes formed by a lack of knowledge about the causes and consequences of impairment, disability, and handicap.

When the impairment caused by broken bones is not properly treated, permanent disability may be the result. When bones do not heal correctly, people become permanently disabled and many can no longer work.

6. Disability can be either the inevitable result of a serious impairment, or the lack of services necessary to prevent impairment becoming permanent. Like impairment, disability can also result in increased long-term poverty.

Barriers can create significant problems in the lives of people with disabilities. For example, mentally handicapped girls may be forced out of their homes and onto the street, where they often become the innocent victims of abuse, both physical and sexual.

7. Disabled persons are often excluded from society, and are unable to get needed assistance because of barriers that are again the result of people's attitudes.

In one programme, a young girl who could not walk, was not attending school. A community programme identified this as her major need and went to work to obtain a wheelchair for her, and to persuade the local schoolmaster to allow her to go to school. However, when the community workers returned some weeks later, they found that the young girl had died. They learned that her death was the result of disability and gender barriers that resulted in her long-term malnutrition and the lack of medical care, once she became seriously ill.

8. Finally, barriers often result in the isolation and marginalisation of disabled people, that leads to premature death.

A FRAMEWORK FOR DEVELOPING CAHD PROGRAMME ACTIVITIES

Making the transition from the negative to the positive cycle of impairment, disability, and handicap, primarily means changing the attitudes of people and organisations. Doing this effectively, requires simultaneous implementation of activities in the following four component areas.

1. **SOCIAL COMMUNICATION:** Providing awareness and knowledge to people and organisations about:
 - Causes of impairment, disability, and handicap.
 - Roles of family members and organisations, in creating handicap.
 - Activities that will prevent impairment, disability, and handicap.
 - Rehabilitation practices that will minimise the impact of impairment and maximise the personal development of disabled persons.
2. **INCLUSION AND RIGHTS:** Providing disabled persons the equal opportunity to access their rights as citizens, and to participate in all of the activities in their families and communities enables:
 - Disabled persons to improve the quality of their lives.
 - People and their organisations have positive experiences with disabled persons, which will change their attitudes.
 - Organisations to include disabled persons in their existing programmes, to give them equal access to opportunities for education, economic activities, and health services.
 - Disabled persons to promote their right to play active roles in social and economic activities, in their families and communities.
 - National organisations to promote for legislation, policy and regulations, for recognition of the rights of disabled persons.
3. **REHABILITATION:** Providing assistance to people who have impairments and to disabled persons, that will minimise the functional difficulties which are the result of their impairments and maximise their personal development by:
 - Providing basic rehabilitation service in the community.
 - Providing referral and transfer services to meet the special needs of disabled persons.
 - Developing linkages and transfer options between basic therapy service delivery in the home, and referral services.
4. **MANAGEMENT:** An organisational function, necessary to make sure that the previous three activities are implemented simultaneously, and that these activities are relevant, efficient and effective by:
 - Developing a monitoring, research and evaluation system.

- Capacity building of local partners.
- Including disabled persons, their families and the community in the design and monitoring, research and evaluation process to ensure accountability of the CAHD system.
- Developing and facilitating networks.
- Documenting the development and evaluating the impact of the CAHD system.
- Using monitoring, research, documentation, and evaluation information to facilitate and direct the creation of changes to the CAHD system.

When community has the broad meaning that is used in CAHD, different activities in each of the above component areas need to be implemented at different levels. In CAHD, these levels or sectors are defined as follows.

1. **PRIMARY SECTOR:** The micro-level, family situations, where people live out most of their lives (family and local geographic community).
2. **SECONDARY SECTOR:** The first macro-level where, people as members of organisations, work to provide governance or goods and services, and create social change, in the primary sector (local government, NGOs and civic institutions).
3. **TERTIARY SECTOR:** The second macro-level where, people as members of organisations, work to provide indirect governance, manufacture goods, provide in-direct services, and create social change in the primary sector (national and international government and NGOs).

The relationship between CAHD components and sectors is illustrated in the following table.

AN OUTLINE FOR PLANNING CAHD PROGRAMME ACTIVITIES

This section of the chapter, illustrates the extent and nature of a CAHD programme by giving an example of the range of activities that are necessary to fully implement CAHD, and the number of different players that could be involved. Note that this is only one example. Practical experience in programme implementation has shown that simultaneous implementation of activities in all four of the component areas, dramatically increases their effectiveness. Because the range of activities is so wide, it becomes necessary to share responsibility for implementing them among independent organisations in both the same, and in different sectors. The scope of activities becomes even broader when, other vulnerable groups are included. However, it is important to note that this broadening of scope increases both effectiveness and efficiency, by ensuring greater programme relevance to a wider range of community members. This relevance is emphasised and used in CAHD, as a strategy to engage the minds of community members, and lead them towards a shift in attitudes towards all vulnerable groups.

Sharing responsibilities for different aspects of a single programme requires co-ordination, co-operation, and collaboration, if the programme is to succeed. In CAHD, this process is called developing networks, which is shown as one of the primary functions of management in the following tables. It is the process of networking that makes CAHD possible. This is especially true when existing programmes, either development or disability focused, start to make the transition to CAHD. The need for networking is even more evident, when it is noted that very few organisations have the necessary technical and financial resources to work in all areas simultaneously. The necessity of networking increases the need for effective monitoring and centralised control at the national level.

IMPLEMENTING PLANNED ACTIVITIES

The broad categories of organisations that are necessary to establish a CAHD programme are described below. Normally these organisations are linked in through networks.

1. Initiating organisation: The organisation, usually an international non-governmental organisation (INGO), or a local organisation supported by an INGO, that has the interest, technical skills and resources to facilitate the development of CAHD in a particular region or country.
2. Implementing organisation: Community development or community-based rehabilitation (CBR) organisations that are actively assisting people in communities.
3. Research Organisation: An organisation with the technical skills and capacity to develop monitoring, research, and evaluation activities as part of a CAHD programme. Normally, this organisation should be involved in the development of CAHD from the very beginning.
4. Referral organisations: Organisations that have the capacity to provide professional, medical and rehabilitation services to disabled persons.
5. CAHD Networks: Informal groups of organisations, that work together to achieve a common purpose, such as the implementation of CAHD. For effectiveness and efficiency, CAHD network activities should be included among the activities of existing networks that are trying to develop co-operative and collaborative solutions to community problems.

There are a number of steps within each of the implementation processes shown in the following table. These steps are not included in this paper, however, they are included in the CAHD ToolKit referred to, above.

SUMMARY OF THE PROCESSES REQUIRED TO IMPLEMENT CAHD

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|-----|---|---|
| 1. | Starting the Development of CAHD from the National Level | Initiating Organisation |
| 2. | Develop the Strategic analysis and Information Framework (SAIF) | Research Organisation |
| 3. | Developing National CAHD Training Capacity | Initiating Organisation
National Training Organisation |
| 4. | Developing CAHD in Implementing Organisations | Implementing Organisation(s) |
| 5. | Implementing Social Communication in the Primary Sector | Implementing Organisation(s) |
| 6. | Implementing Social Communication in the Secondary Sector | Implementing Organisation(s) |
| 7. | Implementing Social Communication in the Tertiary Sector | National Training Organisation |
| 8. | Including Disabled Persons in Family Activities | Implementing Organisation(s) |
| 9. | Including Disabled Persons and Their Families in Development Activities | Implementing Organisation(s) |
| 10. | Including Disabled Persons in Secondary and Tertiary Sector Organisations | Secondary and Tertiary Sector Organisations |
| 11. | Providing Rehabilitation Services in the Primary Sector and Referral to Rehabilitation Service Organisations. | Implementing Organisation(s) |

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| 12. | Providing Rehabilitation Services in the Secondary and Tertiary Sector
Secondary and Tertiary Sectors | Secondary and Tertiary Sector
Organisations |
| 13. | Developing Networks in the Secondary and Tertiary Sectors | Initiating Organisation
Implementing Organisation(s) |
| 14. | Establish Monitoring, Research and Evaluation System | Secondary and Tertiary
Sector CAHD Networks |
| 15. | Including Beneficiaries in the Monitoring and Feedback Process | Secondary and Tertiary Sector CAHD
Networks |
| 16. | Establish Reporting and Information Sharing system | Secondary and Tertiary
Sector CAHD Networks |

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