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# Poverty and Disability: A Survey of the Literature

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# **POVERTY AND DISABILITY**

## **A SURVEY OF THE LITERATURE**

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## **ABSTRACT**

This review summarizes the literature on disability and its relationship to poverty, including education, employment, income, and access to basic social services. Despite the dearth of formal analysis, it is clear that in developing countries, as in more developed areas, disabled people (and their families) are more likely than the rest of the population to live in poverty. It is a two-way relationship -- disability adds to the risk of poverty, and conditions of poverty increase the risk of disability. Disability in developing countries stems largely from preventable impairments associated with communicable, maternal and perinatal disease and injuries, and prevention has to remain a primary focus. An increasing emphasis on community based participatory rehabilitation reflects growing recognition of the inadequacy of past official programs, particularly involving specialized and exclusionary institutions.



# POVERTY AND DISABILITY

EXECUTIVE SUMMARY .....	iii
POVERTY AND DISABILITY.....	1
I. Introduction .....	1
II. Definitions and Concepts .....	2
III. The Prevalence and Structure of Disability.....	5
IV. Education, Employment, Income and Poverty .....	10
Education.....	11
Labor Force Participation.....	12
Income.....	14
Poverty .....	15
V. Causes of Disability.....	16
Causes of disability in children.....	17
Mental conditions.....	18
Conflict and Disability.....	19
VI. The Path from Poverty to Disability.....	21
The Poor and Poor Health .....	21
The poor and their work environment .....	23
VII. The Path from Disability to Poverty .....	24
Costs of disability .....	24
Barriers .....	27
The Elderly .....	28
Gender.....	28
VIII. Policies for Disabled People.....	31
IX Conclusions .....	33
Indications for Further Work.....	36
BIBLIOGRAPHY .....	37





# POVERTY AND DISABILITY

## EXECUTIVE SUMMARY

i. Although linkages between poverty and disability are often noted, they have not been systematically examined. This review summarizes the literature on disability and its relationship to poverty, including education, employment, income, and access to basic social services. In developed countries there has been a focus on the impact of disability on educational achievement and income, and on the adequacy and equity of government programs, with a current emphasis on removing barriers and increasing the participation of disabled people. Because information about disability in developing countries is very limited, the literature tends to focus on what is generally known about health, disabilities, poverty and vulnerable populations, and relies heavily on anecdotal evidence and case studies.

ii. *Disability* is a relative term (restriction of the ability to perform a normal human activity), and its measurement is beset with problems, including the lack of reliability and validity of the instruments, most of which are poorly standardized and produce non-comparable estimates. The global prevalence of disability has been estimated only in broad orders of magnitude, and national estimates vary considerably, and are generally not comparable. Estimated disability rates tend to be higher in developed than in developing countries: possible contributory factors include differences in definition and in the way information is collected, as well as the higher age structure in developed countries, and a greater capacity to diagnose some conditions.

iii. In general, rural disability rates appear to be higher than urban rates. Disability rates for women seem to be higher than those for men in developed countries, and lower in developing countries. Lower female rates may indicate that severe impairments may be male-dominated, and/or females with disabilities may be under-reported or may receive less care and die sooner. For the childbearing age groups, female rates tend to be slightly higher, possibly because of ill-health resulting from too many pregnancies, inadequate health and medical care, and poor nutrition

iv. Disabled people have lower education and income levels than the rest of the population. They are more likely to have incomes below poverty level, and less likely to have savings and other assets than the non-disabled population. These findings hold for both developing and developed countries. In developed countries, official programs do not appear to result in incomes for the disabled commensurate with non-disabled peers; even with substantial transfer and employment programs, the disabled still face a higher risk of poverty. Analysis of case studies in some developing countries shows that higher disability rates are associated with higher illiteracy, poor nutritional status, lower inoculation and immunization coverage, lower birth weight, higher unemployment and underemployment rates, and lower occupational mobility.

v. There is relatively little information about the prevalence, incidence or epidemiology of disabling disease in developing countries. It is clear, however, that the proportion of disability caused by communicable, maternal and perinatal diseases and injuries and the proportion of childhood disability are higher than in developed countries. Much of the disability in developing countries stems from preventable impairments, and a large part of the disability could be eliminated through treatment or alleviated through rehabilitation. Nutrition is particularly important, but much of the knowledge on the various forms of malnutrition and their effects on health and intellectual development and disability is recently acquired. Epidemiological classifications do not seem to adequately capture some of the more recently recognized phenomena, such as mild mental retardation thought to be a result of under-stimulation of children in disadvantaged societies. However, detailed estimates of mental handicap, including mental retardation, vary widely, and often vary within the same country.

vi. Accidents and conflict are also an important cause of disability, especially in developing countries. During conflicts, civilians as well as soldiers are at risk from active hostilities, as well as from unexploded ordnance and land mines, and violent excesses. Those who are already disabled, or become disabled during a conflict, are particularly vulnerable to deteriorating health under the severe conditions caused by war. Health care and social assistance systems break down, and some normally treatable conditions can become disabling. Much of the psychological disability brought on by conflict-related trauma often remains undiagnosed and unrecorded.

vii. Correlations between disability and age, education, income, ethnicity, living arrangements and gender cannot determine causality – not only does disability add to the risk of poverty, but conditions of poverty add to the risk of disability. Poor households do not have adequate food, basic sanitation, and access to preventive health care. They live in lower quality housing, and work in more dangerous occupations. Malnutrition can cause disability as well as increase susceptibility to other disabling diseases. Malnourished mothers have low-birth weight babies, who are more at risk of debilitating diseases than healthy babies. Lack of adequate and timely health care can exacerbate disease outcomes, and a remedial impairment can become a permanent disability. Disabled people have been estimated to make up 15 to 20 per cent of the poor in developing countries; and the disabled poor tend to be regarded in their own communities as the most disadvantaged. Parental (especially maternal) education, awareness and access to information, dietary and food preparation habits, and the general level and coverage of primary health care have been found to have a greater (preventive) effect than any specific intervention.

viii. In addition to the income-related factors, additional costs resulting from the disability; and marginalization or exclusion from services and/or social and community activities can also make disabled people or their families worse off. Additional costs include those for extra medical expenses, specialized equipment and services, etc, and costs incurred by care providers. Without income maintenance and other programs available in developed countries, the disabled in poor communities are usually the responsibility of their families; without family support, a disabled person's condition can be very precarious. Even in developed countries, families play a major role in preventing poverty among the elderly through shared living arrangements.

ix. Exclusion and marginalization reduce the opportunities for the disabled to contribute productively to the household and the community, and increase the risk of falling into poverty. Attitudinal barriers as well as physical barriers such as lack of adequate or appropriate transportation, physical inaccessibility, and lack of learning opportunities can affect access to education and employment opportunities, reducing the opportunities for income enhancement as well as social participation.

x. Certain groups within the disabled population are more vulnerable to the risk of poverty, including the elderly, those with mental handicaps, and women. In some communities, disabled girls receive less care and food, and have less access to health care and rehabilitation services and fewer education and employment opportunities. They also tend to have lower marriage prospects than disabled men, and can be at risk of being abused physically and mentally.

xi. Much of the literature on policies for the disabled in developed countries focuses on the adequacy of existing income support programs; whereas in many developing countries, income maintenance schemes, and even reserved employment schemes, have limited applicability where there is no effective labor market. Efforts have to remain focussed on prevention and rehabilitation in developing countries; and, particularly in lower income countries, disabled people have to rely to a large extent on informal systems for support. The detrimental effects of broadly applied institutionalization policies are recognized, and there is an emphasis on integrating the disabled into existing programs, appropriate technology, self-reliant schemes, and participatory approaches, including community based rehabilitation (CBR). Increased public effort is needed, particularly in strengthening prevention measures, i.e., promoting maternal and child health care, and primary health care, including immunization programs, but also in making information on prevention, treatment, and rehabilitation more widely available.

xii. Because little basic research appears to have been done on poverty and disability in developing countries, further investigation is indicated in several areas, including: search for additional data sources and existing analysis to allow more detailed examination of poverty-related factors, such as income, education, employment, access to services, etc., in developing countries; modeling of potential 'poverty paths' in populations that have a particular disability pattern, a special vulnerability, or are at particular risk of poverty; longer-term studies of income and other poverty indicators, using consistent data sets over at least two points of time, where changes in status can be observed; and a focussed study of gender, disability and poverty.

## POVERTY AND DISABILITY

“The combination of poverty and disability is a fearsome one. Either one may cause the other, and their presence in combination has a tremendous capacity to destroy the lives of people with impairments and to impose on their families burdens that are too crushing to bear.”<sup>1</sup>

“As a development indicator, the study of disablement provides a unique perspective on the long-term consequences to individuals and their families of functional loss from disease, accident, trauma and deprivation.”<sup>2</sup>

### I. Introduction

1.1 Poverty and disability seem to be inextricably linked. It is often noted that disabled people are poorer, as a group, than the general population, and that people living in poverty are more likely than others to be disabled. Well-being is associated with the ability to work and fulfill various roles in society.<sup>3</sup> But the links between poverty and disability do not appear to have been systematically examined, even in developed countries.<sup>4</sup>

1.2 In developed countries, a large part of the literature concerned with income-related aspects of disability has tended to focus on the quantitative impact of disability on educational achievement, earnings and income, and on the adequacy and equity of income maintenance schemes and other programs. The costs and benefits of rehabilitation and vocational employment schemes and employment discrimination have also been recurrent themes. Much of the current popular literature has to do with removing barriers of all kinds in order to increase the participation of disabled people in the employment market.

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<sup>1</sup> Acton, N., Secretary General, Rehabilitation International, in Shirley, 1983, p. 79.

<sup>2</sup> UN Disability Statistics Compendium, 1990, p 47.

<sup>3</sup> Consultations with the Poor (Brock, 1999), pp. 1, 29.

<sup>4</sup> From the preface to the papers from the conference “Disability, Exclusion & Poverty: A Policy Conference”, organized by the Combat Poverty Agency, the Forum of People with Disabilities and the National Rehabilitation Board, 1994.

1.3 On the other hand, knowledge about disability *per se* in developing countries is limited: figures are sketchy – and limited, by and large, to very divergent rough estimates based on census, survey, and registration information and on aggregated estimates of the epidemiology of specific conditions, and there is little information about linkages with the correlates of poverty. Statistics on the demographic structure and correlates of disability are available for relatively few countries, and, in general are insufficient for analyzing the underlying relationships, and do not allow cross-country comparisons. Moreover, there is little statistical information on the underlying health conditions and causes of disability. Although differences in concept and definition contribute to the variability of the prevalence estimates, the underlying problem is lack of information.

1.4 Given this dearth of knowledge on disability, the literature on poverty and disability in developing countries tends to be of a generalized nature, focussing on what is generally known about health, disabilities, poverty, and vulnerable populations. Much of it relies on anecdotal evidence and case studies. This review summarizes the literature on disability and its relationship to poverty, broadly defined, to include education, employment, income, and access to basic social services with a view to painting a picture as to what is known and not known, about this relationship.

## **II. Definitions and Concepts**

2.1 The World Health Organization (WHO) has recently released a new version of its International Classification of Functioning and Disability (the Beta-2 version of ICIDH-2) for testing and comment. The aim of the ICIDH-2 classification is to “provide a unified and standard language and framework for the description of human functioning and disability as an important component of health”.<sup>5</sup> The classification organizes information according to three dimensions: body level; individual level; and society level; and incorporates a list of environmental factors, since they have an impact on all three dimensions.<sup>6</sup>

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<sup>5</sup> WHO August 20, 1999.

<sup>6</sup> ICIDH-2 complements the International Classification of Diseases ICD-10 and now deals with functional states (mobility, social integration, etc.) associated with health conditions. ICIDH-2 focuses less than the previous version of ICIDH (International Classification of Impairments, Disabilities and Handicaps; WHO, 1980, pp. 27-29) on perceived deviations from an ideal human health condition and takes greater account of the environment within

2.2 This paper is only concerned with chronic or long-term functional limitations: many people have chronic impairments, some of which do not affect normal activities, and some, which when corrected, do not necessarily restrict normal activity.<sup>7</sup> Although it is beyond the scope of this paper to discuss the definitions in detail, it is important to note that definitional issues underlie some of the difficulties in statistical analysis, and to understand the conceptual questions shaping the efforts of those working in the various fields relating to disability. Disability is a relative term, relying on interpretation of ‘normal activity’. Norms vary; and impairments considered to be disabling in one environment may not be in another. For example, a range of mental and psychological conditions may be classified as disabling in some countries, but these conditions remain unrecognized in many others. The situation may be reversed for other types of impairments; female infertility for example, may be considered disabling in some cultures, but not necessarily in western cultures. A condition such as severe asthma may be disabling in an agrarian economy, but not in an office-based city economy, etc.<sup>8</sup>

2.3 Disability is also inherently difficult to observe; and requires subjective assessment by both the affected individual and verification by members of the individual’s social setting. The subjectivity of these judgements makes disability a behavioral phenomenon; and disability and related topics like disability insurance become political issues. There is thus a large risk of bias in disability statistics -- a recent study of disability insurance notes the large variation in the number of disability benefit recipients as a share of the labor force in several countries and posits that much, if not most, of this variation is linked to the incentives inherent in the various disability insurance programs.<sup>9</sup>

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which the individual is functioning. It makes reference and links to the UN Standard Rules for Equalisation of Opportunity for People with Disabilities. ICIDH-2 is issued for field trial purposes and is undergoing systematic testing. It is subject to further consultation. The final version is planned to be published in 2001.

<sup>7</sup> The question as to whether a “corrected impairment” constitutes a disability has been at the heart of debate within the US Supreme Court recently (see, e.g., “Justices Wrestling with the Definition of Disability: Is it Glasses? False Teeth?” in the New York Times, April 28, 1999, and “The Disabled: Anyone Not Included?” in the Economist, June 26, 1999).

<sup>8</sup> Harriss-White, 1996, p.3

<sup>9</sup> Leo Aarts et al. The rates for disability compensation recipients varied from 7 to 200 per thousand labor force participants in the twelve countries studied. The authors note that the inherent difficulties in assessing disability constitute a program design issue, as they give rise to problems of moral hazard and inefficient compensation schemes.

2.4 Other problems stem from the multiplicity of disability instruments, covering at least six main domains of functioning, i.e., activities of daily living (ADL), physical mobility, cognition, social roles, occupational abilities, and participation and effect of stigma; and for each of these, there may be several measurement scales. The lack of reliability and validity of these instruments and the fact that they are poorly standardized are problematic.<sup>10</sup>

2.5 The UN notes that disability rates from diverse national data collection sources are not yet comparable, given differences in survey design, definitions, concepts, and methods.<sup>11</sup> Regional comparisons can be very misleading if the methodological differences are not taken into account. The use of differing measurement instruments,<sup>12</sup> the older age structure, as well as the larger capacity to observe and diagnose various kinds of disabilities in developed countries, are likely factors in the higher rates of disability generally recorded in developed countries.

2.6 The International Year of the Disabled Person (1981) helped to publicize the plight of disabled people, “expanding awareness about disability’s being a widespread but largely preventable or remediable social problem and stressing that attitudinal barriers were among the most disabling factors”.<sup>13</sup> In the developed world, overcoming barriers, both physical and social, to the full participation of disabled people in economic and social life, is a major theme and much of the writing is concerned with advocacy. This new emphasis, combined with a recognition that the traditional concept of assistance for disabled people (physician- and institution- oriented; emphasis on specialized care, etc.) was neither feasible nor appropriate in the developing world, has led to an emphasis on participatory approaches to rehabilitation in developing countries, which is reflected in recent writings.

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<sup>10</sup> Communication from D. Peters of the World Bank.

<sup>11</sup> UN Disability Statistics Compendium, 1990, p 30. The UN points out that comparisons within national data sets can reveal reasonably consistent relationships between disability and other demographic and socio-economic variables; and that the quality of survey data on disability has been found to be of similar quality to other types of survey data, such as educational attainment or marital status.

<sup>12</sup> In addition to the type of measurement instrument used, estimates of the proportion of disabled people in a population can also vary depending on whether disabled people are identified using a ‘disability screen’ or an ‘impairment screen.’ African and Asian countries tend to use impairment screens in their censuses, surveys and registration systems and generally report lower rates than the countries of Europe and North America, which tend (with some exceptions) to use disability screens. *Ibid.*, p. 15.

<sup>13</sup> Miles, 1989b:3-4, cited in Harriss-White, 1996, p. 15.



### III. The Prevalence and Structure of Disability

3.1 Quantifying Disability. There are relatively few censuses, surveys, and registration sources of information on disability in developing countries, and conceptual and definitional problems abound. However, several attempts have been made to find out roughly how many people in the world are disabled, what the main causes of disability are, and how the disabilities encountered in different countries and regions affect quality of life.

3.2 The World Health Organization noted, in 1981, that it was impossible to accurately estimate the number of disabled people more accurately than at 10% of the total population,<sup>14</sup> and the WHO range of 7-10 percent has often been cited. A higher estimated figure is sometimes used when learning disabilities are included. A 1995 ESCAP paper, noting that the estimated prevalence figure has been the subject of much debate because of differing definitions and the different survey methodologies, concludes that global prevalence is probably lower than 10% estimate, and cites a 1992 UNDP estimate of moderately to extensively disabled people in developing countries of around five per cent of the population.<sup>15</sup>

3.3 In connection with the International Year of Disabled Persons (1981), data from 63 national censuses, surveys and registration systems in 55 countries were collected and stored in the United Nations Disability Statistics Data Base (DISTAT, Version 1). Analysis is presented in the UN's Disability Statistics Compendium, published in 1990<sup>16</sup>. The compendium statistics indicate that the percentage of disabled persons ranges from 0.2% to 20.9% of the population. However, the Compendium cautions that these figures include data from all types of definitions, age ranges, and data systems and cannot be used for comparison purposes.<sup>17</sup>

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<sup>14</sup> WHO, 1981, p. 10.

<sup>15</sup> Helander, UNDP, 1992 cited in ESCAP, 1995 (Helander also carried out the original estimation).

<sup>16</sup> UN, Disability Statistics Compendium, 1990. The data are stored in the United Nations Disability Statistics Data Base (DISTAT, Version 1).

<sup>17</sup> The UN Statistical Office notes that there is no agreed strategy for identifying disabled persons in any data collection method (censuses, surveys, and registration systems) in an acceptable and reasonably standardized fashion. (Compendium p.15). The Statistical Office consequently published a manual in 1996 describing some of the data issues and making some recommendations. (United Nations, Manual for the Development of Statistical Information for Disability Programmes and Policies, 1996). See also, the OECD Social Indicator Development Programme, Special Studies, No. 5, *Measuring Disability*, by John McWhinnie, 1982.

3.4 The DISTAT figures, in general, yielded higher total disability rates for the developed countries than for the developing countries, partly because of the way in which disabilities were identified and other definitional and methodological differences,<sup>18</sup> and also partly because of the older age structure in developed countries. Silberberg, in comparing figures from sub-Saharan Africa, notes that prevalence estimates range from 18% of people under 15 years in Ethiopia in 1979-80 (although this was not a nationwide survey), to low figures such as 3% in Malawi in a 1987 census, although several other countries fall within the often-cited WHO range of 10-15%. WHO, in a recent Child Health Dialogue focused on childhood disability in developing countries, noted that up to 5 per cent of children are either born with a disability or become disabled during their childhood.<sup>19</sup>

3.5 The Global Burden of Disease (GBD) Study produced estimates of disease and injury rates in 1990 and derived an indicator, the Disability Adjusted Life Years (DALYs) lost as a result of either premature death or years lived with a disability<sup>20 21</sup> -- based on opinions from selected experts about the relative disability resulting from various conditions. The GBD Study recognized that, whereas prevalence measures help to define the need for rehabilitation services, prevention requires detailed information on the underlying diseases and injuries that cause disabilities.<sup>22</sup> In 1990, DALYs lost as a result of disability, per 1,000 population, ranged from around 130 in sub-Saharan Africa to around 50 in the established market economies.<sup>23</sup>

3.6 Notwithstanding the use of the ICIDH and the International Classification of Diseases underlying these efforts, it has proved extremely difficult to standardize information on disability.<sup>24</sup> Some categories are particularly problematic, for example learning disabilities and

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<sup>18</sup> UN Compendium, p.15. An illustration of the difference made by improved identification of the disabled population can be seen in the prevalence rate estimated from the 1981 census in Pakistan (0.45%) and that estimated from the 1984-85 survey of disabled persons (4.9%) (Afzal, p. 224).

<sup>19</sup> Wirz and Campbell in "Child Health and Disability" newsletter, dialog 7 on WHO website.

<sup>20</sup> Murray and Lopez, (foreword). For a description of how DALYs are calculated, see the World Development Report, 1993, p. 26.

<sup>21</sup> The DALY indicator is not without critics; see, for example, Metts et al, 1998, noting problems with the definition of disability and with the methodology for estimating the relative severity of disabilities.

<sup>22</sup> Murray and Lopez, 1994, p. 61.

<sup>23</sup> Updated estimates of DALYs for 1998 are available through WHO's website; however, they do not include DALYs lost as a result of disabilities separately.

<sup>24</sup> For a discussion of some of the issues, see Yu, 1991; also for a discussion of the use of ICD rather than ICIDH in the GBD study, see Murray and Lopez, 1994, p. 74. Note also that ICIDH has been revised. ICIDH-2 "attempts to

behavioral problems.<sup>25</sup> These can be important categories, depending on the study and types of conditions. The 1988 National Health Interview Survey (NHIS) in the United States found that among children aged 3 to 17, an estimated 6.5% had learning disabilities, and 13.4% had emotional or behavioral problems lasting three months or more or requiring psychological treatment.<sup>26</sup> The variation in some of these classifications can be large, even within the same country. Peters points out, for example, that the percentage of disabled students classified as having some degree of learning disability ranged from 30 to 67 per cent in the various US states, and from 0 to 73 per cent in large cities. Learning disability is not recognized as a category in several countries (e.g. Japan).<sup>27</sup>

**3.7 Age Structure.** The age-structure of disabled persons is predominantly elderly, while that of the total population is predominantly young or middle-aged. However, disability affects all ages to a greater degree in developing countries. Age specific disability rates increase with age, and the severity of disablement also increases with age. In the oldest age groups, disablement rates can be very high: for example, about 39% by age 65 in Canada, and about 22% by the same age in the Philippines.<sup>28</sup> The proportion of disabled people has been estimated to reach 80% in people over 85 years old.<sup>29</sup>

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provide a synthesis that offers a coherent view of different dimensions of health at both biological and social levels," i.e., to incorporate concepts from both the "medical model" and the "social model" of disablement. Information on ICDIH-2 is available on the WHO website.

<sup>25</sup> A discussion of the definitional issues surrounding various kinds of mental disability is beyond the scope of this paper; however, it should be noted that official definitions affect not only the statistics, but also country policies, and therefore the entitlements of the disabled themselves. Harriss-White (1996, p. 16) notes, for example, that the Indian Mental Health act of 1975 distinguished between mental illness and mental retardation, releasing the mentally retarded from the protection of the State.

<sup>26</sup> Ficke, p. 24. The report notes that disability status among children varies considerably depending on the particular study and the types of conditions involved. The 1988 NHIS, in addition to data on activity limitation, measured child health in terms of delays in growth or development (4% of children under 17); as well as learning disabilities and emotional and behavioral problems.

<sup>27</sup> Peters, p. 5. This reference is a collection of papers on disabled children and education, with reference to the U.S., England and Wales, Hungary, Iran, Japan, Pakistan, and China. Emphasis is on disability as socially constructed; the editor outlines challenges in enhancing educational opportunities for people with disabilities.

<sup>28</sup> From tables on pp. 85 and 103 in the UN Compendium. *Note: these figures are given only in order to illustrate orders of magnitude of disability in older age groups; in order for them to allow comparisons between countries, the definitions and methodologies would need to be reviewed in detail.* In other words, disability in the elderly in Canada may not be about twice as high as it is in the Philippines, unless it is clear that the same conditions are considered as disabilities and the data collection methods are similar, etc.

<sup>29</sup> For example, Canada and the UK, and possibly other countries.

3.8 The proportion of disabled children in developing countries is generally higher than in developed countries. DISTAT figures from *census* sources indicated the proportion of disabled people under 15 years of age in developing countries to be in the range of 10 to 25%, or more; whereas proportions in Canada and Austria were about 11 and 4 percent, respectively. Where estimates were from *survey* data, the proportions in the developing countries were even higher.<sup>30</sup> Disability DALY rates for children in India and sub-Saharan Africa were four to six times higher than those for the established market economies.<sup>31</sup> It is estimated that six to ten percent of children in India are born disabled, and that, because of low life expectancy, possibly a third of the total disabled population are children.<sup>32 33</sup> Silberberg cites findings from Malawi that 46% of disabilities occur before age 5, and from Zimbabwe, where 41% of disabilities occur in the first four years of life.<sup>34</sup>

3.9 **Geographic Differentials.** It has been argued that the prevalence of disability is likely to be higher in urban than in rural areas because of greater risk of injury from accidents, the pull factor of services, institutions and medical care, the existence of sedentary jobs and the possibility of begging.<sup>35</sup> However, the UN Compendium notes that higher disability rates tend to be found among rural residents, with a ratio of rural/urban disability generally less than 2. Urban/rural differences tend to remain when age and sex are taken into account.<sup>36</sup> In India, research attributes high concentrations of disabilities to environmental factors such as lack of iodine, disease factors (poliomyelitis, leprosy, etc.), and social and economic factors (food insecurity, poverty, etc.).<sup>37</sup>

3.10 **Marital status and living arrangements.** Data from a 1990 survey in the United States showed that the proportion of families with a member with a disability was 29.2%, when

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<sup>30</sup> from the Compendium data, pp. 33 and 35. NB: For reasons discussed earlier in the review, these proportions are not strictly comparable, and are given for illustrative purposes only.

<sup>31</sup> Murray and Lopez, 1994, p. 86.

<sup>32</sup> ActionAid Disability News, 2(2), cited in Harriss-White, p.4.

<sup>33</sup> although a recent survey in India found a very high proportion of households with a disabled individual, but hardly any disabled children; it is hypothesized that these children may disproportionately die as a result of neglect.

<sup>34</sup> Silberberg, 1998, p.7, citing figures from the 1987 Survey of Handicapped Persons, from the National Statistical Office of Malawi; and from a report by the Zimbabwe Ministry of Labour and Social Services and UNICEF on the 1981 National Disability Survey.

<sup>35</sup> Coleridge, cited in Harriss-White and Subramanian, 1999, p.142

<sup>36</sup> UN Compendium 1990, p.43

the proportion of individuals with a disability was 13.7%. Individuals living alone were more likely to be limited in activity (27% of those living alone) than those living with others (12.2%). A large part, but not all, of this difference was accounted for by age -- the average age of people living alone was 53 years, compared to 32.5 for those living with others. Adults living with a partner have the lowest rates of activity limitation in all age intervals, regardless of the severity of disability.<sup>38</sup> Swedish data from 1980 also showed that single disabled persons in every stage of the family cycle indicated higher rates of mobility limitation, as well as generally higher rates of work capacity limitation than those who lived with other people.

**3.11 Gender Differentials.** In general, where there was a gender difference, survey results in the Compendium yielded higher disability rates for women than men in developed countries, and lower rates for women in developing countries. The UN noted that differences in the percentage of males and females classified as disabled were partly determined by the type of screening used in the survey, with male:female sex ratios higher when impairment screens were used. Possible conclusions drawn in the Compendium were that severe impairments may be male-dominated, or additional survey probes are needed when surveying women using impairment screens.<sup>39</sup> Disability DALY rates for children were slightly higher for males than for females. At ages 15-59, rates for females were on the whole, slightly higher than for males in developing countries; and at ages over 60, the rates for males tended to be higher than for females.

**3.12 Individual survey results vary greatly.** Estimates from India and Pakistan indicate male disability rates to be higher than female rates.<sup>40</sup> A 1995 study posits that the lower overall number of women than men with disabilities, despite women's usually longer life span, could indicate that girls and women with disabilities receive less care and support, and die earlier. Another possibility is that the gender division of labor is such that disabled women contributing to household activity are not identified as disabled, whereas the visibility of disabled men is greater. The study cites a 1989 ILO study of six Asian and Pacific countries showing a higher

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<sup>37</sup> Harriss-White and Subramanian, 1999, p. 142.

<sup>38</sup> LaPlante, M.P., et al, 1996, p. 1

<sup>39</sup> UN Compendium, p. 30. It should be noted, however, that these conclusions were drawn from surveys in the late 1970s and early 1980s, in 12 countries, only five of which were developing countries.<sup>39</sup>

incidence of disability among women aged 15 to 44 than in the same age group for men, despite the fact that, overall, there are more disabled men than women. It is suggested that this could be explained by the fact that women in this age group suffer more from ill-health as a consequence of too many pregnancies, inadequate health and medical care, and poor nutrition.<sup>41</sup>

3.13 Abu-Habib cites studies from Yemen and Egypt showing a higher prevalence of disability amongst boys, which researchers attribute to a concurrently higher mortality among disabled girls.<sup>42</sup> However, Khan and Durkin, citing results from Bangladesh, report a higher prevalence of disability in girls aged two to nine years than in boys of the same age, and attribute it to the priority given to the male child in Bangladeshi cultures.<sup>43</sup> Based on the sources reviewed, it appears that further analysis is needed before definitive statements can be made regarding gender differentials in any particular developing country or region.

#### **IV. Education, Employment, Income and Poverty**

4.1 A great deal of detailed research has been carried out on the income and welfare effects of disability in developed countries that cannot be reviewed here. Findings of general relationships are presented for illustrative purposes. Even these broad relationships have not been examined for most developing countries. As Neufeldt points out, in developing countries, even where records are kept, their reliability and validity is open to question, particularly in view of the fact that much of the economic activity takes place in the informal sector. He also points out that only four of the 16 countries in the Compendium which provided information on the employment characteristics of disabled persons could be classified as low-income countries, and none of these allowed a comparison between the experience of disabled populations and non-disabled populations.<sup>44</sup>

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<sup>40</sup> Afzal, p. 233 for Pakistan; Harriss-White, p. 4 (citing Dyson, 1992) for India.

<sup>41</sup> Harriss-White, 1996(a), p.1.

<sup>42</sup> unpublished paper entitled "Women with Disability in Egypt", by Dr. A. Ghanem, University of Sanaa', 1993, presented to the seminar on "The roles of the family in integrating disabled women into society" in Amman, 1994; cited in Abu-Habib, 1997, p.2.

<sup>43</sup> Khan and Durkin, p.5.

<sup>44</sup> Neufeldt and Albright, p.11.

4.2 The US Bureau of the Census determined that the factors with the strongest association with disability were age, education, income, race and ethnicity, living arrangements, and gender. Researchers caution, however, that causality often cannot be determined -- while disability can certainly cause poverty, and the reverse may be true as well, the extent of each scenario is not known.<sup>45</sup>

4.3 The UN Compendium, in reference to the internal consistency of survey results, notes that a large proportion of surveys indicate that disabled people are, on the average, less educated, and have lower socioeconomic status and reside in rural or poor areas than do non-disabled persons. Analysis of case studies shows that higher disability rates are associated with higher illiteracy, poor nutritional status, lower inoculation and immunization coverage, lower birth weight, higher unemployment rates, and lower occupational mobility. It goes as far as to say that "in many respects, the disability rate is a socioeconomic indicator, a type of poverty index, or index of development.... It is unique in that it estimates the quality of life of survivorship, or of persons who escape mortality and continue living with significant modifications of function".<sup>46</sup>

4.4 In the rest of this section, illustrative findings are presented, primarily for the developed countries, about relationships between disability and education, labor force participation, income, and poverty.

## **Education**

4.5 On average, disabled people receive less education and are likely to leave school with fewer qualifications than others.<sup>47</sup> Several examples of the striking differences in school attendance and literacy between the general and the disabled populations are available from the UN Compendium text and tables, including:

- Hong Kong: according to the 1981 census, fewer than 4 per cent of the population of people aged 15-24 had never attended school, compared to over 25% of disabled people in the same age group;

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<sup>45</sup> Ficke, p. 13, referring to the Census Bureau, 1986; and to Bennefield and McNeil.

<sup>46</sup> UN Compendium 1990, pp.32, 47.

<sup>47</sup> Neufeldt, p. 12, citing Barnes, 1991, and Neufeldt and Mathieson, 1995.

- Canada: the 1983-84 survey showed that about 6% of the total population aged 15-24 had attended only eight years of schooling or less, while the proportion in the disabled group was 17%; and
- Bahrain: 27% of all persons aged ten and over recorded in the 1981 census were illiterate, but in the same age group of the disabled population, the proportion was 77%.<sup>48</sup>

4.6 US data from the 1989 NHIS survey show that persons without a high school diploma were almost two and a half times more likely to have a functional limitation, and almost four times as likely to have a severe limitation as high school graduates.<sup>49</sup> Neufeldt points out, however, that differences in education level may not completely explain the differences in labor force participation. When data from the UK, Canada, and Hong Kong were analyzed, it was found that fewer than 17% of disabled people with Grade 9 equivalent had a job, compared to 55% for non-disabled persons; while disabled persons with university degrees had an employment ratio of 50%, compared to 87% for all university graduates.<sup>50</sup>

### **Labor Force Participation**

4.7 The International Labor Office pointed out that the unemployment rate for disabled people in industrialized countries has been twice or even three times that of non-disabled people.<sup>51</sup> Statistics showing this disparity include, for example:

- Australia: a 1981 survey shows the proportion of disabled people not in the labor force was around 60%, twice as high as the proportion for the total population (30%).<sup>52</sup> In 1993, 46.5% of the disabled population participated in the labor force, compared with 73.6% for the general population.<sup>53 54</sup>
- Canada: in a 1983/84 survey, only 41% of the disabled population aged 15-64 was employed, compared to 65% of the total population in the same age range.<sup>55</sup> In 1991,

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<sup>48</sup> This information comes from Table 6 of the Compendium, where data on educational characteristics of disabled persons are presented for several countries, but only a few present comparables for the total population.

<sup>49</sup> Ficke, 1991, p. 18.

<sup>50</sup> Ibid, p. 12.

<sup>51</sup> ILO, 1984, p. vi.

<sup>52</sup> UN Compendium, 1990, Table 7.

<sup>53</sup> Neufeldt, 1998, p. 173, citing Australian Bureau of Statistics, 1993.

<sup>54</sup> Note, figures given for illustration of orders of magnitude only; without further review, the 1981 and 1993 figures should not be compared).

<sup>55</sup> Table 7 of the Compendium; again only a few tables present comparables for the total population.



44% of disabled people were not in the labor force, compared to 19% of non-disabled people.<sup>56 57</sup>

- The United Kingdom: in 1981, 16% of the registered disabled people were unemployed -- twice as many as in the workforce as a whole.<sup>58</sup>
- The United States: in 1981-1988, disabled people had only a 31.6% participation in the labor force, compared with 78.9% for the non-disabled. Of those in the labor force, the unemployment rate for disabled people was over twice the rate for those without disabilities.<sup>59</sup> A 1984 study of the US and several European countries found that, in terms of labor market participation, persons with disabilities were less likely to work, and when they did work, it was more likely to be part-time.<sup>60</sup>

4.8 Citing the various findings from these and other countries (including Japan and Sweden), Neufeldt concludes that, taking into account differences in definition, data collection, etc., in high-income countries, employment of disabled people is roughly half the rate of non-disabled people, and at least twice as many disabled people as compared with non-disabled people are not in the labor force. And, when disabled people are employed, there is a greater tendency for them to be under-employed relative to their levels of training.<sup>61</sup>

4.9 Although data from developing countries are scarce, the little existing information shows that disabled people are much less likely to be engaged in economic activity than the rest of the population. SIDA reports that only 16% of the disabled population in Mauritius is engaged in economic activities compared to 53% of the total population; and that in Botswana, the figures are 34% and 51%, respectively.<sup>62</sup>

4.10 Glendinning and Baldwin, referring to studies in the UK, point out that the difficulties of obtaining employment affect disabled people of all ages. Upon leaving school, disabled people are more likely than non-disabled people of the same age to experience under- or unemployment.

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<sup>56</sup> Neufeldt, 1998, p. 186, citing the Health Activity Limitation Survey in Canada.

<sup>57</sup> Note, figures for illustration only; the 1983/4 and 1991 figures may not be comparable.

<sup>58</sup> Glendinning and Baldwin, 1988, p. 65, and citing Townsend, 1981.

<sup>59</sup> Bennefield and McNeil, 1989, cited in Metts and Metts, 1998.

<sup>60</sup> Neufeldt, pp. 8-9, citing Haveman et al, 1984; and Metts and Oleson, 1993.

<sup>61</sup> Ibid, p. 10.

Disabled people tend to work longer hours than non-disabled people, and their lower take-home pay reflects lower rates of pay rather than fewer hours worked. They are also more likely to have a poor physical working environment and poor promotion prospects; and are at greater risk of becoming unemployed, and for longer periods. They are more likely to withdraw early from the labor force through voluntary redundancy and early retirement. The probability of a disabled person being employed also decreases with the severity of the disability.<sup>63</sup> People with certain forms of disability, for example, the visually and hearing impaired, and people with epilepsy and multiple sclerosis, and particularly those with mental handicap or mental illness, were found to have especially severe problems finding and keeping employment.<sup>64</sup>

## **Income**

4.11 The evidence from the developed countries is that disabled people have lower incomes than non-disabled people, even when age is taken into account.<sup>65</sup> Surveys of the US surveys carried out from the late 1950s to the late 1970s showed substantial disparities between incomes of disabled and non-disabled people; the average wage rates of disabled people were only 60% of those without disabilities. In a 1987 survey, average earnings of disabled men were only 50% of those of non-disabled men.<sup>66</sup> Data from 1990 showed that, in general, median family income is substantially lower if a *householder* has a disability, while income is affected much less by the presence of other family members with disabilities.<sup>67</sup>

4.12 Studies in the United Kingdom also found that fewer disabled than non-disabled people owned their own homes; fewer had substantial assets and fewer had rights to pensions and other welfare benefits, yet many had a need for higher incomes than those without disabilities.<sup>68</sup> Glendinning and Baldwin, also in reference to the UK, note the lower earnings of disabled workers, and note that earnings decrease as the severity of the disability increases.<sup>69</sup> They point

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<sup>62</sup> Swedish International Development Authority, 1995, p. 2.

<sup>63</sup> Glendinning, 1988, p.66, citing Harris et al, 1971 and Townsend, 1979.

<sup>64</sup> Townsend, 1981, pp. 59-60.

<sup>65</sup> The Disability Alliance, 1975, p. 9 points to research in the US and Denmark as examples.

<sup>66</sup> Burkhauser and Daly.

<sup>67</sup> LaPlante, M.P. et al, 1996, analyzing data from the 1990 National Health Interview Survey.

<sup>68</sup> Ibid. p.9.

<sup>69</sup> Ibid, p.66, citing Harris et al, 1972; Layard et al, 1978; Jordan, 1979; Townsend, 1979; and Lonsdale and Walker, 1984.

out that the lower incomes of disabled people observed during their working years continue in old age (albeit to a lesser extent), since the higher rates of unemployment, interrupted employment, and employment in low paid jobs with poor prospects experienced by disabled people affect their income after retirement. Disabled people are less likely to have the kind of pension or the level of provision that will adequately protect them from poverty in old age.<sup>70</sup>

## Poverty

4.13 In developed countries, official programs vary in the amount and kind of assistance provided, but do not appear to result in incomes for disabled people commensurate with non-disabled peers. The 1984 study found that disabled people in countries such as the Netherlands and Sweden which have more generous income support policies, tended to be better off than disabled people in other countries; but were still disadvantaged in comparison to population norms.<sup>71</sup> Analysis of the 1990 NHIS data in the US showed that the poverty rate for partnered families increased from 7.8% (with no disabled people in the family) to 9.5% when one partner (but no one else) has a disability, and to 14.2% when two partners have disabilities.<sup>72</sup> A 1993 study by the Policy Studies Institute in the UK found that one sixth of disabled people were poor, and the proportion increased to almost a half when the extra disability-related costs were considered.<sup>73</sup> A recent study of men with disabilities in Germany concluded that, even with substantial transfer and employment programs, the population with disabilities still faces a substantially higher risk of poverty than the rest of the population.<sup>74</sup>

4.14 Recent research in rural India found that a higher proportion of households with self-reported disabled members were below the poverty line, had lower total assets, smaller land holdings, and greater debt than households without disabled members.<sup>75</sup> Disabled people are estimated to make up 15 to 20 per cent of the poor in developing countries.<sup>76</sup> In some communities, the disabled are regarded as the most disadvantaged by others in the community,

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<sup>70</sup> Ibid, p. 66, and citing Walker, 1986.

<sup>71</sup> Neufeldt, p. 9, citing Haveman et al, 1984.

<sup>72</sup> LaPlante et al, p.11.

<sup>73</sup> Berthoud et al, 1993; cited in correspondence with M. Howard of the Disablement Income Group.

<sup>74</sup> Burkhauser, R. and M. Daly, p.22.

<sup>75</sup> Harris-White, 1996 (b), cited in Harris-White, 1996(a), p.4.

<sup>76</sup> Einar Helander, communication with P. Dudzik of the World Bank.

and it is frequently observed that in low-income countries, the disabled poor are among the poorest of the poor.<sup>77</sup> However, there are examples where this is not the case: a 1991 study found that in Sierra Leone, “the wealth ranking exercise results did not suggest that local people consider disabled people to be poorer” and concluded that, provided that adequate support networks and labor contacts were important in preventing disability from resulting in poverty.<sup>78</sup>

## V. Causes of Disability

5.1 “Knowledge of the disabling sequelae of even well-studied diseases is lacking for part of the developing and, perhaps surprisingly, the developed world as well.”<sup>79</sup> Although it is beyond the scope of this paper to review the causes of disability in any depth, a brief discussion of some issues helps to understand some of the variability in available estimates, and how disability may be linked to poverty.

5.2 Disability in the developing countries has a different cause structure from disability in the developed world. Classifying the causes of disability is a less than exact science, main groupings vary,<sup>80</sup> and there can be a mixing of contributory and causative factors. For example, some earlier classifications attributed a larger proportion of disability to malnutrition than does the structure used in the GBD/WDR. However, regardless of the classification, it is clear that in developing countries the proportion of disability caused by communicable, maternal and perinatal diseases and injuries is much higher than it is in developed countries.

5.3 Helander notes that it is possible to prevent all these causes to a larger or smaller extent. On the health side, large-scale prevention programs are mainly implemented through immunization programs; a great deal of progress has been made towards eradicating poliomyelitis and measles.<sup>81</sup> Communicable eye diseases such as onchocerciasis (river blindness) and trachoma have already been largely reduced. Resources to deal with non-communicable eye diseases, such as glaucoma and cataracts, are insufficient. Micronutrient

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<sup>77</sup> see for example Malinga, 1992, cited in Neufeldt, p. 11.

<sup>78</sup> Welbourn, p32.

<sup>79</sup> Murray and Lopez, p. 201.

<sup>80</sup> See for example, Doyal, p. 8, in Shirley, 1983; Helander, 1995, p. 24, and WDR, 1993, p. 27.

<sup>81</sup> Global vaccine coverage for the two diseases was 78% at the end of 1994, Helander, 1995, p. 24

deficiencies are rapidly diminishing because of large-scale interventions. Progress on preventing chronic non-communicable diseases, accidents, and mental illnesses will require greater effort.<sup>82</sup> In developed countries, the proportion of disability due to non-communicable diseases accounts for the largest proportion. It is illustrative that the greatest single cause of impairment in adults in Great Britain, according to a 1971 study, was arthritis;<sup>83</sup> and the three leading disabling conditions of children in 1980 were mental subnormality (35% of children with disabilities), cerebral palsy (15.2%), and Spina Bifida and hydrocephalus (13.8%).<sup>84</sup>

### **Causes of disability in children**

5.4 UNICEF's list of major causes of disability among children<sup>85</sup> is similar to the general WHO classification, and includes inadequate nutrition of mothers and children, including vitamin deficiencies; abnormal pre-natal or peri-natal events; infectious diseases; accidents; and various other factors, including environmental pollution and impairments of as yet unknown origin.

5.5 The main disabling communicable diseases cited in one source during the early 1980s included poliomyelitis, trachoma, onchocerciasis (river blindness) and leprosy.<sup>86</sup> To these may now be added HIV/AIDS.<sup>87</sup> Classifications vary: Eunson includes poliomyelitis, malaria, measles and German measles as being among the major (non-trauma) causes of disability in children.<sup>88</sup> The spread of trachoma,<sup>89</sup> as well as of polio and schistosomiasis (a debilitating disease affecting some 850 million people),<sup>90</sup> is related to lack of adequate sanitation.<sup>91</sup>

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<sup>82</sup> Helander, 1995, pp. 24-26.

<sup>83</sup> Harris et al, 1971, p. 59.

<sup>84</sup> Baldwin, S. and C. Glendinning, p. 122, in Walker and Townsend, eds., 1981.

<sup>85</sup> UNICEF, 1980, p.12.

<sup>86</sup> Doyal, box p.8, citing WHO sources, and others.

<sup>87</sup> Recent estimates are that more than 33 million people are infected with HIV/AIDS worldwide, a proportion of which are suffering from varying degrees of disability; and nearly 14 million people have died from AIDS-related causes since the epidemic began. (figures are from UNAIDS).

<sup>88</sup> Eunson, 1999 (WHO web newsletter, dialog 7). His list includes other causes (non-communicable diseases, landmines, and motor accidents). Disability related to landmines is covered in the subsequent section on disability and conflict.

<sup>89</sup> Trachoma is estimated to affect some 500 million people, and causes varying degrees of blindness.

<sup>90</sup> Estimate from the early 1980s.

<sup>91</sup> Doyal, p. 9, in Shirley.

5.6 Khan and Durkin note that most information on the prevalence of childhood disabilities in developing countries comes from surveys on specific public health problems of which disability is an outcome; they provide a short summary on where information can be found about some of the surveyed diseases.<sup>92</sup> Silberberg notes that there is relatively little information on the incidence of children's disabilities in sub-Saharan Africa, and that epidemiological knowledge is largely undeveloped. The few relevant surveys are primarily from Southern Africa.<sup>93</sup> The role of nutrition is particularly important in children's disability, and much of the knowledge on the various forms of malnutrition and their effects on health and disability is recently acquired.<sup>94</sup>

### **Mental conditions**

5.7 The relationship between psychiatric disease and disability still needs more investigation; and the distinction between diagnosis of a mental conditions per se and the measurement of any resulting disability needs to be kept in mind. Whether a measure of mild mental retardation (such as measuring the left-side of the bell curve in intelligence testing) is an independent measure of disability is an open question. Epidemiological classifications do not seem to adequately capture some of the more recently recognized phenomena, such as the mild mental retardation thought to be a result of under-stimulation of children in disadvantaged societies.<sup>95</sup> <sup>96</sup> A recent UNICEF report also links impaired intellectual development to child malnutrition.<sup>97</sup> Global prevalence of mental retardation has been estimated at between 1 and 3 percent of the world's population.<sup>98</sup> However, detailed estimates of mental handicap, including mental retardation, vary widely, and often vary within the same country. Some of the variation is due to differences in definition, age group sampled, complexity of the environment – whether urban or rural, sociocultural influences, and measurement tools. Because of all these intervening variables, Sen notes that even after wide ranging surveys in various developed countries,

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<sup>92</sup> Khan and Durkin, p. 1 in Zinkin and McConachie, 1995.

<sup>93</sup> Silberberg, 1998, p.1; and also citing Cooper et al, 1998.

<sup>94</sup> Ebrahim explains some of these relationships. UNICEF, 1998 provides a recent, comprehensive look at malnutrition and health.

<sup>95</sup> Khan and Durkin, p.2, citing Hagberg *et al*, 1981.

<sup>96</sup> It has been estimated that less than one-third of mildly retarded individuals show evidence of organic impairment, and in most cases retardation is due to the impoverishment of their social environment. Sen, 1992 referring to WHO 1985.

<sup>97</sup> UNICEF, 1998, p. 16.

<sup>98</sup> Sen, p. 41, citing WHO, 1968.

researchers have not been able to report a common figure of the prevalence rate of mental handicap among different populations. She notes that the widely quoted 3 per cent is a theoretical model.<sup>99</sup>

## **Conflict and Disability**

5.8 Today's conflicts tend to be internal, characterized by shifting borders and alliances. In addition to the disabling injuries sustained by soldiers, civilians are at risk from sniping, shelling, and other forms of active hostilities, as well as from unexploded ordnance and land mines. They can also become the victims of violent excesses; perhaps some of the most grotesque have been in Rwanda and Sierra Leone. Refugees from conflict are vulnerable to potentially disabling disease because of the conditions during their journeys and in camps.<sup>100</sup> Conflict also has widespread psychological consequences. Studies suggest that the rates of psychological problems among adults are higher than the rates of physical problems,<sup>101</sup> however, there do not appear to be any estimates of the resulting disability rates.

5.9 Those who are already disabled, or become disabled during a conflict, are particularly vulnerable to deteriorating health under the severe conditions caused by war. Disabled people have difficulty moving to safety,<sup>102</sup> and are difficult for relief workers to find and assist. Health care and social assistance systems break down during conflict, health deteriorates, and some conditions that would normally be treated, including those not necessarily directly related to conflict, can become disabling. Preventive programs such as pre-natal and immunization services are often disrupted. It is possible that, although the incidence of impairment increases in war, affected children are less likely to survive, due to inadequate health care, and the overall prevalence may fall.<sup>103</sup> Estimates of the numbers of people with conflict-related disabilities, where they exist, are likely to underestimate some of the psychological disabilities brought on by conflict-related trauma that often remain undiagnosed and unrecorded.

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<sup>99</sup> Sen, pp. 219-220

<sup>100</sup> see para. 8.05 re: strategy for refugees.

<sup>101</sup> Richman, p. 205, in Zinkin et al.

<sup>102</sup> Some of the particular vulnerabilities of the disabled were pointed out by Hastie: for example, deaf people do not hear warning sirens, people in wheel chairs have difficulties getting to safety, etc.

5.10 Information on conflict-related disability is difficult to come by; and estimates can be very unreliable. Without surveys or widespread registration programs and reliable population estimates, incidence and prevalence estimates can only be educated guesses. A recent paper on landmine injury surveillance systems<sup>104</sup> describes the many problems associated with landmine injury figures; some are illustrative of the problems associated with other kinds of conflict-related disability figures:

- there is no single organization collecting reliable information useful for national or international extrapolation;
- most of the data are based on samples without denominators for estimating rates;
- data often come from hospitals and clinics; people treated in their villages may not be included;
- figures are based on old data whereas the situation within a country changes rapidly;
- definitions may be ill-defined; and
- variation in data collection methods means that data from various sources cannot be compared or combined.

5.11 Based on figures from a recent study carried out in 206 communities in Afghanistan, Bosnia, Cambodia, and Mozambique<sup>105</sup> landmine incident rates in the surveyed areas ranged from 1.9% in Afghanistan to about 0.5% in Mozambique. Disability rates, measuring only the survivors, ranged from about 0.9 in both Afghanistan and Cambodia, to about 0.3% in Mozambique. About 6% of households were affected by landmine accidents. In some parts of Afghanistan, the proportion was as high as 22%.<sup>106</sup>

5.12 According to statistics from the Mine Incident Database Project, an estimated 48% of mine victims in Cambodia were civilian, 90% or more were male.<sup>107</sup> The four-country study points out that age and gender-specific rates are largely explained by the activities of the victims, with

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<sup>103</sup> Richman, p.204, in Zinkin et al.

<sup>104</sup> Taylor et al, 1999, pp. 2-3.

<sup>105</sup> Andersson, et al, in British Medical Journal, 1995.

<sup>106</sup> The authors note that the data should not be interpreted as a complete national picture.

<sup>107</sup> Taylor et al, p.39.



economically active men at the highest risk; the highest proportion of child victims was in Afghanistan where they work as herders. In Mozambique, a quarter of the victims were women.

5.13 In mined areas, landmine injuries may not be the most frequent cause of disability, except possibly in very localized heavily-mined areas. In two provinces of Cambodia in 1986, a survey of children found the most common health problems involved hearing and speech, motor performance and learning capacity. The most frequent cause of motor impairment was poliomyelitis, followed by landmine injuries and other accidents, and cerebral palsy. A 1996 survey in Afghanistan also found that polio was more important than landmines as a cause of motor disability.<sup>108</sup>

## **VI. The Path from Poverty to Disability**

### **The Poor and Poor Health**

6.1 Focusing on the specific identifiable diseases can detract attention from the traditional 'diseases of poverty' which continue to be a major cause of disability. The "Consultations with the Poor" noted that illness was considered an effect of poverty in seven Malawi villages out of nine, and a cause of poverty in only two.<sup>109</sup> Acton points out that the interactions between poverty and disability -- "the frequency with which untreated impairment starts or accelerates the collapse of a family's already fragile economic base, and the degree to which social and economic deprivation are themselves fundamental causes of impairment and of consequent life-long incapacity" have not been adequately recognized.<sup>110</sup>

6.2 The cycle of poverty and disease is described in several sources.<sup>111</sup> Poor families often do not have land to grow food, and inadequate income to purchase their basic needs, shelter, sustenance and sanitation are inadequate, and access to health care is very limited. Family members often become ill, and some of the diseases are potentially disabling. Mothers have

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<sup>108</sup> British Medical Journal, 1997; 315: 1424-1425 (29 November).

<sup>109</sup> Brock, p. 29

<sup>110</sup> Acton, p. 79.

<sup>111</sup> Moyes p.3 and Doyal, p. 7 briefly outline this cycle, particularly its relevance to disability; Ebrahim focuses on the nutritional aspects and disability.

low-birth weight babies, who are more at risk of debilitating diseases than healthy babies. Malnutrition in its various forms is a cause of disability as well as a contributory factor in other ailments that increase susceptibility to other disabling diseases. Moreover, given the links between child malnutrition and impaired intellectual development, the large at-risk population is of concern. It was estimated in 1998, for example, that approximately 230 million children (43%) in developing countries are stunted.<sup>112</sup>

6.3 Lack of adequate and timely health care can exacerbate disease outcomes, and can turn impairments into chronic disabilities. Without resources for medical or social services, a remedial impairment can become a permanent disability. Familiar examples, such as the lack of devices such as glasses, hearing aids, and crutches, have motivated many, often localized, interventions. Less obvious are the serious health effects of the kind of pervasive undernourishment often found in poor areas. Citing several studies, Khan and Durkin point out that most studies of childhood disability and consequent intervention programs have been centrally planned, and have failed to consider child health and morbidity against the social, cultural and economic backdrop. Parental awareness and access to information, parental (especially maternal) education, dietary and food preparation habits, and the general level and coverage of primary health care have been found to have a greater (preventive) effect than any specific intervention.<sup>113</sup>

6.4 UNICEF<sup>114</sup> notes that the incidence and serious impact of impairment, disability and handicap are greater in countries at earlier stages of development, as a consequence of factors, many of which are related to poverty, which it describes as:

- (a) A high proportion of overburdened and impoverished families;
- (b) Populations with a high proportion of illiteracy and little awareness of routine measures for health, education, and welfare,
- (c) Absence at all levels – from villagers to senior officials – of accurate information about disability, its causes, prevention, and treatment

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<sup>112</sup> de Onis, et al, p.1

<sup>113</sup> Khan and Durkin, p. 2.

<sup>114</sup> UNICEF, 1980, p. 16.

- (d) Insufficient programs for the prevention of conditions that cause impairments, and inadequate services to respond to impairment and disability,
- (e) Obstacles such as lack of money, geographic distances, and social barriers which make it impossible for many children to take advantage of services that may exist
- (f) Use of limited available resources to operate services that are too highly specialized to reach most children who need them
- (g) The absence or weakness of an infrastructure of related services for health, education, welfare, and vocational preparation
- (h) Low priority in development strategies for activities related to disability prevention and rehabilitation.

### **The poor and their work environment**

6.5 Poor people tend to work more often in demanding or more risky physical labor environments. Examples abound:

- construction workers in developing countries, who work long hours and often do not have protective hats or boots, are much more at risk of serious injury than their counterparts in developed countries, and are less likely to receive treatment to minimize the damage and assist in rehabilitation.
- The majority of civilian mine incidents in Cambodia occurred while foraging in wooded areas for fuel or food.<sup>115</sup>
- Disabled patients seen at a clinic in Bangladesh suffered injuries from falling from trees while gathering fruit or had broken their necks from accidents while carrying heavy loads on their heads.<sup>116</sup>

6.6 Moreover, risks of contamination have been recognized as a major problem in developing countries where environmental standards are likely to be lower, or less rigorously enforced, than in developed countries. Doyal notes, for example, the hazards associated with asbestos processing, and the dangers of chemical pesticides, and the wide use of aldrin/dieldrin, DDT,

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<sup>115</sup> Taylor, p. 40.

heptachlor and chlordane in developing countries.<sup>117</sup> Studies in India have shown a relationship between agricultural equipment and amputations; and a 1987 study found some evidence that pesticides may be a causative factor in limb and visual disabilities.<sup>118</sup>

## VII. The Path from Disability to Poverty

7.1 Studies have identified three types of factors which can make disabled people, or families with disabled people, worse off:<sup>119</sup> (i) loss of income; (ii) additional costs resulting from the disability; and (iii) marginalization or exclusion from services and/or social and community activities, etc. The broad relationships between disability and income, particularly the income of the disabled person, have been outlined earlier. This section discusses some of the costs incurred by a disability, including indirect costs to other family members. It then looks at some of the barriers contributing to marginalization and exclusion, and at some particularly vulnerable groups of disabled people.

### Costs of disability

7.2 Much of the discussion of the financial costs of disability to disabled people and their families refers to the situation in developed countries and has taken place in the context of analysis of various compensation and/or assistance schemes.<sup>120</sup> The costs, regardless of the country context, generally include direct costs relating to the disability; and costs incurred by those providing care to a disabled person, in addition to lower incomes of disabled people.<sup>121</sup> Some of the concepts involved and the difficulties of measuring the costs of disablement to a household are discussed by Baldwin.<sup>122</sup>

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<sup>116</sup> Example from Oxfam news, cited in Hammerman and Maikowski, eds. p.75.

<sup>117</sup> See D. Mohan, 1987 on a study in India finding some evidence that pesticides may be causative factor in limb and visual disabilities.

<sup>118</sup> Ibid, pp. A23-A29.

<sup>119</sup> This review will focus on costs to individuals and households. The literature on the costs of disability and benefits of prevention and rehabilitation to the economy have not been reviewed; however Hammerman and Maikowski, in a Rehabilitation International publication, 1981 outline some of the work done; and Harriss-White, 1996, p. 13, briefly discusses some of the difficulties in carrying out cost-benefit and cost effectiveness analyses.

<sup>120</sup> See for example, Dr. Barbara Murray of the National Rehabilitation Board, Ireland, Barbara Harriss-White, and Glendinning and Baldwin, p. 64.

<sup>121</sup> Harriss-White, identifies the same types of costs to individuals and households in describing the links between disability and poverty in India, 1996 (a) p. 13.

<sup>122</sup> Baldwin, 1985, p.49.

7.3 The extra costs directly related to the disability include such things as: medical expenses, equipment (crutches, wheelchairs, etc.), adaptations to housing, specialized services, etc. These can be considerable. In the US, for example, total per capita medical expenditures alone are over four times greater for people with activity limitations than for people with no limitations.<sup>123</sup> A recent survey of disabled people in India found that the direct cost of treatment and equipment varied from 3 days' to 2 years' income, with a mean of 2 months.<sup>124</sup> Surveys of four countries in 1995 found that between 12 and 60 per cent of landmine victims had to sell assets to meet their medical bills; and 61% of Cambodian landmine victims were forced into debt to pay for medical care.<sup>125</sup>

7.4 The costs of providing care to a disabled person may be borne by the disabled person directly, some may be met by state or local authorities as part of the welfare system, and some fall on friends or relatives providing care. The charter for the 1980s-Summary Declaration notes that an estimated twenty-five percent of people in a community are prevented 'from the full expression of their capacities' by the existence of disability, including not only those who are disabled, but their families and others who assist and support them.<sup>126</sup> Findings in the U.S. indicated that families play a major role in preventing poverty among the elderly through shared living arrangements.<sup>127</sup> On a related point, a study in New Zealand<sup>128</sup> found that housing/accommodation was a 'trigger' in a disabled person's life; i.e., if housing was not organized and stable, other factors were likely to be unstable and the risk of poverty higher, regardless of the severity of the disability. Interestingly, in this study housing was more important than employment and transport, in that order.

7.5 The costs to carers, particularly the loss of employment and earnings, as well as reductions in living standards of other family members because of the loss of the carer's earnings, are increasingly being recognized. A UK study estimated that raising a severely disabled child costs

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<sup>123</sup> Trupin, et al, 1995, p. 1. See also Avery, 1983.

<sup>124</sup> Report on DSA Poverty Study Group meeting: information from Harriss-White on a recent survey.

<sup>125</sup> Andersson et al in British Medical Journal, p. 718.

<sup>126</sup> As noted by the Rt. Hon. Alfred Morris, M.P. was Britain's first Minister for the Disabled from 1974 to 1979, and chaired the World Planning Group set up by Rehabilitation International to draw up the Charter for the 1980s.

<sup>127</sup> Speare and Rendall, p.27; a study carried out on SIPP data found that 1.3 million elderly were prevented from falling below the adjusted poverty threshold; subject to assumptions that the alternative living arrangements would not include institutionalization, inter-household transfers, or changes in income generating behavior.

three times as much as a non-disabled child.<sup>129</sup> In a 1974-75 UK study of the costs of disabled living, the greatest reversal in household income occurred when the disability was so severe that another member of the household had to give up work to care for the disabled person.<sup>130</sup> UK studies showed that mothers of disabled children were much less likely to be in paid work. For example, only 33 per cent of women with severely disabled children were employed, compared to 48 per cent of mothers without disabled children. As children get older, the difference increases, and the proportions become 86 per cent and 45 per cent, because mothers of disabled children are not as likely to return to work as their children grow up.<sup>131</sup> When mothers of disabled children were employed, they worked fewer hours, and at lower pay rates, than their control group counterparts.<sup>132</sup> Recent research has found that people who have looked after disabled relatives or friends for at least ten years have lower average incomes, are more dependent on welfare benefits, have less invested in pension schemes and have less wealthy families. Women who had been long term carers were earning two thirds of the earnings of women who had been carers for a shorter time.<sup>133</sup>

7.6 Without the comprehensive (if not necessarily sufficient) income maintenance programs and other schemes available in the developed countries, disabled people are usually considered to be the responsibility of their families; publicly funded entitlements are rare, and rehabilitation services are often traditional and not widely available. Without support from the family, a disabled person's condition can be very precarious.<sup>134</sup>

7.7 In any society where there is little support from outside the household, the additional resources (including time) needed because of a disability within the family will have an effect on the household's well-being. In poor households, when the disabled person is also responsible for all or part of the household's income or subsistence, the effect can be devastating. A study of the effects of onchocerciasis (river blindness) on rural households in Guinea describes the downward spiral precipitated by the deteriorating vision of the household head, the diminishing cultivation

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<sup>128</sup> Communication from D. Henderson, Secretary General of Rehabilitation International.

<sup>129</sup> Dobson, B. and S. Middleton, cited in correspondence with M. Howard of the Disability Income Group.

<sup>130</sup> Hyman, p.31.

<sup>131</sup> Baldwin and Glendinning, p. 128, in Walker and Townsend, eds., 1981.

<sup>132</sup> Glendinning, p. 72, citing Baldwin, 1985.

<sup>133</sup> British Medical Journal (BMJ), 1995; 310:81.(14 January).

of land and production of food, increasing dependency ratio within the family, and the destitution of the household.<sup>135</sup>

## **Barriers**

7.8 In developing countries, disabled people are often seen as the most disadvantaged by those in their own communities. Local people in Asia and sub-Saharan Africa ranked being disabled at the top of a list of fourteen 'ill-being' criteria -- the second ranked was being widowed, and the third was lacking land.<sup>136</sup> Several researchers point out that disabled people, particularly in developing countries, are often the victims of negative social attitudes and are subject to stigmatization, neglect, and sometimes exacerbation of the disabling condition or the onset of new disabling conditions, as a result. In some cases, disabled people are particularly subject to abuse, either physical (beatings, rape, etc.) or social/mental/psychological (isolation, confinement, being made to feel guilty or inadequate, etc.). Exclusion and marginalization reduce the opportunities for disabled people to contribute productively to the household and the community, and increase the risk of falling into poverty. UNICEF points out that some 150 million disabled children lack access to child care services, schools, recreation and other social services, and are likely to remain illiterate, and untrained, and ultimately join the unemployed.

7.9 Neufeldt discusses the kinds of barriers commonly reported by disabled people's organizations, including lack of adequate or appropriate transportation, physical inaccessibility, lack of learning opportunities, and attitudinal barriers. A survey by the International Center for the Disabled concluded that "job discrimination remains one of the most persistent barriers to the increased employment of disabled people."<sup>137</sup> All of these constraints can affect access to education and employment opportunities, reducing the opportunities for income enhancement as well as social participation.<sup>138</sup>

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<sup>134</sup> Neufeldt, 1998, p.13.

<sup>135</sup> Evans.

<sup>136</sup> Compilation by R. Chambers, 1995, cited by Helander, 1995, pp. 13, 14.

<sup>137</sup> Metts and Metts, citing the International Center for the Disabled, in Neufeldt, 1998, p. 240.

<sup>138</sup> Neufeldt, 1998, p. 13.

**7.10 Access to Services.** Peters cites a 1988 UNESCO review showing that of 51 countries reporting data, 34 provided for the needs of fewer than one percent of students identified as disabled.<sup>139</sup> Access to rehabilitation and other services for disabled people is very limited in developing countries. Harriss-White notes that a small fraction of rural disabled people in India have access to government or NGO programmes, and that the majority are “profoundly socially excluded.” In many poor communities, particularly in rural areas, access is likely to be constrained by lack of information, travel costs, etc.<sup>140</sup> ESCAP notes that rehabilitation services in the region’s developing countries are still inadequate and poorly coordinated, and that commuting to rehabilitation centers poses serious difficulties for disabled women and girls, and is expensive for their families in terms of money, time, and effort. UNICEF has reported that women and children receive less than 20 percent of rehabilitation services.<sup>141</sup>

### **The Elderly**

7.11 Studies in the UK showed that the proportion of elderly people living at or below the poverty line is very much higher than of younger people.<sup>142</sup> A national poverty survey found that a much higher percentage of elderly people with appreciable or severe incapacity (73%) than with none (48%) had incomes below or on the poverty line, and that this correlation remained significant after standardizing for age and household composition.<sup>143</sup>

### **Gender**

7.12 Disabled women are, in general, more disadvantaged than disabled men. In developed countries, the indicators on income, education, and employment levels of disabled people show consistent, but not necessarily large gender differentials. Analysis of data from the 1981 and 1982 Current Population Surveys in the US showed that 15.7% of disabled women had 13 or more years of schooling, compared to 22.7% of disabled men; disabled men are almost twice as

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<sup>139</sup> CERI, 1989

<sup>140</sup> Harriss-White, 1996, p.5

<sup>141</sup> UNICEF, 1990, cited in ESCAP, 1995, p.10.

<sup>142</sup> Townsend, 1981, p. 98.

<sup>143</sup> Ibid, citing Townsend, 1979, pp. 712, 816.



likely as disabled women to have jobs; and disabled women working full time earned only 56% as much as did disabled men with full time jobs.<sup>144</sup>

7.13 Several articles contain case studies and other types of reports on the poor social status afforded to disabled women.<sup>145</sup> A study by ESCAP<sup>146</sup> notes that the difficulties faced by disabled girls can start at birth, and that if disabled girls are allowed to survive, they can face discrimination within the family, receive less care and food, and be left out of family interactions and activities. They also have less access to health care and rehabilitation services, and fewer education and employment opportunities. Disabled girls and women are at high risk of being abused physically and mentally, sometimes by those within the household.<sup>147</sup> Abuse from outside the family is often unreported because of the additional shame to the family which is already stigmatized for having a disabled daughter.<sup>148</sup>

7.14 Having a disabled person in the family is sometimes thought to damage marriage prospects. Although figures are not given, most of the case studies cited in Abu-Habib point out that a disabled man is much more likely to marry than a disabled woman. ESCAP states “Universally, the incidence of marriage for disabled women is lower than that for disabled men”, and notes that in Nepal, where marriage is the norm for women, 80% of women with disabilities are reported to be unmarried.<sup>149</sup> In China, 52% of disabled women over 18 years old are unmarried.<sup>150</sup>

7.15 Abu-Habib makes similar observations: “Discrimination starts at home, in the early years of the life of a disabled woman. This discrimination brings with it a reluctance on the part of families, or rather decision makers within the families, to make tangible and intangible resources available to disabled women, thus further undermining their life chances”... “their social

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<sup>144</sup> Bowe. 1984.

<sup>145</sup> See for example, Driedger D. and S. Gray (eds.), 1992, cited in Neufeldt, p. 11.

<sup>146</sup> ESCAP, 1995.

<sup>147</sup> Ibid, p. 8.

<sup>148</sup> Boukhari, in Abu-Habib, p. 41.

<sup>149</sup> Paudel, Sushila in a paper contributed to the Training Workshop for Women with Disabilities, 22-23 June, 1995, Bangkok, cited in ESCAP, 1995.

<sup>150</sup> China Disabled Persons Federation, in a paper for the 1995 Bangkok workshop, also cited in ESCAP, 1995.

isolation as women is deepened by their disabled status”<sup>151</sup> She concludes that disability often blocks the chances of a fulfilling life for a woman, in a way that does not seem to happen in the case of men. She cites a UNDP study showing that women with disabilities are twice as prone to divorce, separation, and violence than able-bodied women.<sup>152</sup> She also refers to a 1987 paper demonstrating that disabled women have limited access to the labor market because of the double disadvantage of being both female and disabled.<sup>153</sup>

7.16 ESCAP notes that the access problems confronting women with disabilities are more severe in rural areas; higher illiteracy rates, and longer distances compound the difficulties of inadequate access to information, health care and rehabilitation services. The Blind Men Association in India’s attribution of higher rates of blindness among rural women to the lower likelihood of females to be transported to the city to have the necessary medical care for eye diseases.<sup>154</sup> Data from one source in Angola indicate that 23% of the women victims of landmines had prosthetics, compared to 37% of the male victims.<sup>155</sup>

7.17 Although men tend to receive more care, including treatment, women are more likely to be carers for disabled children and other family members, often meaning that they are unable to invest in themselves. Moreover, in some areas, mothers are usually blamed and stigmatized for the birth of a disabled child. It is not unusual in some areas for disabled women to be kept hidden, and never receive visitors.

7.18 An analysis of the situation in India notes that “the relationships between poverty, ‘weakness’ (social disability) and (medicalized) disability result in a condition of simultaneous deprivation – a syndrome composed of ideological reinforcement, punitive experience, psychological extinction (the lack of consequence in behavioural development), stimulus deprivation and a cognitive and verbal development which probabilistically affects the participation of low caste groups.” This syndrome sets up barriers to the participation of

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<sup>151</sup> Boylan, 1991.

<sup>152</sup> Abu-Habib, citing UNDP, 1995.

<sup>153</sup> Stance, pp. 301-316, 126(3).

<sup>154</sup> Personal communication with the BMA in 1995, cited by Abu-Habib, 1997, p.2.

<sup>155</sup> Taylor, 1999, citing information from Medico’s database.

disabled people of all types, but especially the mentally disabled, and especially girls.<sup>156</sup> Acton describe a kind of disablement that does not enter into the usual statistics, noting that the lassitude and inertia observed among poverty-stricken people are often products of disabling conditions such as malnutrition, endemic disease and infection, with possibly serious impairment of both physical and mental development.<sup>157</sup>

## VIII. Policies for Disabled People

8.1 There have been several international initiatives, such as the Vocational Rehabilitation and Employment (Disabled Persons) Convention (No. 159) and Recommendation (No. 168),<sup>158</sup> and the Standard Rules of the Equalization of Opportunities for Persons with Disabilities.<sup>159</sup> It is beyond the scope of this paper to review these initiatives or their success, but it is clear that, despite the growing recognition of the need for policy changes, the ratification process can be slow and many implementation difficulties remain to be overcome.<sup>160</sup>

8.2 The literature on policies for disabled people reflects the dichotomy between the developed and the developing countries. Much of the literature in developed countries focuses on the design of public programs, or in some cases publicly regulated private programs, to cover the risks and costs of disability. Within this literature, there is an emphasis on program adequacy and the adjustments needed as more is learned about the real costs of disability. Most developed countries have separate programs to cover the risk of work-related disability (arising from work-related accidents and occupational diseases) and the risk of non-work related disability (a general disability program covering the population at large, including those who are handicapped before entering the labor force and employees whose disability is not work-related). In some countries all disability risks are pooled nationally; in others, the narrower class of work-related liabilities are covered by employers, while general disability risks are insured nationally. Several countries provide a comprehensive infrastructure of rehabilitative and re-training services and target

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<sup>156</sup> Harriss-White, 1996(a), p. 4

<sup>157</sup> Acton, p. 82.

<sup>158</sup> Adopted by the ILO in 1983.

<sup>159</sup> Adopted by the UN's General Assembly in 1993.

<sup>160</sup> See, for example ILO's Survey on the effects of the Convention and Recommendation (ILO, 1998), and interview with Mr. B. Lindqvist, Special Rapporteur on Disabilities for the UN's Commission for Social Development.

disability benefits only to people who are fully incapacitated, promoting employment rather than compensation, and increasing the efficiency of the program.<sup>161</sup> In middle income countries, most formal pensions systems involve disability pensions – about 70% of the labor force in the ECA region, 50% in LAC and Asia, 25% in MENA, and 5-10% in Africa.

8.3 In many developing countries, particularly lower income countries, publicly funded programs, and even those funded largely by employers, are not an option for those outside the formal labor market. Disabled people in agrarian societies and urban dwellers in the informal sector have to rely on themselves, or be financially dependent on their families and communities. Rehabilitation and other services provided by the state are often inaccessible. Services provided by volunteer organizations tend to be small single sector projects, e.g., support to a school for blind children, etc.<sup>162</sup>

8.4 In countries where the causes of disability typically indicate a higher proportion of impairments due to communicable diseases and malnutrition than in developed countries, the importance of *prevention* is clear. Moreover, indications are that there is still a great deal of scope for preventing or alleviating disability through relatively simple interventions. Recent research in India found widespread needs for equipment such as glasses, crutches, and hearing aids; and the 1981 National Sample Survey in India showed that nearly 50% of visually impaired rural population and 29% of those in urban areas had no treatment at all

8.5 There is an awareness that, even with the most diligent efforts of voluntary organizations, specialized *ad hoc* services are not reaching enough of the disabled people in poorer communities. This has coincided with the recognition of the detrimental effects on child development of broadly applied institutionalization policies, such as were the norm, for example, in some of the Eastern European countries.<sup>163</sup> Some groups cite greater economic cost to families and societies when people with disabilities, especially children, are placed in special

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<sup>161</sup> The advantages and disadvantages of a range of public-private mixes in administering and funding disability insurance are described in Aarts and De Jong, 1999.

<sup>162</sup> Helandar, p. iv

<sup>163</sup> including, but not limited to, inadequate social environment and education and health services for disabled children; in some cases, children with only mild, or otherwise treatable, disabilities (such as diabetes) have been institutionalized. One reference is Tobis.

institutions. As a result, there is a strong theme in the recent literature encompassing appropriate technology,<sup>164</sup> self-reliant schemes, and participatory approaches, including community based rehabilitation (CBR), with reports from a range of international organizations, NGOs, advocacy groups and researchers outlining new approaches with particular relevance for developing countries.<sup>165</sup> It is beyond the scope of this paper to review the many studies or programs already under implementation, but some examples are a study on the feasibility of implementing the CBR strategy amongst refugees and disabled persons in camps in Kenya<sup>166</sup> and a similar program in slum communities,<sup>167</sup> both being carried out by WHO.<sup>168</sup>

8.6 Disabled people are increasingly being heard and are strong advocates for removing barriers and accommodating people with disabilities within ordinary workplaces. Similarly, there is a move towards integrating disabled people in existing educational and training programs rather than relying on separate institutions, an example being the emerging literature on 'inclusive schooling practices.'<sup>169</sup> Experience with *inclusive* approaches has led to several recent papers describing the advantages of accommodating children with special educational needs in mainstream schools. There seems to be a consensus that the vast majority of children with special needs can be cost-effectively accommodated, to their advantage and without disadvantage to other students; although the need for more research and evaluation of the various approaches is noted in several studies.<sup>170</sup>

## IX Conclusions

9.1 Disabled people have lower education and income levels than the rest of the population. They are more likely to have incomes below poverty level than the non-disabled population, and

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<sup>164</sup> For example, a range of ILO publications on accessibility, tool and job adaptations, and new technologies.

<sup>165</sup> For example, Helandar, on CBR and including the disabled in sustainable human development projects; ILO, 1982 on experience in community based rehabilitation; Neufeldt on self-directed employment; NU (Nytt om U-landshalsovad), etc.

<sup>166</sup> WHO, 1996

<sup>167</sup> WHO, 1995

<sup>168</sup> among the many other organizations using community-based approaches are OXFAM and the Save the Children Fund (SCF).

<sup>169</sup> See, for example, McGregor and Vogelsberg.

<sup>170</sup> See, for example, Lynch's review of the experience with special educational needs in the Asia Region, and Dyssegaard and Robinson on lessons learned in special needs education in developing countries.

they are less likely to have savings and other assets. These findings hold for both developing and developed countries.

9.2 The links between poverty and disability go two ways – not only does disability add to the risk of poverty, but conditions of poverty add to the risk of disability. Poor households do not have adequate food, basic sanitation, and access to preventive health care. They live in lower quality housing, and work in more dangerous occupations.

9.3 Research findings on disability in the developed countries reveal much more than the universalities above, e.g., about links between education and employment, choices made by disabled people, the effects of disability on families, etc. They have guided policy mostly toward programs to *compensate* for some of these factors with income maintenance schemes, reserved employment, etc. Much of the more detailed research is only relevant to countries with effective labor markets and the capacity to fund assistance programs.

9.4 Major differences lie in the causes of disability and in the availability of preventive and rehabilitation services in developed and developing countries. Much of the disability in developing countries is a result of ‘preventable’ impairment, in the sense that much of it is a consequence of conditions which no longer prevail in developed countries; and a large part of the disability could be eliminated through treatment or alleviated through rehabilitation.

9.5 The *number* of disabled people is growing, partly as a result of population growth, but also because of increasing life expectancy, and the accompanying increase in the number of elderly who have higher disability rates. Some researchers anticipate that with development, there will also be an increase, rather than a decrease, in the *proportion* of population with disabilities. Harriss-White, for example, refers to a ‘disability transition’ akin to demographic and epidemiological transitions, whose causative factors include increased survival rates from disabling accidents and disease, as well as population aging. With increasing life expectancy, visual and hearing impairment increase,<sup>171</sup> as well as other impairments associated with aging.<sup>172</sup>

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<sup>171</sup> Harriss-White, 1996 (a), pp3-4.

Some researchers point to the environmental health risk factors, including the large numbers of people without adequate sanitation, and the increasing use of potentially harmful substances, etc.,<sup>173</sup> as factors of such an increase. However, other indicators point in the opposite direction, such as some encouraging downward trends in malnutrition, and the progress made in immunizations. Silberberg refers to increasing socio-economic levels being associated with safer reproductive practices, and thus the number of disabilities occurring at birth.

9.6 It is not clear what effect these trends would have on overall disability prevalence. However, it is clear that increases in the number of elderly (as well as the proportions of the elderly) will occur in both developed and developing countries, and although the associated increases in disabilities associated with the elderly will occur in both, the risks of poverty and the potential for addressing them are very different. In the developed countries, maintaining the well-being of the disabled elderly will mean extraordinarily large resources devoted to income maintenance and medical and other services. In the developing countries, where the resources are not available, the increasing numbers of elderly people will continue to rely primarily on family and possibly community resources.

9.7 Efforts have to remain focussed on prevention and rehabilitation in developing countries. Approaches that encourage increased participation of disabled people, their families and their communities seem to hold out the most promise. Income maintenance schemes, and even reserved employment schemes have limited applicability where there is no effective labor market. Increased public effort within the health sector is needed, particularly in strengthening prevention measures, i.e., promoting maternal and child health care, primary health care, including immunization programs, etc., but also in education and training so that information on prevention, treatment, and rehabilitation is more widely available.

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<sup>172</sup> For example, there is concern about the mental health of the elderly. Levkoff, et al, 1995 discuss the growing numbers of the elderly and the possible rise in age-related mental diseases such as dementia associated with stressors such as changes in families' abilities to provide care for them.

<sup>173</sup> In 1983, Doyal cited a 1976 WHO assessment that only one third of the urban population of developing countries had waterborne sewerage systems, and another third had no sanitation; and its estimation that the population without sewage disposal would double over the next ten years, leading to an increase in fecally-transmitted diseases.

## Indications for Further Work

9.8 Some first ideas follow. However, since little basic research appears to have been done on poverty and disability in developing countries; and the topic spans several other fields of research, the identification of directions for additional research would probably benefit from some discussion among those most currently involved.

- Search for and investigation of data sources and analysis of disability in developing countries that would allow for more detailed analysis of poverty-related factors, such as income, education, employment, access to services, etc., in developing countries. This would need to be a larger study, looking into university work, local sources, etc. It could also look at what could be done with LSMS data,<sup>174</sup> and other existing studies.<sup>175</sup>
- Less aggregated (than GBD) projections of disability in populations that have a particular disability pattern, a special vulnerability, or at particular risk of poverty (e.g., children in sub-Saharan Africa; the elderly in former socialist economies, women in South Asia, etc.) with a view to modeling ‘poverty paths’ based on what is known about disability and factors of poverty.
- Longer-term studies of income and other poverty indicators in households with a disabled person, using consistent data sets over at least two points of time, where changes in status can be observed.
- Focussed household studies of factors such as housing, employment, transport, etc. identifying ‘triggers’, with a view to formulating specific focussed policy interventions.
- Focussed study of gender, disability and poverty.<sup>176</sup>
- Basic research on validating measures of disability.

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<sup>174</sup> Data sets contain information for investigation of education and employment, identification of disabled persons could be problematic. At first look, only Jamaica, Romania, Bulgaria, and Albania appear to have any potential at all; however sample sizes may be too small.

<sup>175</sup> E.g. a nation-wide survey-based study on Ecuador (in Spanish only), by Edgar de Labastida, cited by Robert Vos.

<sup>176</sup> More information may be available from existing data sets. India, through B. Harriss-White.



# POVERTY AND DISABILITY

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### Summary Findings

This review summarizes the literature on disability and its relationship to poverty, including education, employment, income, and access to basic social services. Despite the dearth of formal analysis, it is clear that in developing countries, as in more developed areas, disabled people (and their families) are more likely than the rest of the population to live in poverty. It is a two-way relationship—disability adds to the risk of poverty, and conditions of poverty increase the risk of disability. Disability in developing countries stems largely from preventable impairments associated with communicable, maternal and perinatal disease and injuries, and prevention has to remain a primary focus. An increasing emphasis on community based participatory rehabilitation reflects growing recognition of the inadequacy of past official programs, particularly involving specialized and exclusionary institutions.

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