CAMPAIGN 2000 for the Asian and Pacific Decade of Disabled Persons, 1993 - 2002

Plenary Session I
Tuesday 12 December, 2000

"Breaking Barriers for Social Integration : *Translating Targets for the Asian and Pacific Decade of Disabled Persons Into Action*"

Presented by
Mr. Douglas Krefting

BREAKING BARRIERS FOR SOCIAL INTEGRATION
Translating Targets For The Asian And Pacific Decade Of Disabled Persons Into Action

Prepared by: Douglas Krefting, CAHD Coordinator, Handicap International (HI)
In cooperation with: Christoffel Blinden Mission (CBM) and Center for Disability in Development (CDD)

1.0 INTRODUCTION

- In this document the terminology used to talk about handicap and disability are defined below. This terminology does not conform to the new WHO definitions[i] for the same reason that it does not conform to the old standard medical terminology. Taking a different perspective on handicap and disability problems, thinking of them as development issues that can be mediated 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 mediating handicap and disability: community members and development workers, as well as medical and rehabilitation professionals.

- In this adapted terminology the cause of the condition being defined is as important as the condition itself, because only the cause can be mediated.

1. **Life circumstances:** The social, political, economic, and environmental circumstances that affect people's lives. For most people, life circumstances are caused by the decisions and actions of other people acting out their roles as members of families and organizations. It is life circumstances that cause the events that can lead to impairment.

2. **Life event:** An incident that causes impairment (disease, accidents, etc.).

3. **Impairment:** The temporary or permanent loss of the use of one or more parts of the body. Impairments can be:

   - Preventable (most diseases).
   - Non-preventable (genetic factors).
   - Temporary (a broken leg).
   - Permanent (the broken leg does not heal properly).

4. **Rehabilitation:** Assistance for people that have received impairments that can:

   - Prevent the impairment from becoming a disability.
   - Minimize disability.
   - Maximize the personal development of the person who is disabled.

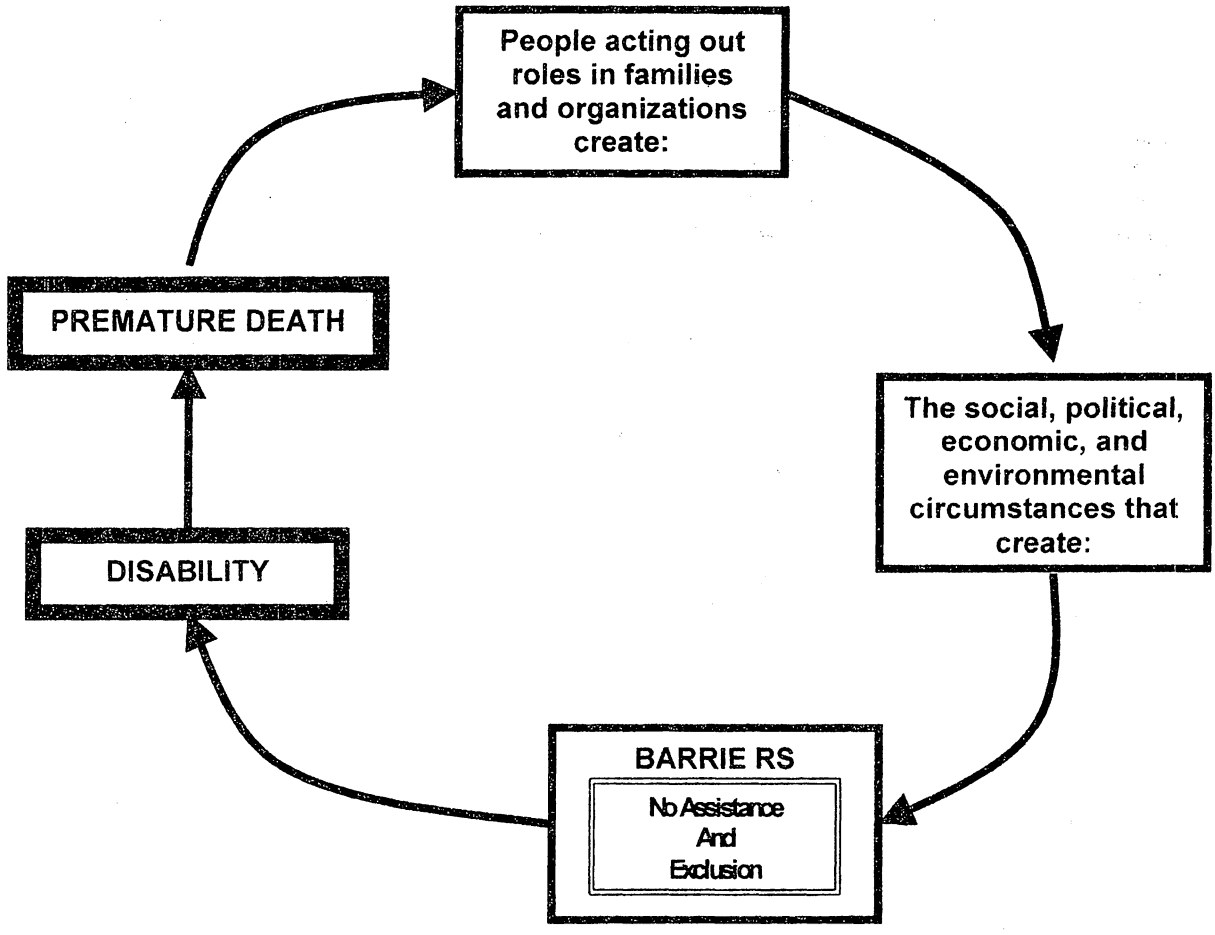
5. **Disability:** The functional limitations that are the result of impairment.

6. **Handicap:** The results of decisions and actions of people and organizations that cause:

- Life circumstances for other people that increase their risk of experiencing a life event that will result in them receiving impairment.

- Barriers for other people that result in 1) their exclusion; and/or, 2) lack of rehabilitation for those who have received impairment.

7. **Handicap Creation Cycle:** The above sequence of terms and their definitions describe the handicap creation process as illustrated in the following diagram.



2.0 THE HIDDEN DIMENSIONS OF HANDICAP

2.1 Introduction

- In the above noted terminology, and in the way of thinking used to derive it, the area that where mediation is needed is handicap. Therefore, the major focus of this document is mediation of handicap.

- Normally the major focus of handicap mediation activities is the lives of people with disabilities. In CAHD this extremely important focus is not lost, it is included in this document. In CAHD, not only are the needs of people with disabilities met their role in mediating handicap is emphasized. Including people with disabilities at all levels, is the most effective way of creating changes in the decisions and actions of others—changes that will minimize the impact of handicap.

- The following sub-sections of this document explore some of the hidden dimensions of handicap, dimensions not generally considered in mediation activities even though they are a large part of the problem.

2.2 The 'Missing People'

- There are strong indications that the same life circumstances that result in events leading to impairment and disability can, and often do, result in premature mortality that is probably directly related to disability. It is these people who die prematurely that are the 'missing people'.

- A strong indicator of the numbers of missing people is the relationship between the prevalence rates of disability between developing and developed countries.

- The WHO estimates[ii] that the world average prevalence rate of people with disability as being about 5%. However, many developing countries report rates that are even lower.

- In some developed countries (Australia, Britain, Canada, and USA) the average prevalence rate of 18%[iii] is much higher than the world average.

- The difference between these two average prevalence rates, representing more than 10% of the population of developing countries, is a strong indicator that the number 'missing people' is very significant.

> ***One estimate[iv] shows a mortality rate of 80% for disabled children under five where the overall mortality rate for children under five is below 20%.***

- This means that in the Asian and Pacific region there were more than 400 million people who have either not survived or not been counted because handicap has not been mediated.

- The fact of 'missing people' can also be corroborated by comparing prevailing rates of occurrence of preventable impairments with prevalence rates of disability. In developing countries the rate of occurrence of preventable impairments is much higher than in developed countries while, as is noted above, the prevalence rates of disability (survivors) is much lower.

2.3 Poverty

- Poverty is the primary cause of the 'missing people' phenomena that is so prevalent in the Asian and Pacific Region. Poverty that is the direct result of gross inequity in the sharing or the world's resources at all levels; locally, regionally, nationally and internationally.

- The impact of poverty in terms of handicap is that:

  - In poorer regions and countries inequity in resource sharing results in a markedly increased risk of: conflicts, poor nutrition, inadequate health and rehabilitation services, poor or non-existent education, bad communication and transportation facilities, increased levels of hard physical labor, high personal and familial stress levels, increased risk of exposure to natural disasters, increased risk of exposure to environmental disasters, etc.

> ***DFID[v] estimate that more than 50% of the impairments that result in people being included in current disability prevalence rates "are preventable and directly linked to poverty."***

- The above noted increased risks, in their turn, will result in an increased prevalence of impairments and disability that lead to the premature death of so many people.

- Including the phenomena of the 'missing people' in our agenda makes mediation of poverty an even more urgent concern for all of us.

2.4 The Indirect Impact of Disability

- Other people, especially family members, are also indirectly affected by disability.

> ***A study[vi] in India indicates that for every person directly affected by disability, an additional 4 to 5 people are affected indirectly.***

2.5 Rehabilitation Service Shortages as a Cause of Disability

- Lack of adequate rehabilitation services not only affects the lives of people with disabilities, it also directly affects others who have a temporary impairment as a result.

- People who have received impairments need rehabilitation services to prevent disability. When rehabilitation services are not available for people who have temporary impairments, there is a strong probability that their impairments will result in permanent disabilities—disabilities that could have been prevented.

> ***An estimate from Nepal indicates that more than 30% of the permanent impairments that result from trauma could have been prevented if adequate rehabilitation services were available[vii].***

2.6 The 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 people with impairments and disabilities not surviving as is noted in the following sequence of events:

  - People who have become disabled are at increased risk of not surviving which results in a relatively low disability prevalence rate.

  - Low disability prevalence rates decreases funding priorities for handicap and disability related activities. Prioritization of funding is also a result of poverty.

  - Barriers to inclusion also affect funding priorities.

  - Low funding priorities for disability related activities results in an increased risk of: people getting impairments; impairments causing disability; and, an increased probability that these people will not survive.

2.7 The Economic Cost of Handicap

FIGURE 2: MEDIATING HANDICAP -- COST BENEFIT FACTORS

COST FACTORS	BENEFIT FACTORS
❑ Cost of minimizing the risk of receiving impairments.	❑ Value of increased production by people with disabilities.
❑ Cost of providing assistance for people who have received impairments.	❑ Value of increased production by families and caregivers.
❑ Cost of providing assistance to people with disabilities.	❑ Value of production by people whose impairments do not become permanent
❑ Cost of eliminating barriers to assistance and inclusion.	❑ Social benefits of improving the quality of life of people with disabilities.
	❑ Social benefits of preventing needless, premature deaths.
	❑ Social benefits of improving the quality of life of family members.

- Estimates of costs and benefits associated with the 'missing people' should also be included in these calculations.
- While it is not possible, at this time, to make a reasonable estimate of the economic cost of handicap, it is reasonable to state that:
  - The economic costs are very significant given the numbers of people affected by handicap.
  - The benefits, as shown above, may well exceed the costs, or at the very least, provide a significant balance to these costs.

3.0 CHANGING THE HANDICAP PROCESS IN THE ASIAN AND PACIFIC REGION

3.1 Activity components

- Handicap, by definition in section 1.0 above, is the direct result of decisions made and actions done by people in their roles as either: 1) family members; or, 2) members of organizations.
- Changing the decisions and actions of people requires creating new knowledge through the simultaneous implementation of activities in each of the following four components:

1. **Social communication:** Provision of knowledge for all family members about: 1) peoples roles in creating the life circumstances of others; 2) causes of impairment;

and, 3) ways to minimize the functional difficulties and maximize the personal development of people who receive impairments.

2. **Inclusion:** Provision of experience of knowing and working with people with disabilities for all community members by creating opportunities for both groups to participate equally in routine activities. These shared activities improve the lives of people with disabilities and demonstrate to others that disability does not mean changing into someone other than a person with the same needs as everyone else. They humanize everyone and make each person aware of their relevance to the others.

3. **Rehabilitation:** Making the experience gained from inclusion more effective requires simultaneous implementation of rehabilitation for people with disabilities so they can more effectively demonstrate that they are people with much the same needs as everyone else.

4. **Management:** An organizational function needed to make sure that the previous three activities are implemented simultaneously in each geographical area and that these activities are relevant, efficient and effective.

3.2 Levels of activity

- The different roles that people have as 1) members of families and 2) members of organizations are influenced and governed by different types of information. In families the primary influence on roles is what people have learned. In organizations peoples' roles are influenced by: 1) what people have learned outside the organization; and, 2) by formal and informal organizational policy. Therefore, changing peoples' roles to mediate handicap requires different activities at three levels:

  1. **Primary level:** The micro-level, family situations, where people live out their lives. It is important to note that everyone is part of the primary level.

  2. **Secondary level:** The first macro-level where people, as members of organizations, affect the life circumstances of others by the way they provide direct governance, services and goods to people living in the primary level.

  3. **Tertiary level:** The second macro-level where people, as members of organizations, provide indirect governance, services and goods to people living at the primary level. Normally it is the organizations at the secondary level that are the targets of the decisions and actions made by tertiary level organizations.

- Changing the roles of people in their families and in the organizations where they work requires the implementation of activities with specific objectives for each of the components at each level. The overall objectives, for each of the above noted four components at each of the three levels, are shown below in Figure 3 on page 7.

4.0 ANALYSIS OF THE ESCAP TARGETS FOR THE ASIAN AND PACIFIC DECADE OF DISABLED PERSONS

- The emphasis, in terms of the above four components and three levels, in the ESCAP Targets is graphically shown below in Figure 3 on page 7.

- The title of resolution E/ESCAP/1176 dated 7 March, 2000, "Equalization of opportunities: Inclusion of disabled persons in the development process" lists the targets that were analyzed.

- An analysis of the clusters of targets indicates that:
  - The targets cover extensive areas of work that needs to be done to meet the overall objective of the Decade—equalization of opportunities for people with disabilities.
  - In terms of components, the greatest emphasis is on inclusion that focuses national coordination, education and training and employment.
  - In terms of components, the second greatest emphasis is on management that focuses on coordination and monitoring.
  - In terms of components, there is a very uneven distribution of targets among equally important areas of activities.
  - In terms of levels, the greatest emphasis has been placed on tertiary level activities, policy, legislation and coordination.
  - In terms of levels, the least number of targets are directly associated with creating change at the primary level.
  - In terms of levels, the few secondary level targets will not adequately guide the organizations that will implement mediation activities.
- The analysis of targets did not include a close review of contents and the relevance of the targets to achieving specific objectives. However, the cursory review conducted for the development of this paper indicated that:
  - Several targets overlap each other in terms of content and objectives.
  - Most of the targets do not include any practical reference to activities that will meet these targets.
  - There is no prioritization of targets or schedule of activities that will meet these targets.
  - The majority of targets are associated with inclusion, however, there are no targets or strategies associated with ways of making inclusion happen.
  - Within most of the targets there is no specific separation between information to change peoples' decisions and actions as opposed to information to change organizational decisions and actions.

FIGURE 3: THE TARGETS FOR THE ASIAN AND PACIFIC DECADE OF DISABLED PERSONS IN AN ACTIVITYOBJECTIVE MATRIX

COMPONENT	OBJECTIVES AND ESCAP TARGETS		
	PRIMARY LEVEL	SECONDARY LEVEL	TERTIARY LEVEL
1. SOCIAL COMMUNICATION	Objective: Creating knowledge in families that will mediate handicap. ESCAP Targets: **4.1; 4.4; 6.4; 8.1; 8.3; 8.7; 8.10;**	Objective: Transmitting knowledge to people in families and organizations. ESCAP Targets: **8.7; 8.10; 9.5;**	Objective: Developing capacity for knowledge transmission at all levels. ESCAP Targets: **1.8; 2.7; 3.3; 4.3; 4.5; 6.4; 8.1; 8.2; 8.3; 8.4; 8.5; 8.6; 8.7; 8.10; 9.5;**
2. INCLUSION	Objective: Sharing experience through joint activities in the family and community. ESCAP Targets: **6.11;**	Objective: Including and accepting people with disabilities in all organizational activities. ESCAP Targets: **4.2; 4.7; 6.1; 6.2; 6.3; 6.5; 6.10; 6.14; 7.1; 7.2; 7.6; 7.7; 7.9; 9.3; 9.5;**	Objective: Developing capacity for inclusion of people with disabilities at all levels. ESCAP Targets: **1.5; 1.6; 2.1; 2.2; 2.3; 2.4; 2.9; 2.11; 4.7; 4.8; 5.1; 5.2; 5.3; 5.4; 5.5; 5.7; 5.9; 6.1; 6.2; 6.3; 6.5; 6.6; 6.7; 6.8; 6.9; 6.12; 6.13; 6.14; 6.15; 7.1; 7.2; 7.3; 7.5; 7.8; 7.10; 7.11; 7.12; 9.3; 9.5; 9.9;**
3. REHABILITATION	Objective: Making sure that all people with impairments receive rehabilitation assistance. ESCAP Targets:**8.8; 8.11;**	Objective: Providing primary rehabilitation and referral services to all people with impairments. ESCAP Targets: **8.8; 8.9; 8.11; 9.5; 9.6;**	Objective: Developing capacity for rehabilitation services at all levels. ESCAP Targets: **2.5; 2.6; 2.8; 5.8; 5.10; 5.11; 8.8; 8.11; 9.5; 9.6; 10.1; 10.2; 10.3; 10.4; 10.5; 10.6; 10.7;**
4. MANAGEMENT	Objective: Participating in system design, monitoring and management. ESCAP Targets: **7.13; 9.1; 11.6**	Objective: Developing capacity to manage, coordinate and monitor activities to meet the communities' needs. ESCAP Targets: **1.3; 1.11; 7.13; 9.1; 11.2;**	Objective: Developing capacity to manage, coordinate and monitor activities to meet the communities' needs at all levels. ESCAP Targets: **1.1; 1.2; 1.4; 1.7; 1.9; 1.10; 1.11; 2.5; 2.10; 3.1; 3.2; 4.6; 5.6; 7.4; 7.13; 7.14; 9.1; 9.2; 9.4; 9.7; 9.8; 11.1; 11.2; 11.3; 11.4; 11.5; 11.6; 12.0**

Note: The first part of each of the numbers for the ESCAP Targets is the number of the following sector from the Agenda for Action.
Agenda for Action Sections: **1.** National coordination; **2.** Legislation; **3.** Information; **4.** Public Awareness; **5.** Accessibility and communication; **6.** Education; **7.** Training and employment; **8.** Prevention of causes of disability; **9.** Rehabilitation (community-based rehabilitation; health and social development); **10.** Assistive devices; **11.** Self-help organizations; **12.** Regional cooperation.

5.0 SUMMARY

- An adapted terminology is needed for mediating handicap in a development context. This adapted terminology needs to be understandable by the broad range of people (community members, development workers, government officials, and rehabilitation and medical professionals) necessary to effectively mediate handicap.

- The hidden dimensions of handicap make activities to mediate handicap even more imperative than was previously thought.

  - **'Missing people':** more than 10% of the population of developing countries.

  - **Poverty:** The inequitable sharing of resources in today's world is one of the major causes of handicap.

  - **Indirect impact of disability:** every occurrence of impairment and disability indirectly affects 4 to 5 other people.

  - **Lack of rehabilitation services:** creates disability: More than 30% of impairments that result from accidents can cause disability when there are no rehabilitation services available.

  - **Impairment risk spiral:** increased probability, for each person in a developing country, of either becoming disabled and/or of dying prematurely.

  - **Economic cost of handicap:** in a cost/benefit analysis, costs of mediating handicap will probably balance the total benefits.

- These hidden dimensions of handicap demonstrate the real, overwhelming and continuous presence of the results of handicap in the developing world. It is this presence that creates much of the negative attitudes that effect peoples' decisions and actions that in turn, cause even more handicap.

- Effective and efficient mediation of handicap requires implementation of activities within the following matrix of components and levels.

Component	Level		
	Primary	Secondary	Tertiary
Social Communication			
Inclusion			
Rehabilitation			
Management			

- To be effective, the activities implemented within this framework must include people with disabilities as doers, not only as beneficiaries.

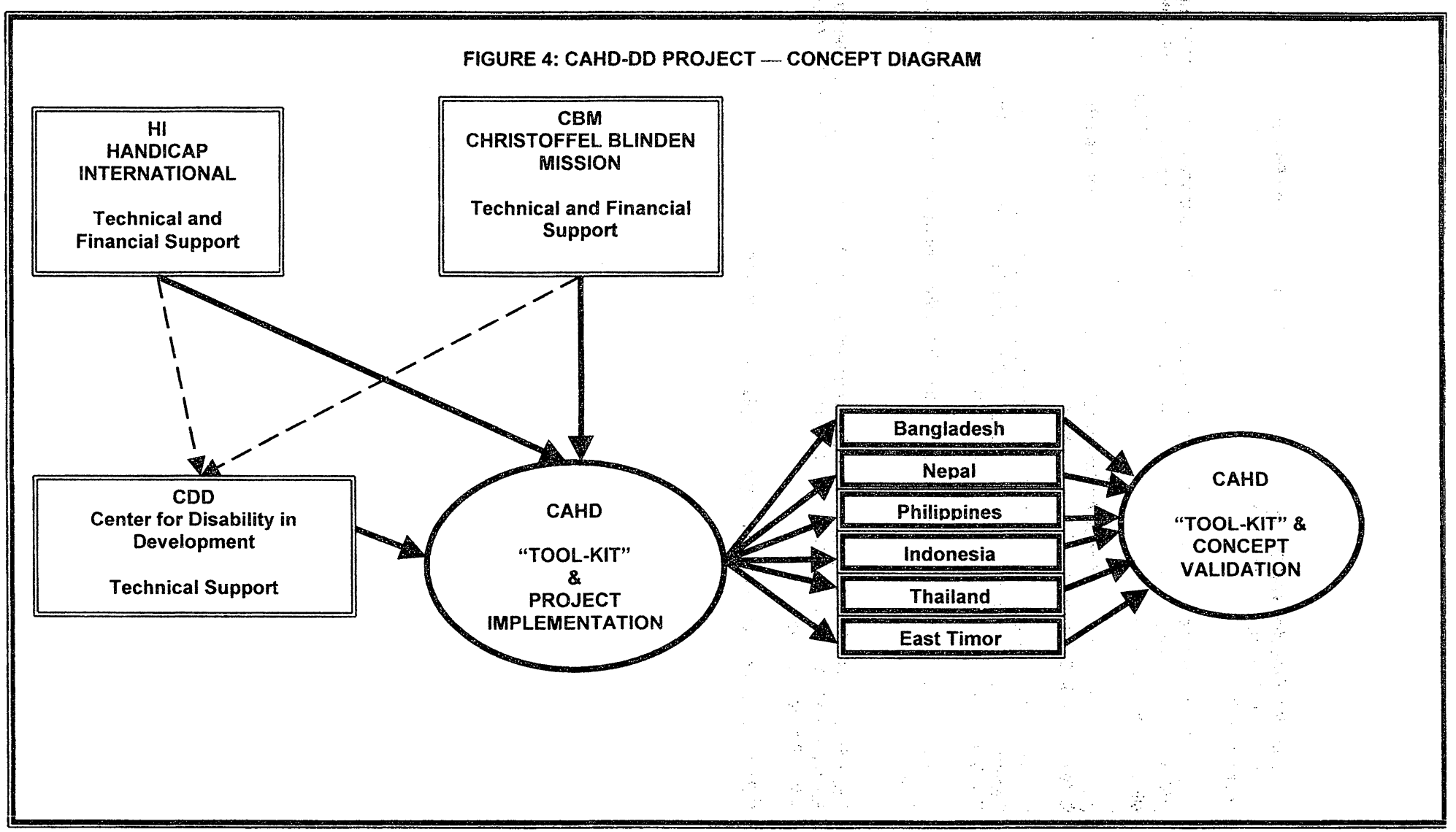
- The review of the ESCAP Targets for the Asian and Pacific Decade of Disabled persons was done utilizing the above matrix designed to guide the development of effective and efficient action to mediate handicap in the Asian and Pacific Region.

- Within this framework the targets spell out many necessary objectives, however, they do not provide a strategic approach for implementing activities to achieve the objectives.

- The framework used and described in this document has been derived from current work being done by Handicap International, Christoffel Blinden Mission, and the Center for

Disability in Development. These three organizations are currently working together to prepare the back ground material, the "Tool Kit," necessary to implement an international project to further develop and test a strategy for implementing activities to mediate handicap. The overall concept for the Community Approaches to Handicap in Development (CAHD) Development and Dissemination Project is illustrated in Figure 4 on page 11.

FIGURE 4: CAHD-DD PROJECT — CONCEPT DIAGRAM



[i] See

[ii] 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.

[iii] 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.cihi.ca; www.gov.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

[iv] B. Hariss-White, Presentation tot he 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.

[v] Department for International Development (DFID), *Disability, poverty and development*, February 2000.

[vi] S. Erb and B. Harris-White; paper to the Development Studies Association Annual Conference, 13 September 1999, University of bath, *Adult Disability, poverty and Downward Mobility: The Macro and Micro Picture from India.*

[vii] Personal communication from a physiotherapist working in Nepal.