

COLLECTION

Handicap and Development

**Understanding
Community
Approaches
to Handicap
in Development
(CAHD)**

March 2001

**HANDICAP
INTERNATIONAL**

Vivre debout

**Understanding
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Approaches
to Handicap
in Development
(CAHD)**

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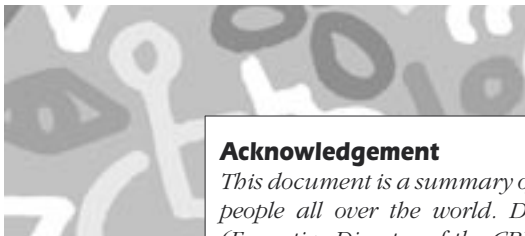
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Acknowledgement

This document is a summary of many years' works by many people all over the world. Dr. Handojo Tjandrakusuma (Executive Director of the CBR Development and Training Center in Solo, Indonesia) started the process. With support from the Nippon Foundation (Japan) his ideas for including community development concepts in CBR were developed through workshops and finally in the field in Bangladesh. He generously accepted and encouraged the involvement of many people in this process.

Neither CAHD nor this document would exist without the hard work and ideas of the staff of the Center for Disability in Development (CDD) in Bangladesh. In fact, CAHD and CDD cannot be separated as they both came into being together. This is especially true of the disabled persons who work at CDD, their example and input to the process of the development of both CDD and CAHD kept all of us honest.

If any of the words or ideas contained in this document look familiar it is probably because you have heard them or seen them before, or they may even be your own! In short, this document is the summation of many ideas into a systematic approach to creating a better world that will include all vulnerable people, especially disabled persons, in its ongoing creation and development.

The development of the CAHD concept and the publication of this document were made possible through the support of CDD's work in Bangladesh by Handicap International and Christoffel Blindenmission.

Dedication

The concept of CAHD and this book are dedicated to all those children in the developing world who would be alive today if only someone had been there to help.

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Executive summary

This document is intended to provide a basic orientation on an expanded concept for implementing CBR (Community Based Rehabilitation) that is called **CAHD**:

COMMUNITY

People, their families and the organizations that influence their daily lives.

APPROACHES TO

The two-way, inter-active relationship within communities needed to change attitudes so that disabled persons will be included and have access to the services and assistance that will minimize their disability and maximize their personal development.

HANDICAP

Not recognizing the existence of disabled persons, excluding them from society, and not providing services to meet their needs.

IN DEVELOPMENT

Including disabled persons in the continuing processes: of increasing personal freedom; and, of sharing in a more equitable distribution of the world's resources.

CAHD starts with an organization's current work and understanding of communities and other organizations. It is designed to expand this existing work, in disability and/or development, to deal with a broader understanding of the "hidden dimensions" of handicap.

CAHD changes the focus of an organization's work. Many organizations now use a telescopic-lens to focus only on disabled people and their problems. In CAHD, organizations use a wide-angle lens to focus on society as a whole, including the social construction of the problems faced by disabled persons, as well as their special needs.

CAHD is a program concept and as such may or may not be implemented by a single organization. Often, single organizations do not have access to the considerable range of skills and resources necessary to fully implement CAHD. When this is the case, development of networks with other organizations to ensure full implementation of CAHD becomes a necessity.

The "hidden dimensions" of handicap and its causes are inter-locked in a cycle that creates negative attitudes among people and organizations. These negative attitudes are responsible for poverty and the barriers that result in the isolation, marginalization and premature death of two out of every three disabled persons.

CAHD recognizes that eliminating handicap does not mean eliminating disability. Disabled persons have always been with us and always will be. In fact, eliminating handicap means increasing the numbers of disabled persons who survive to contribute to the on-going development of their societies. The number of disabled persons, and their ability to contribute to

society, is a measure of the decline of the presence of handicap.

Disabled persons are central to the development of CAHD. They have major roles in changing attitudes, advocating for changed policy and new legislation, ensuring program activities are effective and efficient, and finally, and most importantly, as members of the organizations that will implement CAHD.

In CAHD, development is the enhancement of personal freedom and increasing access to the worlds' resources so that there is more equitable sharing locally, nationally and internationally. This broad understanding means that CAHD has to work to create change locally, nationally and internationally. At national and international levels CAHD programs participate and create change by participating in formal and informal networks of organizations.

Implementing CAHD starts with the expansion of existing disability and/or development activities to include knowled-



Community disability worker

ge creation, inclusion of disabled persons, initiating or expanding existing rehabilitation services, and management for effectiveness and efficiency.

CAHD means implementing cross cutting development activities related to impairment, disability and handicap. These activities need to be implemented simultaneously in the following matrix of social sectors and component areas in all levels of society.

COMPONENT	SECTOR		
	Primary	Secondary	Tertiary
Social communication			
Inclusion and rights			
Rehabilitation			
Management			

Expansion of existing programs and projects starts in the primary sector (people and their families) with direct service organizations that exist in the secondary sector. Normally primary sector activities, implemented by secondary sector organizations, would include community education, inclusion of disabled persons in existing development activities and provision of basic rehabilitation services in the community.

While primary sector activities are starting, implementing organizations will find the need to develop networks to connect them with other organizations working in disability and/or development activities. As networks develop and more people and organizations get involved, the need to change policies and legislation that will allow inclusion will become evident. Getting policy changed and legislation passed and implemented will require further expansion of networks into the tertiary sector,

which includes international organizations and agencies.

Management, monitoring, research and evaluation of all activities, including input from beneficiaries, are essential to ensure that the work being done is effective and efficient.

Training is the key to the successful implementation of CAHD. Implementing CAHD within the above noted scope of activities and areas of work requires new tools and additional staff training.

The training necessary to understand and implement CAHD is being made available to enable other organizations with the distribution of the CAHD Toolkit.

**For people with visual impairment
who want to access the entire text,
please contact us.**

Introduction

c h a p t e r

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1.1. Introduction

This document has been written to introduce an expanded concept of CBR. It is a technical document, prepared as an introduction to CAHD, for those people who are interested in developing this program in their own organizations. It is the introductory section of the CAHD Toolkit (see section 5.2 below) which is being developed and tested by CBM and Handicap International in a number of asian countries.

Impairment and disability are as old as history; they always have been and always will be with us. However, the way that societies deal with them can and does change.

In developed countries, the reality of impairment and disability is now being recognized. Consequently, efforts are now being made to include people affected by impairment and disability and to provide the services necessary to meet their needs. The recognition and inclusion of these people, and the development of services to meet their needs, means that handicap is declining in developed countries.

In many developing countries, the reality of impairment and disability is only just starting to be recognized, and people affected by impairment and disability are barely

accepted. These people are excluded and the services necessary to meet their needs have yet to be developed. In these countries handicap is still a significant factor that must be dealt with.

Community Approaches to Handicap in Development (CAHD) is defined as:

1. **Community:** people, their families and the organizations that influence their daily lives.
2. **Approaches:** the two-way relationship within communities that creates knowledge that will change attitudes so that community practices will include disabled persons and provide them with services and assistance.
3. **Handicap:** not recognizing the existence of disabled persons and people with impairments, their exclusion from society, and no provision of services to meet their needs.
4. **Development:** including disabled persons in the ongoing process of increasing personal freedom and sharing in a more equitable distribution of the world's resources.

Community Approaches to Handicap in Development (CAHD) is an inter-active process

that enables communities to make the transition from:

1. The presence of handicap: not recognizing the existence of disabled persons and people with impairments, their exclusion from society, and no provision of services to meet their needs.

2. To the absence of handicap: recognition of the existence of disabled persons and people with impairments, the inclusion of these people in society, and the subsequent

provision of services to meet their needs.

Disabled persons are central to the effective development of CAHD. Changing attitudes to eliminate handicap requires an active interchange between disabled and non-disabled persons. This interchange is an interactive process that will change and enable both parties so that handicap can be eliminated. It is this process of enabling both disabled and non-disabled persons that will ensure that services and assistance will be provided and inclusion happen.

1.2. Terminology

The terminology used in this document does not conform to the new WHO (World Health Organization) definitions or the old standard medical terminology; it is different because the approach to overcoming the causes of impairment, disability and handicap is different. The terminology in this document was derived after due consideration of a number of factors¹. After considering these factors, it was decided to continue to use the words that are in common use in English in most developing countries in spite of the overwhelming logic and need for change.

For clarification, critical terms are defined in the glossary at the end of this document.

This decision was made with complete awareness of the sensitivity of this topic. While the need for change is very evident, the ideas that are being transmitted to others need first to be understood before they can be acted on. If a completely new terminology is introduced in the developing world at the same time as new ideas, confusion will be the result. The risk of these important ideas getting lost in the debate over language will

(1) The problems considered while deriving the terminology used in this document are:

- 1. The terminology used to describe impairment, disability and handicap has become a very politically sensitive topic as disabled persons have gained a voice and have removed the terminology from the realm of medical experts. Many of the words that were once in common use are now deemed to be derogatory by the people that they are used to classify and describe, and for this reason they should be changed.*
- 2. However, 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 many other languages, the terminology has not yet been developed at all—there are no words to talk about the problems we are trying to describe.*
- 3. The terminology used to talk about impairment, disability and handicap is a matter of language and as such the meaning of the words used must be readily translatable. It must be recognized that in most developing countries the terms impairment, disability and handicap are just now starting to be understood—making significant changes to the meaning of these terms at this time will only create further confusion.*
- 4. Both the old and the new terminologies were developed by specialists, working in a developed rehabilitation service-delivery system, to deal with problems associated with the presence of disabled persons in society. However, we are now in a situation, as is noted in subsequent sections of this document, 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 no, or at best, only a few specialists and no systematic approaches to providing assistance.*
- 5. Developing new approaches to 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 of those who will have a role in decreasing handicap: community members and development workers, as well as medical and rehabilitation professionals.*

increase significantly. In the end, the ideas are more important than language; it is the ideas and the practices that come from them that will bring about social change. Social change will help to ensure the survival of more disabled persons and empower them so that they can someday enter the debate about terminology too.



Mentally disabled child included in formal school

**Impairment, disability
and handicap
in the developing world**

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2.1 Introduction

Until recently most of the work in the field of impairment, disability and handicap has focused on disabled persons and their problems. However, in this document the focus is shifted to the causes of their problems.

The results of this shift are an increased awareness of the “hidden dimensions” of impairment, handicap and disability as described in section 2.2 below.

Exploring the causes of these “hidden dimen-

sions” and their linkage to people other than those who are disabled leads to the conclusion that an expanded focus and strategy are necessary².

Expanding the focus does not mean neglecting disabled persons. It is a plea to include them in development; to increase the resources made available to assist them, and to create social changes that will ensure their inclusion as full citizens with equal opportunities and full access to participation.

2.2 The “hidden dimension” of handicap

The “missing people”

A comparison of the prevalence rates of disability between developed and developing countries indicates that there are many “missing people” in developing countries.

(2) Jimmy Carter, former US president, notes in his plea for action to curb the spread of AIDS in Africa, “it is necessary to avoid the natural tendency to focus most or all of our resources and attention on caring for the sick”. In the case of impairment, handicap and disability the “natural tendency” has been to focus on disabled persons. However, as the following information shows, this focus has to be expanded to deal with the major cause of the situation of most disabled persons living in developing countries.

(3) The 18.4% average prevalence rate is based on current data for Canada (18%), United Kingdom (19%), United States (17.5%), and Australia (19%). Some data was obtained from the following web sites: Canada (www.statcan.ca); www.cibi.ca; www.gou.nb.ca), United Kingdom (www.cabinet-office.gov.uk); www.drc-gb.org), and United States (www.census.gov.dsc.ucsf.edu). Australian data was obtained from Australian Bureau of Statistics, Catalogue 4430.0 Disability, Aging and Careers, 1998.

In some developed countries (Australia, Britain, Canada, and USA) the prevalence rate of disability is about 18%³ of the total population.

In developing countries the WHO estimates

that the prevalence rate of disability is about 5%⁴ 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 group⁵.
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 leaves the last factor as being responsible for the largest part of the difference, say 10% of the total population. This conclusion is difficult to verify without specific research

that may or may not be able to verify it. However, anecdotal and other evidence obtained from people experienced in working in the development of disability related projects indicates that premature death is a significant factor.

One estimate⁶ shows a mortality rate of 80% for disabled children under five where the overall mortality rate for children under five is below 20%.

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, as is noted in the section below, 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.

Poverty

Poverty plays a very significant role in terms of handicap. It not only affects those who

(4) E. Helander, Prejudice and Dignity: an Introduction to Community Based Rehabilitation, UNDP, 1992, as reported in Department for International Development (DFID), Disability, poverty and development, February 2000.

(5) A significant percentage of the populations 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 being disabled. However, disability prevalence rates for all age groups in developing countries are significantly higher than the average rate for developing countries. For example, in the US 9% of the population under 14, and in the UK 19% of the working population are reported as having a disability.

(6)-(7) B. Hariss-White, Presentation to the Development Studies Association Annual Conference, 13 September 1999, University of Bath, as reported in Department for International Development (DFID), Disability, Poverty and Development, February 2000.

have become disabled, it is also one of the major causes of impairments and handicap.

One of the main indicators of the difference between developing and developed countries is measured in terms of average Gross National Product (GNP). These differences are very large, in the order of \$200 as compared to \$25,000.

This inequity in the sharing of the world's resources locally, nationally, and internationally is a global problem although the resulting poverty may be local. Poverty is underdevelopment that results in locally increased risk of:

1. Conflicts (domestic, communal, inter-family, inter-religious and even inter-national).
2. Malnutrition.
3. Inadequate health and rehabilitation services.
4. Poor or non-existent education facilities.
5. Inadequate communication and transportation infrastructure.
6. Increased levels of hard physical labor.
7. Increased personal and familial stress levels.
8. Increased exposure to natural disasters.
9. Increased exposure to environmental hazards and disasters.
10. Little or no access to disability preven-

tion information and activities.

Each of these symptoms can cause impairments, disabilities and ultimately the handicap that can lead to premature death.

Another significant linkage between poverty and impairment and disability is the impact on families. In families that live in poverty, each person has to contribute to the family welfare or the survival of other family members is put to risk. When the productive capacity of one member of the family unit is decreased by impairment or disability, the other family members often do not have the ability or the opportunity to provide extra to make up for the deficit.

Poverty means that family members do not have time to provide basic care for a member that has either impairment or disability. This lack of basic care often results in the impairment or disability getting worse and in premature death.

For every person who has an impairment and/or disability, 4 to 5 other family members are also affected⁷. Including families of disabled persons in development program activities helps to minimize the impact of impairment/disability and allows other family members to provide the care that will increase the probability of disabled persons surviving.

Impairment risk spiral

In much of the Asian and Pacific Region there exists a spiral of increasingly higher risk, for everyone, of receiving an impairment. This increased risk then causes a

subsequently higher risk of impairment leading to disability and of disabled persons not surviving as is noted in the following sequence of events:

1. People who have become disabled are at increased risk of not surviving which results in a low disability-prevalence rate.
2. Low disability-prevalence rates decrease funding priorities for handicap and disability related activities. The need for prioritization of funding is also a result of poverty.
3. Barriers to inclusion also affect funding priorities.
4. Low funding priorities for disability related activities results in less prevalence awa-

reness and fewer services. This results in an increased risk of: people getting impairments; impairments causing disability; and, an increased probability that these people will not survive.

Shortage of rehabilitation services

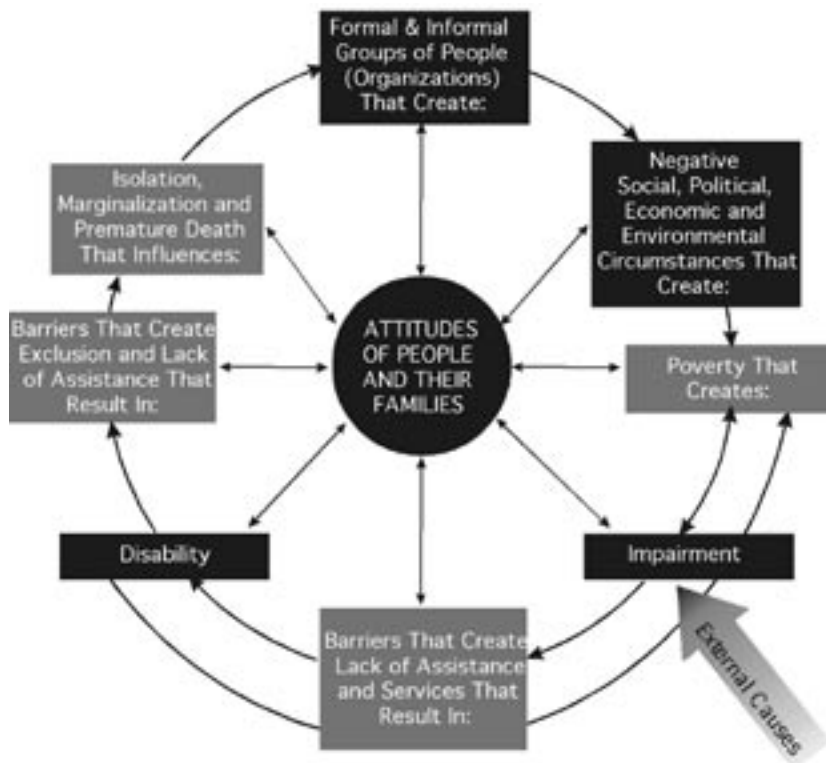
Lack of adequate medical and rehabilitation services not only affects the lives of disabled persons, it also directly affects everyone who has an impairment.

People who have impairments often need rehabilitation services to prevent and/or reduce disability. When these rehabilitation services are not available, there is a strong probability that their impairments will result in permanent disabilities -disabilities that could have been prevented.

2.3 Negative cycle of impairment, disability and handicap

The “hidden dimensions” of handicap are the result of the negative cycle of impairment, disability and handicap that is shown here under⁸.

Negative cycle
of impairment, disability and handicap



(8) This diagram was derived during a CAHD-DD team meeting in Manila in November 2000. The team consisted of staff from Overseas Development Group (ODG), University of East Anglia, Center for Disability in Development (CDD), Christoffel Blindenmissie (CBM), and Handicap International.

2.4 Causes of the cycle

People and their families are at the center of the above cycle because their attitudes create the circumstances that are the major parts of this cycle.

The engine that drives this cycle is **people's negative attitudes**.

1. The cycle starts at the top with organizations. Organizations are formal and/or informal groups of people working together outside the family home to achieve specific objectives. For example, organizations work to provide governance, or goods, or services, and to create social change. They include formal and non-formal organizations and businesses both governmental (GO) and non-governmental (NGO). **Organizations and people** create the circumstances that govern the lives of others.

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

2. After organizations, continuing clockwise is **negative, social, political, economic**

and environmental circumstances.

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 decline in health care services and an increase in illiteracy rates.

3. These negative circumstances create inequitable sharing of the world's resources: locally, regionally, nationally and internationally, that results in **poverty**.

DFID⁹ estimates 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. Poverty is a major cause of **impairment**. Impairment also enters the cycle through external or natural causes such as genetics, disease, aging, accidents, etc. Impairment can also increase the impact of the cycle by creating short-term poverty when people are

(9) Department for International Development (DFID), Disability, Poverty and Development, February 2000.

unable to engage in productive activities.

An estimate from Nepal indicates that more than 30% of the disability that results from trauma could have been prevented if adequate rehabilitation services were available¹⁰.

5. Services and assistance for disabled persons are not provided because of **barriers** created by people and their organizations. Most often, these barriers are the result of attitudes formed by 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 program, a young girl who could not walk was not attending school. A community program 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 mal-nutrition and the lack of medical care once she became seriously ill.

8. Barriers often result in the **isolation and marginalization that lead to premature death.**

People's negative attitudes that result in the situations where disabled persons are neglected result in increased fear about disability and its consequences. This fear increases negative attitudes that result in increased negative results of each of the circumstances described in the cycle.

Poverty and barriers are the symptoms that indicate the presence of handicap.

(10) Personal communication from a physiotherapist working in Nepal.

2.5 Calculating the cost

The existence of the negative cycle of impairment, disability and handicap has a tremendous cost, primarily in terms of its social impact.

Estimates of costs and benefits associated with the “missing people“ and the impact of impairment, disability and premature death should also be included in these calculations if they are to be complete.

Based on the information shown in the

following figure, it is not possible, at this time, to make a reasonable estimate of the economic cost of the existence of handicap. However, it is reasonable to state that:

- The economic costs are very significant given the numbers of people affected by handicap.
- The benefits, as shown below, may well exceed the costs, or at the very least, provide a significant balance to these costs.

Eradicating handicap - the costs and the benefits

Cost factors

- Cost of minimizing the risk of impairment.
- Cost of providing assistance for people with impairments.
- Cost of providing assistance to disabled persons.
- Cost of eliminating barriers to assistance and inclusion.

Benefit factors

- Value of increased production by disabled persons.
- Value of increased production by families and caregivers.
- Value of production by people whose impairments do not become permanent.
- Social benefits of improving the quality of life of disabled persons.
- Social benefits of preventing needless, premature deaths.
- Social benefits of improving the quality of life of family members.

**Changing attitudes
CAHD**

c h a p t e r

3

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3.1 Introduction

Recognizing the permanence of impairment and disability

As noted previously, the prevalence of disability increases with the increase of development and the resulting decrease of handicap.

This tells us that the focus of intervention strategies should be on the eradication of handicap, as well as the eradication of impairment and disability.

This does not mean that the work to eradicate diseases that cause impairment and disability should be neglected. These efforts are of tremendous importance and should be continued, and if anything expanded. However, these efforts should be coupled with a strategy that includes changing the attitudes and behavior of people and their organizations in order to maximize their impact on handicap.

When handicap is eliminated the cycle of impairment and disability will still be with us, however it will exclude poverty, barriers and premature death as is illustrated in the following diagram¹¹.

The engine that drives the following cycle is **people's positive attitudes**.

1. This cycle also starts at the top with organizations. Organizations are formal and/or informal groups people working together outside the family home to achieve specific objectives. For example, organizations work to provide governance, or goods, or services, and to create social change. They include formal and non-formal organizations and businesses both governmental (GO) and non-governmental (NGO). **Organizations and people** create the circumstances that govern the lives of others.

An example of organizations creating positive economic circumstances is Jubilee 2000, a consortium of non-governmental organizations that have worked together for debt relief for developing countries.

2. After organizations, continuing clockwise **is positive, social, political, economic and environmental circumstances**.

Debt relief promises to ensure more fun-

(11) This diagram was derived during a CAHD-DD team meeting in Manila in November 2000. The team consisted of staff from Overseas Development Group (ODG), University of East Anglia, Center for Disability in Development (CDD), Christoffel Blindenmission (CBM), and Handicap International.

ding for basic needs in developing countries. For debts to be forgiven governments have to use the same money locally to provide basic education, health care and poverty alleviation. As movements like Jubilee 2000 become more prevalent and the world becomes a more equitable place, poverty will become less of a factor in handicap, and may even disappear someday.

3. As poverty decreases disability will still be prevalent, in fact it will increase. However, the nature of the disabilities experienced in populations will change from those caused by diseases and neglect to those caused by old age, genetics, and accidents.

4. When attitudes are positive services will be readily available for people with impairments.

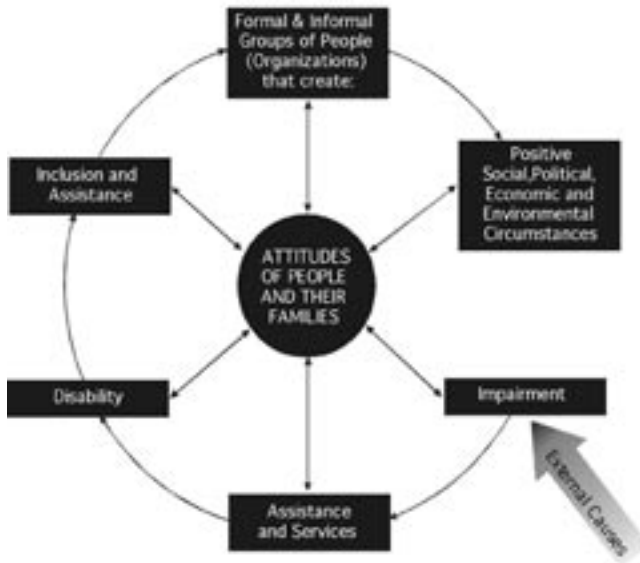
5. However, disability will still occur.

6. In a positive atmosphere, disabled persons are still included and services are readily available. Disabled persons will survive and live productive lives. They will make significant contributions to the development of their families and countries.

People's positive attitudes that result in the situations where disabled persons are included and given necessary assistance, fear is removed and the positive attitudes are reinforced.

The symptoms of handicap and handicap itself disappear. When this happens, the term handicap will no longer be needed, and it will disappear from common use.

Positive cycle
of impairment, disability and handicap



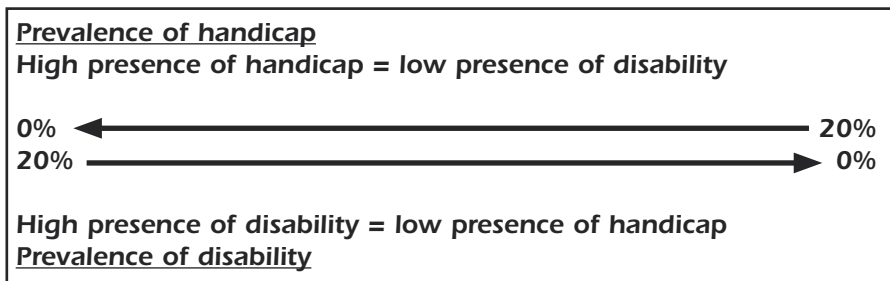
Measuring the impact of CAHD

the effectiveness of CAHD.

The linkage between the decrease of handicap and the increase of the prevalence of disability gives us a new way of measuring

This connection is illustrated graphically in the following figure.

Approximate relationship between disability and handicap



The history of CAHD: CBR and other initiatives

Today, many development initiatives do not include disabled persons in their activities. In some cases, these organizations have policies that specifically exclude them and their needs. In other cases, this exclusion happens because organizations do not know about nor understand the impact of disability. Other organizations often think that disability is only a medical problem, or as a problem that can only be solved by disability organizations. For example, advisory boards believe that disabled persons cannot work and create policy to exclude them as a bad risk in loan programs. Over the past few

years, this situation has started to change and development organizations are now seeking ways to include disability. For example DFID¹² have recently developed new policies that include disabled persons, as have several UN organizations¹³.

In developing countries, rehabilitation assistance is scarce. Current estimates¹⁴ show that only about 2% of disabled persons are provided with some form of rehabilitation assistance. The impact of the lack of rehabilitation services is made even worse when the needs of other people who have impairments are included.

One of the major efforts to provide service for disabled persons has been the develo-

(12) Department for International Development (DFID), Disability, Poverty and Development, February 2000.

(13) ESCAP, Asian and Pacific Decade of Disabled Persons, Mid-point Regional Perspectives on Multi-sectoral Collaboration and National Coordination, United Nations, 1999.

(14) Leandro Despouy, 1993, Human Rights and Disabled Persons (Study Series 6), Center for Human Rights Geneva and UN, New York, as reported in Department for International Development (DFID), Disability, Poverty and Development, February 2000.

ment of community-based rehabilitation (CBR). However, as many authors have noted¹⁵, CBR and the way it is implemented need to and are changing in order to meet the current needs of disabled persons and their families. Some CBR programs have already evolved into programs very similar to CAHD.

CAHD evolved from CBR and shares most of the principles and concepts developed over the twenty years since CBR started. In fact, CAHD is another way of implementing CBR. In addition to CBR programs there are many other examples of disability related activities being implemented.

1. The WHO and many other organizations, both GO and NGO, have initiated many medically based activities to minimize the risk of impairment through mass immunization programs, nutritional awareness programs, and development of better health care services.

2. There are and have been many awareness initiatives by many different organizations to create knowledge about disability as an issue that needs action now. Two examples of social communication activities are:

- The UN Charter of Rights and the campaign to have it signed and adhered to by all governments.

- The ESCAP Asian and Pacific Decade of Disabled Persons and the activities of the many associated NGO who use the decade

and these meetings as a platform to create more awareness about disability.

3. NGO and governments have started to create opportunities for education for disabled persons.

4. Organizations have actively worked to create employment opportunities for disabled persons in many different areas. For example, many CBR programs now include skill training for disabled persons.

5. There are and have been many efforts, particularly by ESCAP, to create a coordinated response to developing assistance for disabled persons in this region.

The most important factor in all of these initiatives is the lack of connection between them. In spite of a call for a multi-sectoral approach to CBR¹⁶ and for development of national coordinating bodies¹⁷, there has been little progress towards achieving the objective of developing the essential cooperation.

It is for this reason that development of coordination and cooperation are major activities in CAHD programs.

CAHD and Primary Health Care

The concepts of Primary Health Care (PHC) service delivery and CAHD are closely related. When PHC was developed in the early 1980's, it was the strategy for improving

(15) *Maya Thomas and M.J. Thomas (eds.)*, Asia Pacific Disability Rehabilitation Journal, Selected Readings in Community Based Rehabilitation, Series 1: CBR in Transition, January 2000.

(16) Understanding CBR, *UN document*.

(17) Asia and Pacific Decade of Disabled Persons-1992-2003: Agenda for Action, *UN document*.

the health and the lives of people living in the developing world. At this time, the intent was to include disability services. However, in spite of CBR being developed by the World Health Organization as a way of including disability issues in PHC, inclusion never really happened.

In the 1990's, the concept of Primary Health Care began to get less support when the results did not match the expectations, and CBR is now reaching a similar point. It would seem that PHC currently gets less support because:

1. Over emphasis of the idea of community members being willing to give freely of their time and resources. This is particularly notable with regards to the use of volunteer community health workers.
2. In some countries, PHC was perceived as being a threat to the vested interests of political groups and professionals because it would create social change. In one case, in the Philippines, when the creation of change was de-linked from the political arena and implemented through religious NGO, the Primary Health Care concept did provide good results.
3. Many PHC projects were developed in isolation from other development activities rather than being integrated with them.
4. Most of the PHC schemes were implemented without development of: adequate policy measures; poor integration and commitment; inadequate training, support, supervision and finance; and, lack of monitoring, research and evaluation.

These valuable experiences in the evolution of PHC have helped to shape the development of the CAHD concept.

CAHD as a concept

CAHD, as described in this document, has two very different parts. The first part, described in this section, is the concept behind CAHD. This concept has been derived from actual experience in the field. The CAHD concept includes the principles, ideas and basic components that will be used to construct a model.

The second part, section 4 below, describes the different strategies for implementing the principles and ideas from the concept. The process of implementing these strategies will develop a CAHD model that is relevant and suitable for the context in which it will operate.

CAHD models are based on various strategies that are suitable for the varying contexts where activities are to be implemented. CAHD models will be very different in different countries and should even vary within countries. The major areas of context that will cause variation are culture, economics, geography, politics and stages of development.

3.2 CAHD principles

Introduction

CAHD implementation starts with the idea that impairment, disability and handicap are development issues that can best be addressed through inclusion in all development activities as cross cutting issues.

Implementing activities effectively and efficiently requires utilization of existing resources and organizations whenever possible.

The vision

The major vision for CAHD is to establish sustainable, effective and efficient activities that will minimize the impact of the negative cycle of impairment, disability and handicap and work towards eliminating handicap and changing the cycle from negative to positive. To achieve this vision CAHD programs must effectively and efficiently implement intervention activities that will:

1. Change the attitudes of people and their organizations to create a more equitable sharing of resources for all people, especially those who are disabled, locally, regionally, nationally and internationally.
2. Change the social environment and the

attitudes of people and their organizations to eliminate the barriers that result in the exclusion of disabled persons and ensure that there is little or no assistance for them.

3. Reduce the impact of impairment and disability on individuals and families through prevention of impairment and provision of adequate services.

Impairment, disability and handicap as development issues

Impairment, disability and handicap are development issues because of their close connection to poverty.

1. Poverty is the major cause of impairment and disability.
2. Poverty is the major reason that there are few services and little assistance available for people who have impairments and disabled persons.
3. Impairment, disability and handicap create poverty.

Development is primarily focused on eradication of poverty and a large part of development activities focus on changing

the attitudes and practices of people. As will be seen below, these strategies are the same for CAHD as they are for development programs.

In addition, many development organizations focus on the global aspects of poverty and work together to change the attitudes of people and organizations that create poverty. An example of this is Jubilee 2000, an alliance or network of international organizations and individuals that have worked together for cancellation of debts for some of the poorest nations.

While impairment, disability and handicap are development issues and as such need to be included in all development programs, there are several differences in focus between community development programs and CAHD.

1. The target population of CAHD is typically different from the target population of community development programs. Community development programs usually focus on specific groups: slum dwellers, women, landless rural populations, tribal groups, refugees, etc. CAHD focuses on:

- All groups and the disabled people that are part of each of them.

- Groups that are not normally included in development programs: landowners, middle-class and upper class families.

2. Another difference between community development and CAHD is inclusion of creating service provision as part of its activities.

It is these differences and the impact of

impairment, disability and handicap on everyone that make them crosscutting issues that need to be addressed in every development program.

Sustainability

The idea of sustainability is included in CAHD although it is recognized that it will only be achieved once attitudes have changed and governments are prepared to find ways of sharing costs in some areas.

In CAHD developing sustainability as a long-term goal has been considered differently in each of the following three parts of the system:

1. The organizations that create change.
2. The changed attitudes and practices of people and organizations.
3. The services that provide assistance to people who have an impairment and disability.

Sustainability in any of these areas, especially in service provision, will be difficult to achieve as long as under-development and poverty exist. The significance of this fact is that it means long-term external commitment is needed to make global equity in resource sharing a reality.

Each of the above three parts of the system needs a different sustainability strategy.

1. Organizations that create change require short-term sustainability strategies, because their job will be completed, and these organizations will have to either transform or

disappear once social changes become established in local custom and culture.

2. Once the attitudes and practices of people and organizations are changed and have become social norms in society, sustainability has been achieved. However, longer term monitoring, research and evaluation of both the norms and the modes of operation should be maintained to make sure that the desired changes are maintained.

3. Service delivery, whether it is basic rehabilitation services provided in homes and communities or specialized referral and transfer services will always be needed. Sustaining these services, requires perpetual funding that can be provided either on a user pay basis or through various social welfare schemes.

Attaining these different levels of sustainability must be a long-term objective of CAHD programs and should be planned for from the very beginning of projects.

Ensuring the sustainability of the activities used to create change and results of change in each of the above three areas requires effective long-term monitoring, research and evaluation.

Within all three of these areas, the primary sustainability strategy is to develop capacity in local organizations -both GO and NGO.

Effectiveness and efficiency

Effectiveness measures the extent that activities meet objectives.

Efficiency measures the use of resources (human, material, and financial) when implementing activities in terms of meeting required objectives.

Effectiveness and efficiency are best achieved by:

1. Using existing organizations that have already gained peoples' trust to implement new activities.
2. Developing a comprehensive strategy and plan of action before starting to implement activities.
3. Initiating relevant monitoring, research, evaluation, and ways of creating change at the same time as implementation activities are started.
4. Providing all staff with proper training before activities are implemented.

3.3 Creating change

As noted earlier in this document, the vision for CAHD is creating changes in the attitudes of people and their organizations to counter the existence of handicap.

CAHD means changing attitudes of people and organizations. Changing attitudes means changing knowledge, attitudes and practices (KAP).

1. **Knowledge:** Changing attitudes requires creation of knowledge by provision of information and creating experience. In CAHD, information transfer is called social communication and experience is gained through participating in inclusion activities.

2. **Attitudes:** Once knowledge is assimilated and combined with experience, it results in specific attitudes or ways of thinking about certain topics. For example, when people do not know about disability and are afraid of it and its consequences, they have negative attitudes about all disabled persons.

3. **Practice:** The objective of CAHD is to change practice by changing attitudes. When attitudes about disabled persons are negative, practice results in lack of provision of services and assistance and their exclusion from social activities. This is handicap. When

attitudes are positive practice results in services and assistance being made available for disabled persons. They are also included in social activities.

Changing the attitudes of people

People create the barriers that result in lack of assistance for people who have an impairment and exclusion of disabled persons:

1. Services and assistance for disabled persons are not provided because of barriers created by lack of knowledge about the causes and consequences of impairment, disability and handicap.
2. Barriers cause impairment, disability and handicap.
3. Barriers cause premature death.
4. People in their families, and the organizations they create and work in, are the major cause of barriers.

People will change their attitudes and practices when they find that it is to their advantage. People need information from three kinds of activities to convince them to change their attitudes.

1. Sharing positive experiences with disabled persons.
2. Gaining knowledge about impairment, disability and handicap.
3. Recognition that society will no longer accept the negative attitudes that result in handicap.

Positive experience with disabled persons is created when they are included in family and community activities.

Change is easier and occurs more quickly when: sharing, learning and societal changes happen at the same time.

Changing attitudes requires time, the more interaction there is among the various sectors the faster change will occur. However, this type of change does take time and requires long-term commitment to make sure it is complete and has become a self-sustaining part of the social and cultural context.

Changing the attitudes of organizations

Organizations are people working together outside the family home to provide governance, or goods, or services, and to create social change. They include formal and non-formal organizations and businesses both governmental (GO) and non-governmental (NGO).

The attitudes of organizations will change when:

- The people who work there have changed

their attitudes.

- The social and legislative rules that govern them change.

- They have revised their policy.

- They have changed their corporate behavior.

- Disabled persons are included as staff in these organizations.

Changing the negative cycle of impairment, disability and handicap

Eliminating handicap and changing the negative cycle of impairment and disability to positive requires interventions that will create the following changes:

1. Change the attitudes of people and their organizations so that there is equitable sharing of resources; locally, regionally, nationally and internationally.
2. Change the attitudes of people and their organizations to eliminate the barriers that result in little or no assistance to people who have an impairment and disability.
3. Reduce the impact of impairment and disability on individuals and families through provision of adequate services.

Changes in society that are the result of new attitudes assumed by people and their organizations, will in turn influence others to change.

3.4 Components and sectors

The following sections describe the areas or components and sectors where activities must be implemented to create the sustainable changes necessary to minimize the impact of handicap in developing countries.

The components

Changing the attitudes of people and organizations effectively requires simultaneous implementation of activities in the following four component areas.

1. SOCIAL COMMUNICATION: Providing knowledge to people and organizations about:

- Causes of impairment, disability and handicap.
- Roles of family members and organizations, in creating handicap.
- Activities that will prevent impairment, disability and handicap.
- Rehabilitation practices that will minimize the impact of impairment and maximize the personal development of disabled persons.

2. INCLUSION AND RIGHTS: Providing disa-

bled 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 organizations have positive experiences with disabled persons, which will change their attitudes.



Social communication workers using flashcard

- Organizations to include disabled persons in their existing programs 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 organizations to promote for legislation, policy and regulations for recognition of the rights of disabled persons.
- 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.

3. REHABILITATION: Providing assistance to people who have impairments and disabled persons that will minimize the functional difficulties that are the result of their impairments and maximize their personal development by:

- Providing basic rehabilitation service in the community.
- Providing referral and transfer services¹⁸ 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 organizational 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.

• Using monitoring, research, documentation, and evaluation information to facilitate and direct the creation of changes to the CAHD system.

The sectors

Effectiveness requires implementation of handicap intervention activities in three sectors:

1. PRIMARY SECTOR: The micro-level, family situations, where people live out most of their lives.
2. SECONDARY SECTOR: The first macro-level where people, as members of organizations, work to provide governance or goods and services, and create social change, in the primary sector.
3. TERTIARY SECTOR: The second macro-level where people, as members of organizations, work to provide in-direct governance, manufacture goods, provide in-direct services, and create social change in the primary sector.

(18) Transfer services refers to making sure that people can find and afford transportation to and from referral service centers.

3.5 Implementing action

The concept of CAHD consists of implementing activities in each of the four component areas in all three sectors that will meet specific objectives in each sector for each component in the matrix.

COMPONENT	SECTOR		
	Primary	Secondary	Tertiary
Social communication			
Inclusion and rights			
Rehabilitation			
Management			

The table in the sections below shows the goals, outcomes and expected activities that should be implemented in order to achieve the vision of CAHD as described in section 3.2 above.

The goals and outcomes described in section 3.5.2 define what should be achieved over time in a CAHD program. It is important to remember that these goals and outcomes need not all be achieved by one organization, nor all at one time. However, it is expected that they will be achieved over time by a consortium of organizations working together through well-established networks.

The activities shown in section 3.5.2 are illustrative only, their exact nature and number will vary depending on what has already been done by the initiating organizations and the partners participating in its network.



Community disability worker at work with a young child

3.5.2 Social communication goals, outcomes and expected activities

Component	Goals, expected outcomes and activities		
	Primary sector	Secondary sector	Tertiary sector
Social communication	<p>Goal: Creation of knowledge in families that will decrease handicap.</p> <p>Expected outcomes: People will know about the causes and prevention of impairment, disability and handicap.</p> <p>Activities: Secondary sector organizations will use social communication tools to provide relevant and appropriate information to people and families about:</p> <ol style="list-style-type: none"> 1. Causes and prevention of impairment, disability and handicap. 2. Early identification of impairments and basic early intervention techniques. 3. The availability of rehabilitation resources. 	<p>Goal: Transmission of knowledge to people in families and organizations.</p> <p>Expected outcomes: Secondary sector organizations will have the necessary skills to transmit social communication information to people and families in the primary sector and to organizations in the secondary sector.</p> <p>Activities: Secondary sector organizations will transmit relevant social communication information to all people in the primary sector.</p> <p>Secondary sector organizations will transmit relevant social communication information to all other secondary sector organizations.</p>	<p>Goal: Development of capacity for knowledge transmission in all sectors.</p> <p>Expected outcomes: Tertiary sector organizations will have the capacity to develop social communication tools and disseminate them through appropriate training courses to secondary and tertiary level organizations.</p> <p>All national awareness campaigns will include disability issues in the information that they disseminate.</p> <p>Activities: Tertiary sector organizations will acquire and/or develop appropriate social communication tools and training courses for local use and distribution.</p> <p>Tertiary sector organizations will select appropriate secondary sector organizations and provide their staff with social communication training.</p> <p>Tertiary sector organizations will transmit relevant social communication information to all other tertiary sector organizations.</p>

3.5.3 Inclusion goals, outcomes and expected activities

Component	Goals, expected outcomes and activities		
	Primary sector	Secondary sector	Tertiary sector
Inclusion and rights	<p>Goal: Creation of opportunities for disabled persons to participate in the normal activities of their families and communities.</p> <p>Expected outcomes: Disabled persons will have equal access to activities available to other community members.</p> <p>Non-disabled family and community members will have positive attitudes about disability because of their shared experience in joint activities in the family and community.</p> <p>Disabled persons will be aware of their rights as members of their societies.</p> <p>Activities: Including disabled persons in all routine family and community activities, especially those that are directed at maximizing peoples' personal development.</p> <p>Including disabled persons rights and disabled persons in all rights awareness campaigns.</p>	<p>Goal: Inclusion and acceptance of disabled persons in all organizational activities.</p> <p>Expected outcomes: All disabled persons and people who have impairments will have full access to secondary sector organizations and services.</p> <p>All secondary sector organizations will include disabled persons as staff.</p> <p>Activities: Providing disability orientation and inclusion training for the staff of service delivery organizations.</p> <p>Assisting disabled persons to prepare for inclusion in routine activities.</p> <p>Including disabled persons in all routine secondary level services (health care, education, income generation, etc.).</p> <p>Providing support for disabled persons to advocate for their rights.</p>	<p>Goal: Development of inclusion capacity for disabled persons in all sectors.</p> <p>Expected outcomes: Legislation, policy and regulations to ensure inclusion of disabled persons.</p> <p>Activities: Providing inclusion training for organizational staff in the secondary and tertiary sectors.</p> <p>Advocating for inclusion legislation and opportunities.</p> <p>Providing policy development training for managers of secondary and tertiary sector organizations.</p>

3.5.4 Rehabilitation goals, outcomes and expected activities

Component	Goals, expected outcomes and activities		
	Primary sector	Secondary sector	Tertiary sector
Rehabilitation	<p>Goal: Provision of rehabilitation services and assistance to all disabled persons and people who have impairments.</p> <p>Expected outcomes: All disabled persons and people who have impairments will have access to rehabilitation and transfer services and assistance.</p> <p>Families and communities will provide basic assistance to disabled persons and ensure their access to services within the limits of current circumstances.</p> <p>Activities: Providing basic rehabilitation services in homes and/or the community.</p> <p>Developing in-family and between-family networks to provide support for disabled persons where necessary.</p> <p>Providing family members with basic skills and knowledge about assisting disabled persons.</p>	<p>Goal: Provision of basic rehabilitation and referral and transfer services to all disabled persons and people who have impairments.</p> <p>Expected outcomes: Comprehensive rehabilitation service delivery capacity that is accessible financially and geographically (close to the community) to provide routine, relevant assistance (including transfer) to all disabled persons and people who have impairments.</p> <p>Activities: Providing appropriate training for community disability workers.</p> <p>Developing rehabilitation service capacity.</p> <p>Providing assistance to disabled persons and their families where needed.</p>	<p>Goal: Development of rehabilitation service and transfer capacity in all sectors.</p> <p>Expected outcomes: Policy and budget for development of an appropriate rehabilitation service delivery system.</p> <p>Standardized and accredited CAHD training for rehabilitation and medical personnel: from community workers to specialized staff.</p> <p>Effective referral and transfer facilities in all sectors.</p> <p>Tertiary sector specialized services available on a referral basis.</p> <p>Activities: Advocating for development of appropriate essential rehabilitation services.</p> <p>Providing technical and financial resources for development of rehabilitation training and service delivery capacity.</p> <p>Development of standardized and accredited community worker training capacity.</p>

3.5.5 Management goals, outcomes and expected activities

Component	Goals, expected outcomes and activities		
	Primary sector	Secondary sector	Tertiary sector
Management	<p>Goal: Creation of opportunities for community participation in system design, monitoring, research, evaluation and management.</p> <p>Expected outcomes: All aspects of CAHD are accountable to beneficiaries and relevant to the needs of the community.</p> <p>Activities: Including participation in design, monitoring, research, and evaluation of CAHD in self-help group activities.</p>	<p>Goal: Development of management, coordination, monitoring, research and evaluation capacity to make sure that the communities' needs are being met in the primary and secondary sectors.</p> <p>Expected outcomes: Comprehensive, relevant, efficient and effective CAHD programs in the primary and secondary sectors.</p> <p>Participation of beneficiaries in the design, monitoring, research, and evaluation of all CAHD activities in the primary and secondary sectors.</p> <p>Activities: Developing competent management, coordination, monitoring, research and evaluation systems in the primary and secondary sectors.</p> <p>Developing secondary sector networks of organizations to develop and share information and resources.</p> <p>Advocating for complete development of CAHD in the primary and secondary sectors.</p>	<p>Goal: Development of management, coordination, monitoring, research, and evaluation capacity to make sure that the communities' needs are being met in all sectors.</p> <p>Expected outcomes: Complete, relevant, efficient and effective CAHD programs in all sectors.</p> <p>Participation of beneficiaries in the design, monitoring, research and evaluation of all CAHD activities in all sectors.</p> <p>Relevant legislation, policy and regulations developed and implemented in all sectors.</p> <p>Activities: Developing competent management, coordination, monitoring research, and evaluation systems in the tertiary sector.</p> <p>Developing tertiary sector networks of organizations to develop and share information and resources.</p> <p>Advocating for complete development of CAHD.</p>

**CAHD implementation
strategies**

4

c h a p t e r

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4.1 Introduction

This section describes different strategies for developing models that will be based on implementing the CAHD concept in local circumstances.

4.2 Implementing CAHD through development activities

Impairment, disability and handicap are development issues and as such the most obvious strategy for implementing activities to decrease their impact is to use existing community development organizations and activities.

The following figure illustrates how development

activities can be used as effective ways to create positive attitudes about impairment, disability and handicap.

The following table provides examples of different ways of including disabled persons in normal development activities.

DEVELOPMENT SECTOR	REGULAR DEVELOPMENT ACTIVITY	HANDICAP INCLUSION ACTIVITY
Human rights	<ul style="list-style-type: none"> Promoting gender equity 	<ul style="list-style-type: none"> Invite a disabled woman as chief guest to speak on women's rights at a rally for International Women's Day.
Health and survival	<ul style="list-style-type: none"> Maternal child health and family planning clinic. 	<ul style="list-style-type: none"> Include early detection of disability screening at during immunization program. Provide basic therapy services during clinic hours.
Education	<ul style="list-style-type: none"> Non-formal primary education. 	<ul style="list-style-type: none"> Include children with disabilities.
Economic security	<ul style="list-style-type: none"> Providing skill training and start up resources. 	<ul style="list-style-type: none"> Include disabled persons and family members in training and getting help to begin.
Infrastructure development	<ul style="list-style-type: none"> Building a health clinic in a rural area. 	<ul style="list-style-type: none"> Include ramp for accessibility.
Monitoring, research and development	<ul style="list-style-type: none"> Community Participatory Rapid Appraisal (PRA). 	<ul style="list-style-type: none"> Include disabled people and questions about their needs in the community meeting.
Management	<ul style="list-style-type: none"> Program monitoring. Program research. 	<ul style="list-style-type: none"> Include disability data in monitoring information. Include disability issues in research activities.

4.3 Networks in CAHD

CAHD is an interactive process with partners in all sectors. It is complex and requires input from many people, both disabled and non-disabled, and different types of organizations, both GO and NGO (including disabled peoples' organizations).

The range of technical skills required is also quite large, everything from knowing how to facilitate community involvement (development training) through to advocating for change with national level politicians.

The best way to ensure an effective interaction between people and organizations and to obtain the required range of skills other inputs from diverse people and organizations is to establish networks in and between all sectors.

Using formal and informal networks to facilitate the development of and ensure the ongoing maintenance of CAHD is both effective and efficient.

Designing networks that will actually produce results is in itself a complex activity. For this reason it is recommended that existing networks be used wherever possible and that all networks have a clearly defined purpose and potential benefits for all that

participate in them.

Networks should also be used to develop effective research partnerships to complement standard monitoring and evaluation processes.

The development and maintenance of effective networks is one of the key strategies used in implementing CAHD. Network development strategies are outlined in the CAHD Toolkit for each of the following key areas:

- 1. In-family networks:** The major role of in-family networks is to establish coordinated support for family members who have impairments or disabilities. In-family networks will also strengthen relations between all family members.
- 2. Between-family networks:** Between-family networks are a strategy for breaking down barriers at the personal and family level and ensuring that all families have access to sufficient resources to enable participation of their disabled family members. These local or neighborhood networks can also provide personal support for disabled persons.
- 3. GO/NGO networks:** The major role of GO/NGO networks is to maximize effectiveness and efficiency through coordinated

sharing or resources. The major objective of these networks is to ensure inclusion of disability issues in all aspects of development and to make sure that disability coverage is complete in CAHD program areas.

The extent of networking required, especially in the secondary sector, will vary significantly

depending on the capacity of individual organizations. Often, single organizations do not have access to the considerable range of skills and resources necessary to fully implement CAHD. When this is the case, development of networks with other organizations to ensure full implementation of CAHD becomes much more of a necessity.

4.4 Expected roles in CAHD

The CAHD concept and associated materials have been designed to work to help them carry out the following roles.

Disabled persons

Participate in the development of CAHD.

Advocate for the development of CAHD.

Provide positive role models for other people.

Monitor the development and implementation of CAHD.

Participate in self-help groups and the monitoring, research and evaluation of CAHD activities.

Families

Include disabled persons as equal members of the family.

Learn about and prevent causes of impairment, disability and handicap.

Ensure access to rehabilitation services for all disabled persons.

Provide support for other families and disabled persons.

Advocate for the development of CAHD.

Participate in the development of CAHD.

Develop in-family networks to provide support for disabled family members.

Develop between-family networks to provide support for families in need.



A mother practising basic therapy

Governmental organizations

When implementing CAHD it must be realized that different government organizations will have different roles and will need to be approached and involved in different ways. The following roles are directed at the three broad areas of government; political, legislative and technical groups within specific ministries.

Politicians need to be convinced that meeting the needs of disabled persons and eliminating handicap are issues that will affect voters. The best way of doing this is to create specific advocacy initiatives with voter groups while trying to convince politicians that it is in their best interest to:

- Provide a legislative framework for development of all aspects of CAHD¹⁹.
- Provide financial resources for the implementation of CAHD activities.
- Ensure, within the framework of CAHD, development of an effective and efficient system for delivery of rehabilitation services.
- Ensure effective communication about impairment, disability, handicap and the development of CAHD to all sectors of society.

At the same time technical groups within specific ministries need to be provided with support, information, training and funding, for developing new and better ways developing the referral system and including disabled persons in government services.

International organizations (e.g. United Nations agencies)

Develop international standards and protocols for disability issues.

Strengthen existing international networks through inclusion of disability issues.

Provide an international forum for sharing of information about CAHD²⁰.

Provide linkages between disability and development organizations.

Ensure that the role of development agencies is expanded to include disability issues.

Disabled peoples' organizations

Advocate for development of CAHD services.

Develop linkages between disability and development organizations.

Participate in the monitoring, research and evaluation of CAHD.

Non-governmental organizations (NGO)

Advocate for and facilitate the development of a CAHD coordination framework.

Include disabled persons in the development and implementation of CAHD in all sectors.

Monitor, evaluate and suggest changes to the

(19) Information about developing legislation is available from the United Nations in the document: Legislation about Equal Opportunities and Full Participation in Development for Disabled Persons: Examples from the ESCAP Region; Document number ST/ESCAP/1651; United Nations, New York, 1997.

implementation of CAHD.

Advocate for changes in donor organization policies.

International non-governmental organizations (INGO)

Initiate the development of CAHD.

Provide technical resources for the initial development of CAHD.

Provide financial resources for the initial development of CAHD.

Participate in and support the development of a CAHD coordination framework.

Starting CAHD

c h a p t e r

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5.1 Introduction

The first decision to be made when designing CAHD is whether to start with a pilot program or to implement CAHD as a national plan.

The two most important factors to be considered before making the choice between starting a pilot program and a national plan are:

1. The geographic reality of the country where CAHD is being started. Large areas and diverse populations tend to point to the pilot program approach.

2. The availability of skilled, experienced personnel or assistance. CAHD is complex, it has been designed to deal with a complex problem that requires implementation of diverse activities. When experienced personnel are not readily available it is better to start with the pilot program concept where personnel gain experience as they work to develop the CAHD system.

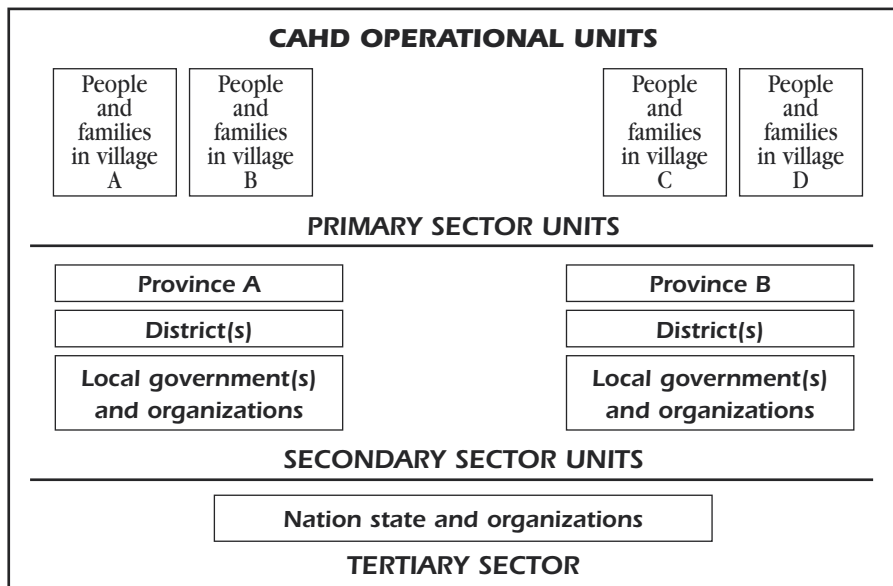
Once the choice has been made between pilot program and national plan, the implementation steps are the same.

The major difference between the two will be the time scale –the pilot program phase will necessarily precede the development of a national plan. This choice means that it will take longer to bring equal opportunities and full participation for all disabled persons. However, a pilot program is much surer than a national plan approach as various implementation strategies can be tried and verified before a total commitment is made.

The following figure illustrates the possible composition of a CAHD pilot program in terms of operating units. There may be multiple primary and secondary units that will operate under a single, tertiary sector unit.



A girl with Down's syndrome following school like others



5.2 Introduction to the CAHD Toolkit

The CAHD Toolkit, as described below, is the major source of information for developing CAHD. The Toolkit has been specifically designed to be flexible to allow for the development of many different models within the framework of the CAHD concept.

Part A: Understanding CAHD

This document and presentation material to use to describe CAHD to others.

Part B: Social communication tools

Materials, messages, and methods for developing and presenting locally appropriate messages that will create knowledge about

impairment, disability and handicap.

Part C: Inclusion tools

Tools for developing inclusion of disabled persons, in the activities of their families, communities and organizations.

Part D: Rehabilitation tools

Tools for developing and maintaining effective and efficient, community-based basic rehabilitation services.

Part E: Management tools

Tools for developing CAHD capacity and networks, and for researching, monitoring,

research and evaluating implementation activities in all sectors.

Part F: Training courses

Training course materials (outlines, session plans, and reference materials), in module format, for training social communicators, managers, and community, disability resour-

ce persons. These training courses are designed for use with all categories of organizations; NGO, INGO, disabled persons organizations, and government organizations.

5.3 Phases in the development of a CAHD pilot program

The major factor in establishing successful CAHD programs, whether they are national or pilot, will be the selection or development of entry point or initiating organizations in both the primary (local) and tertiary (national) sectors.

Guidelines for developing and/or selecting appropriate organizations are included in the CAHD Toolkit.

Phase I: Preparing implementation

Complete the CAHD Situation Analysis and Information Framework (SAIF).

Use the SAIF data to develop a strategic program plan for implementing CAHD.

Initiate development of CAHD training capacity.

Adapt and translate the CAHD Toolkit information to conform to the strategic plan and relevant social conditions and languages.

Select appropriate partner organizations for implementation of pilot projects.

Phase II: Starting implementation of primary and secondary sector activities

Provide training to implementing partners.

Implement pilot project activities.

Initiate development of organizational networks in the pilot project area.

Initiate development of essential referral and transfer services in pilot project area.

Monitor, review and adjust the implementation process.

Phase III: Starting implementation of secondary and tertiary sector activities

Initiate development of national organizational networks.

Add advocacy for CAHD to present CAHD advocacy activities.

Initiate development of a national CAHD coordinating body.

Strengthen existing rehabilitation services or initiate their development if there are none.

Ensure passage of a legislative framework that enables disabled persons and the development of CAHD including essential referral services.

Expand implementation of CAHD beyond the initial pilot project area.

Continue to monitor, review and adjust the implementation process.

Phase IV: Maintaining CAHD

Constant ongoing monitoring, research and evaluation will be required far beyond the implementation phase. The monitoring, research and evaluation information will

always be needed to create change in the service delivery system as the needs of communities will constantly change as they grow and develop.

One of the major components of CAHD is the development of a permanent management system that should be part of existing national structures. The objective of these management systems will be to ensure the equal opportunities and the full participation of the increasing numbers of disabled persons that will survive as handicap diminishes.

5.4 Training for CAHD implementers

All CAHD training courses start with creating an understanding about impairment, disability and handicap and the impact that they have on the lives of people.

All CAHD training courses are specifically designed to create positive attitudes in all participants and to motivate them to ensure effective CAHD activities.

As development and a development approach are central to CAHD, the staff of implementing organizations must have adequate development training if their work is to be effective. Development training has not been included in the CAHD Toolkit as it assumed that this type of training will either already have been done for development organizations or will be readily available

from one of many development training organizations.

Disability awareness for managers

The full course outline and individual session plans completed with training materials or references to sources of training materials can be found in the CAHD Toolkit.

Senior and mid-level managers will be trained to:

1. Create commitment in their organization.
2. Analyze their own organizations to see where CAHD activities will fit.
3. Develop relevant policy.
4. Change organizational behavior.
5. Hire disabled people as organization staff.
6. Include disabled persons in their development activities.
7. Develop cooperative networks with other organizations.
8. Monitor and assess the work of CAHD staff.
9. Use monitoring and research information to create changes in their programs.
10. Participate in ongoing research activities.

Managers will continue to develop a better understanding of CAHD through network meetings, follow-up visits by experienced staff, and refresher courses.

Social communication

Social communication skills will be provided to community disability workers as a separate module in their training course. This option is used as experience has shown that disability social communicators need to have enough technical knowledge about disability and its causes to be able to answer a wide range of questions. If these questions are not adequately answered during the social communication session, the effects of the messages will be greatly decreased.

The full course outline and individual session plans completed with training materials or references to sources of training materials can be found in the CAHD Toolkit

Community workers will be trained to:

1. Share their knowledge with the staff of the organization where they work and with other organizations working in their area.
2. Use information and techniques provided in the CAHD Toolkit to adapt the social communication materials to their local situation and to develop new materials.
3. Use adapted and newly developed materials to provide knowledge and information to community members.
4. Use information provided in the CAHD Toolkit to create new techniques for sharing knowledge and information with community members.
5. Train other staff to share knowledge and

information with community members.

Community disability workers

The full course outline and individual session plans completed with training materials or references to sources of training materials can be found in the CAHD Toolkit.

Community disability workers will be trained to:

1. Provide basic rehabilitation services for all types of impairments.
2. Train family members and others to provide basic assistance to disabled persons.
3. Refer disabled persons to relevant specialized services.
4. Facilitate inclusion of disabled persons into development activities.
5. Develop in-family and between-family support networks for disabled persons.
6. Motivate other people in their organizations and communities to include disabled persons.

Community workers training and motivation will be reinforced by:

1. Refresher training.
2. Follow-up visits by experienced field staff.

**CAHD in action:
a case study**

6

c h a p t e r

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6.1 The impact of CAHD on an organization

The Community Development Organizations (CDO) was established fifteen years ago and has grown from a small group of local volunteers to an organization with 25 projects and a staff of over 200 people. CDO's development activities include: saving and credit groups, fish cultivation, agricultural support and technology innovation, housing, education, health and nutrition, legal aid, and women's justice. CDO also operate a small fifteen-bed hospital with an active outpatient clinic to support their health and nutrition activities.

Until five years ago, CDO was not aware of the existence of disabled people in their project areas. In fact, when asked, one of the managers insisted that there were no disabled people in living their working area. CDO started to do some blindness prevention activities and soon learned about disabled people and their needs. They then got interested in providing increased levels of assistance to disabled persons and, at the suggestion of one of their national donors, CDO decided to try to include other disabled people in their work using the CAHD approach. Initially, the health-sector manager attended disability awareness training for managers. Although he was still skeptical about including disabled people in their

work, he identified a staff member for community disability worker training. Once the community worker had completed her training and was working in the field, the health manager saw that CAHD worked. He then suggested that more staff be trained. Over the next eighteen months, the head of the credit sector and a program coordinator also attended the manager's training courses. Another community disability worker was also trained and one of community organizer attended social communication training.

During this time CDO's management team decided that written policy was necessary to make sure that long-term support would be provided for disabled persons people with disabilities by their organization. After the policy was completed, adopted and implemented CDO started activities in each of the following CAHD component areas.

Awareness about disability - Community disability workers and social communicators regularly give awareness messages at savings group meetings, and CDO has integrated disability into their mass awareness activities. Of their twenty-five large billboards bearing development messages, three are about disability. All new CDO staff are given basic training before starting work and disability

is now part of the standard curriculum. The community workers have also given two days awareness training to the forty-five health and nutrition workers and traditional birth attendants. They also provide short informal staff training on specific issues at staff meetings.

Inclusion of people with disabilities

- CDO's new inclusion policy resulted in changed standards for savings group membership that allowed participation of disabled persons and their families. Therefore, 310 disabled people and family members are now included in savings groups. Monitoring information in the credit sector was expanded to include disability information, and other program sectors are revising their monitoring forms to identify CAHD outcomes. Progress reports given by thirty-five assistant managers in all CDO monthly meetings must now include disability information. Disability is also a regular item on the monthly agenda of the regional manager's meetings. The sector managers have also promoted affirmative action policy in hiring disabled staff (currently there are six) and have recently recruited a disabled person to receive training as a community disability worker.

Providing rehabilitation - CDO's community disability workers (who have been working for less than a year) provide basic therapy to forty-five clients and usually visit three clients each day, four days a week. More than 150 disabled persons have been referred to other organizations for services that the community workers cannot provide. Savings group field-staff contact the community disability workers about specific

disabled people when assistance is required. However, less than one-third of the disabled persons in saving groups needed assessment by, or assistance from, the community disability workers.

Management, advocacy and networking

- CDO has also introduced disability as a topic in coordinating meetings held with the Ministry of Health and Family Planning every three months. One of the important issues at these meetings has been access to services for disabled people. CDO also advocates development donors to provide support for inclusion of disability in all development activities.

6.2 The impact of CAHD on families

Razzak's story

Razzak is twenty-four years old but acts more like a ten years old boy. When he was eight, he fell out of a mango tree and injured his brain. Since that time he drags one leg and can not think very quickly. Often he forgets things but he can do simple household tasks.

Razzak's parents moved from the village to the city because they were getting old and could no longer manage their small piece of land. They did not realize how expensive living in town would be and soon all of their money was gone. In order to provide food Razzak's father finds occasional employment as a day laborer, but their life is hard.

CDO has made a difference in the lives of Razzak and his family. Their involvement with CDO started when a nutrition worker noticed Razzak sitting at the edge of a nutrition group where she was teaching about gardening. After the group meeting she asked one of the members about him and was taken to meet his parents. They agreed to have the community disability worker come to visit him to see if she could help him. The community disability worker now visits Razzak every week and is teaching him to count and do simple math.

The nutrition worker also linked Razzak's mother with a local credit and savings group. Because of CDO's policy to support disabled people, she was given priority for a loan and soon, with the help of a loan from the group, her husband was able to open a shop in the market. Now Razzak helps his father with cleaning and carrying heavy merchandise in the shop. He also helps some of the nutrition group members when there is heavy work to do in their home garden. By doing this, he has learned about gardening and his parents hope that he will soon be able to start a garden for them with the help of the community disability worker and CDO.

Saiful's story

Saiful is the youngest of Aisha and Hamid's seven children. They all live in a small tin-shed teashop on the main road into town where Hamid makes just enough money to feed and clothe his family.

Although Saiful lives in an area covered by a CDO disability survey, he was not identified as being disabled. Instead, a neighbor, a CDO savings group member, identified him. At her regular savings group meeting the CDO community organizer used flashcards to teach about preventing disability through

fever management. The neighbor remembered Saiful's acute respiratory infection when he was few months old. The infection caused a high fever and convulsions that resulted in Saiful not being able to walk. After the savings group session, the neighbor told the CDO organizer and her group about Saiful and his problem. The organizer suggested her to bring Saiful and his mother to the CDO office, where a community disability worker could assess him. The community disability worker recognized that Saiful had cerebral palsy that affected both of his legs.

After the assessment, the community disability worker stated to visit Saiful weekly for about a year, helping him with exercises. As his legs got stronger, Saiful started to use a walking frame. Soon, he was walking on his own and had developed enough confidence to go out into the community. Next, the community disability worker took him to a teacher at one of CDO's non-formal schools. They agreed on a plan. Before Saiful started school, the community disability worker and the teacher conducted awareness activities with the other children who would be in his class. Once Saiful started at the school, he was accepted by the other children. Later, after Saiful successfully completed one year of non-formal schooling, the community disability worker arranged for him to be included in the regular class in the government school, where he now attends first grade.

Nasir's story

Nasir was thirteen years old and could not walk because of polio and lack of assistance for his impairment. He never went to school but then neither had any of his brothers

and sisters. The school was too far away and they were always busy gathering wood and straw for cooking fuel for their mother. Nasir's father is a day laborer when he can find work, sometimes carrying bricks on his head or driving a rickshaw. Nasir, his parents and four brothers and sisters live in a one-room house made of mud and straw in a village of about 300 families.

One day a CDO field worker, Ali, was in their village to supervise the building of a new latrine. He saw Nasir sitting alone outside his house. Ali had just received a three days training on disability from a CDO community disability worker and recognized Nasir's disability. He reported meeting Nasir to Sharif, the community disability worker, and together they visited Nasir. Sharif decided that Nasir's legs could be strengthened with simple exercises and taught Ali and Nasir how to do them. Ali stopped by once or twice a week to visit Nasir and encouraged him to do the exercises. He also helped Nasir to walk to the teashop every time he visited to help strengthen his legs.

Sharif also contacted a carpenter and had a crutch made for Nasir. Nasir's father paid for the wood and the carpenter donated his time. When the crutch was finished Sharif and Ali visited Nasir again and both of them learned how to use the crutch. Sharif also contacted the local ward chairman and persuaded him to give Nasir a special "vulnerable group" status that entitled Nasir to get food at reduced cost.

Ali also met Nasir's family and encouraged them to join one of CDO's 180 savings groups. After a few months Nasir's father



took a loan from the group to buy a cow and attended training in animal husbandry. Nasir's mother began to attend some meetings about health and for the first time, she took one of her children to get polio vaccine after being motivated at one of the meetings.

Ali also encouraged Nasir to help with the new latrine project by mixing cement. Another of CDO's activities was a sports day held to celebrate Child Rights Day. Ali asked Nasir to help plan the games and to participate. Nasir was very proud of the red ribbon he won for the hammer throw.

Sharif visited Nasir once a month for a year and then decided he could no longer help, as Nasir's legs were as strong as they could get. Although therapy was no longer needed, Nasir still worked with CDO for the latrine project and other community activities. He

also goes to some of the savings groups meetings to talk about his disability and to promote immunization.

Naseema and Amina's stories

Naseema is a thirty years old woman with low vision who lives with her aged parents in one of the villages where CDO works. Islam, the community disability worker, noticed her outside her parent's house when he was on the way to one of his savings group meetings. He asked the group members about her and, with the help of one of the members, motivated her to join the savings group. At first, Naseema was reluctant to participate because she did not think she could do any kind of business. However, within a few months she had started a small fabric business. She buys fabric made by people on hand looms in the village and sells it in the bazaar in the city. When she is away in the city one of the group members

looks after her parents. After a few months, Naseema also started to attend the women's groups meetings and to learn more about her legal rights. She also met with other women who had small businesses and learned how to better manage her money.

Islam also identified Amina, a forty-three years old woman living with her six years old daughter, Sashi, and her husband who has been bed-ridden for five years as the result of an accident. Amina spends most of her day caring for her husband who will only allow her and Sashi to feed and help him. Sashi also works long hours as a helper in the home of a local landowner.

Like Naseema, Amina was asked to join one of the savings groups. Soon she was given a loan to buy a rickshaw, which she rents out

on a daily basis to a young neighbor. Islam also registered Sashi in a non-formal school run by another local NGO. It was difficult for her parents to let Sashi do this because they needed the food that she got in payment for her work as a helper. The landowner was also reluctant to let her attend school. However, after Islam and the head of the local NGO visited him, he agreed to allow her to go to school for four hours a day with no reduction in pay. Islam also visited Amina's husband three times to assess his condition and to try to motivate him to help the family. However, his health is very poor and he refused to help or to be helped. Islam was not able to provide any primary rehabilitation therapy, so he gave Amina and Sashi some simple instructions about preventing bedsores and the development of contractures.

Glossary

Assistance:

Help required by some disabled persons for activities of daily living including education and employment.

Attitudes:

The core way people have of thinking about disability and disabled persons. It is this thinking that will lead to practices that either exclude or include disabled persons.

Community:

People, their families and the organizations that influence their daily lives. This community in its large sense.

Development:

The ongoing process of increasing/enhancing individual freedoms and sharing in a more equitable distribution of the world's resources.

Disability:

Permanent lack of function (physical, mental, sensory) that results from impairment.

Disability incidence:

The rate or frequency of the occurrence of disability in any given population.

Disability prevalence:

The number or percentage of any given population that are classified as disabled persons and are counted.

Effectiveness:

The extent that activities have an impact and work towards achieving goals and objectives.

Efficiency:

The cost of implementing activities in terms

of their effectiveness as compared to alternative ways of achieving the same goals or objectives.

Evaluation:

Using monitoring and research data to determine program effectiveness and efficiency.

Handicap:

Not recognizing the existence of disabled persons, excluding them from society, and not providing services to meet their needs.

Impairment:

An anatomical change or deficiency that results in decreased functional capacity.

Monitoring:

Collection of relevant, current data about activities that are being implemented for use in monitoring and research activities.

Operating units:

An existing demographic or political unit used to define the geographic boundaries for component areas of a CAHD program or the complete program area.

Organizations:

Organizations are formal and/or informal groups people working together outside the family home to achieve specific objectives.

Referral services:

The complete spectrum of services needed to provide assistance to all disabled persons including:

- Medical
- Eye care service
- Hearing services
- Physiotherapy

- Occupational therapy
- Orientation and mobility training
- Speech therapy
- Psychological counselling
- Orthotics and prosthetics
- Other assistive devices

Rehabilitation:

Minimizing the impact of impairment and maximizing the personal development of disabled persons.

Roles:

Day-to-day practices based on attitudes that are the result of knowledge and experience.

Sectors:

In CAHD, three sectors of society (people and families, direct service organizations, and in-direct service organizations) have distinct roles in making the transition from a handicap to a no-handicap situation.

Services:

Medical, rehabilitation and other special services required by some disabled persons to minimize the impact of their impairments and maximize their personal development.

Social communication:

Providing knowledge and information about a specific topic to create changes in individual attitudes and practices related to the topic. Knowledge and information are adapted and provided in a manner that is compatible with local knowledge and customs.

Sustainability:

The extent to which an activity can maintain itself without external inputs (usually economic or technical).

Transfer services:

Adequate transportation for disabled persons and their families to and from referral service centers.

Units:

Demographic or political divisions that form program areas.

“For people who want to know more about CAHD and practical experiences, we invite you to read the Bangladesh case study in the same collection. This document is available in Handicap International”

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