Disability Policies, Statistics, and Strategies in Latin America and the Caribbean: A Review

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This working paper is being published with the sole objective of contributing to the debate on a topic of importance to the region, and to elicit comments and suggestions from interested parties. This paper has not gone through the Department's peer review process or undergone consideration by the SDS Management Team. As such, it does not reflect the official position of the Inter-American Development Bank.

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Acronyms and Abbreviations

CACL	Canadian Association for Community Living
DALY	Disability Adjusted Life Year
GBD	Global Burden of Disease
GDP	Gross Domestic Product
ICIDH	International Classification of Impairments, Disabilities, and Handicaps
ICIDH-2	International Classification of Impairments, Activities, and Participation
IDB	Inter-American Development Bank
ILO	International Labor Organization
LAC	Latin America and the Caribbean
OAS	Organization of American States
РАНО	Pan American Health Organization
UN	United Nations
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development
WHO	World Health Organization
WPA	World Program of Action

Summary

This study is an attempt to review the current status of inclusive disability policies, statistics, and strategies in Latin America and Caribbean (LAC). Discussion focuses on six key elements:

- Conceptual framework, including key definitions, for disability analysis;
- United Nations (UN) commitment to equalize opportunities for people with disabilities;
- Ramifications of the UN commitment on regional and national policies in LAC;
- Summary of current knowledge on prevalence and causes of disability;
- Economic and social costs of disability; and
- Key characteristics of inclusive policies and strategies.

The 1982 UN World Program of Action Concerning Disabled Persons (WPA) focused on promoting effective measures for disability prevention and rehabilitation and realization of the equality and full participation of persons with disabilities in social life and development (UN 1982). In 1994, the UN General Assembly unanimously adopted the Standard Rules on the Equalization of Opportunities for Persons with Disabilities. Grounded in the WPA principles, these rules became the international legal standards for disability programs, laws, and policies.

In LAC, the 1993 Declaration of Managua, based on the principles of the WPA and Standard Rules, became the framework for establishing laws on disability issues in the region. In 2000, the Organization of American States (OAS) promulgated the Inter-American Convention on the Elimination of All Forms of Discrimination Against Persons with Disabilities to promote full integration of persons with disabilities into society.

Ramifications of these international and regional initiatives are evident in the various policy

instruments that have been established to address a range of disability issues across the LAC region—from health, accessibility, and education, to labor, human rights, and the media. Nonetheless, policy implementation and enforcement remain inadequate.

Detailed data on causes of disability—in LAC and other developing regions—is scarce. The prevalence reported (in household surveys and censuses) ranges from 1.2% in Colombia to 13.1% in Peru. (Wide, in-country variations stem from differences in definitions and methods.) In addition to direct causes, such as disease or accident, disability has many indirect causes. These include poverty, malnutrition, poor standards of public health services, and armed conflict.

The Inter-American Convention rightly rejects the notion that people with disabilities constitute a burden. Instead, the Convention emphasizes that only the disability, not the person with a disability, can be considered a cost imposition. The economic costs to persons with disabilities and their families include 1) those directly related to the disability, 2) those that caregivers incur, and 3) income that persons with disabilities and caregivers forgo. their Economic benefits include increasing the functional capacity of persons with disabilities and their participation in all aspects of productive life.

Disability is linked to poverty through limited access to rehabilitation, education, training, and employment. Children and women with disabilities, the elderly, and those with severe disabilities are particularly vulnerable.

To be effective, disability policies and strategies must be designed to facilitate the passage of people with disabilities through three distinct, but interrelated, stages of physical and social integration: 1) adapting to the disabling condition and maximizing functional capacity, 2) interacting with the community and society, and 3) gaining access to social and economic activities that give life meaning and purpose (e.g., contributing to family and community or becoming productively employed).

Comprehensive policies and strategies are required, based on the following principles of inclusiveness:

- Adoption and promotion of inclusive policies and practices;
- Removal and prevention of architectural and design barriers;
- Adoption of affirmative strategies that include people with disabilities in mainstream educational, vocational, political, and recreational activities;
- Support for and constructive engagement with organizations of people with disabilities; and
 - Provision of cost-effective, assistant technology.

Introduction

Over the past 25 years, technological improvements in medicine and rehabilitation have greatly increased the lifespans and functional capabilities of millions of people with disabilities worldwide. In recognition of this population's rights to greater socioeconomic participation and benefits, a global commitment has been made to equalize opportunities for people with disabilities.

This commitment, fully articulated and unanimously endorsed by the United Nations Member States in the 1982 World Program of Action Concerning Disabled Persons (WPA), is now reflected in the national policies of most LAC countries. Across the region, governments and international organizations are now attempting to develop national and regional policies and strategies that foster inclusion of people with disabilities throughout all aspects of community, society, and economy. Global progress, however, has been hindered by a policy environment characterized by lack of data and inadequate understanding of the elements that are key to successful, cost-effective policies and strategies.

Conceptual Framework for Disability Analysis

The most appropriate conceptual framework for disability analysis is the International Classification of Impairments, Activities, and Participation (ICIDH-2). Set forth by the World Health Organization (WHO), ICIDH-2 is a refinement of the WHO's initial framework, known as the International Classification of Impairments, Disabilities, and Handicaps (ICIDH). Both frameworks are currently in use in LAC (WHO 1980, 1997).

The original ICIDH represented a breakthrough in disability policy and research because it was the first time that personal, social, and environmental factors of people with disabilities were formally incorporated into such a framework. It was, therefore, the first to embody the fact that social policy can alter environmental contexts (e.g., cultures, institutions, and both natural and constructed environments), thus affecting the socioeconomic opportunities available to people with disabilities.

In the original ICIDH, disablement comprised three interrelated factors: impairment, disability, and handicap. The term disability was defined as a restriction or lack of ability to perform an activity in a manner or within a range considered normal for a human being (UN 1990). Α disability was viewed as being caused by an *impairment*, defined as a loss or abnormality of psychological, physiological, or anatomical structure or function. Impairment and disability were causally linked to the term handicap, defined as a disadvantage that limits or prevents the fulfillment of a role considered normal, depending on age, gender, and social and cultural factors (WHO 1980). Figure 1 illustrates the relationship between diseases or disorders and these three factors.



Figure 1. Disablement Phenomena as Conceptualized in the Original ICIDH

Source: WHO, 1997.

As defined within the ICIDH framework, an impairment (caused by a disease or disorder) can result in a disability, which, in turn, can lead to a handicap. For example, polio (a disease) can cause paralysis (an impairment); this, in turn, can result in limiting a person's mobility (a disability), which can lead to a person's inability to secure employment (a handicap). It is also possible for an impairment to create a handicap without causing a disability. For example, a facial disfigurement (an impairment) limits a person's ability to interact socially (a handicap) without causing a functional limitation (a disability).

The ICIDH-2, now in field trials, is an attempt by the WHO to respond to criticism from the

disability community over use of the term handicap and to expand on ways to take advantage of insights gained using the original ICIDH (Box 1). Division of the impairment dimension into two components (structure and combined with function). including environmental and personal factors as contextual elements that may restrict activity and limit participation, allows ICIDH-2, more fully than its predecessor model, to encompass the significant roles that personal and environmental factors play in determining the extent of disablement associated with a given disabling condition.

Box 1. ICIDH-2 Definitions for Disability Analysis

The ICIDH-2 framework defines key disability-related terms, as follows:

Disablement—Broadly defined term that covers three dimensions: body structure and function, personal activities, and participation in society

Impairment—Loss or abnormality of body structure or of physiological or psychological function, activity, or participation in society

Activity-Nature and extent of functioning at the level of the individual

Participation—Nature and extent of a person's involvement in life situations in relation to impairments, activities, health conditions, and contextual factors. Activity restrictions and limitations on participation are influenced by environmental factors (e.g., natural or constructed environments, culture, institutions, and prevailing attitudes toward those with disabilities) and personal factors (e.g., gender, age, education, social background, and life experience).

Source: WHO, 1997.

Figure 2, which outlines the expanded range of possible links between health conditions and contextual factors incorporated into the ICIDH-2, embodies the fact that a person may experience:

- An impairment without any activity limitation (e.g., a disfigurement that produces no activity limitation),
- An activity limitation without any evident impairment (e.g., poor

performance in daily activities caused by a disease),

- Limited participation without any impairment or activity limitation (e.g., discrimination resulting from HIV/AIDS or past mental illness), or
- A degree of influence in a reverse direction (e.g., muscle atrophy caused by inactivity or loss of social skills caused by institutionalization).



Figure 2. Current Understanding of Interactions within ICIDH-2 Dimensions

Source: WHO, 1997

Trends in Disability Policy

International Policies and Regional Initiatives

The UN's approach to disability has tended to mirror the evolution of disability thinking among the world's high-income countries. As early as the 1950s, the UN assisted governments with disability prevention and traditional rehabilitation services. Over the subsequent two decades, in response to advocacy and political pressure from an increasingly vocal. international disability community, the UN shifted its approach toward fostering the fuller participation of persons with disabilities in one integrated society (UN Secretariat n.d.). This objective was initially expressed through General Assembly resolutions in 1971 and 1975^{1}

In 1982, the WPA more fully articulated the new concept of equalizing opportunities for people with disabilities. Its focus was to

Promote effective measures for prevention rehabilitation of disability, and the of "full realization the goals of participation" of persons [with disabilities] in social life and development, and of "equality." This means opportunities equal to those of the whole population and an equal share in the improvement in living conditions resulting from social and economic development. These concepts should apply with the same scope and with the same urgency to all countries, regardless of their level of development. (UN, 1982, p. 1)

The WPA requires member states to:

 Plan, organize, and finance activities at each level;

- Create, through legislation, the necessary legal bases and authority for measures to achieve objectives;
- Ensure opportunities by eliminating barriers to full participation;
- Provide persons with disabilities rehabilitation services in the form of social, nutritional, medical, educational, and vocational assistance and technical aids;
- Establish or mobilize relevant public and private organizations;
- Support the establishment and growth of organizations of persons with disabilities; and
 - Prepare and disseminate information relevant to WPA issues.

In 1994, the General Assembly further clarified the new concept when Member States unanimously adopted the landmark Standard Rules on the Equalization of Opportunities for Persons with Disabilities. Although not legally binding, these rules have provided the "basic international legal standards for [programs], laws, and policy on disability" (UN 1994; Metts 2000). They are based on the fundamental WPA principle that people with disabilities "have a right to equal opportunities for participation in the life of society" (Michailakas 1997).

These international policy instruments have led to various regional initiatives. In Central America, the 1993 Declaration of Managua, which is based on the WPA principles and Standard Rules, is envisioned as a framework for the creation of laws on disability issues. Endorsed by the Central American Parliament and the Forum of Presidents of all Central American Countries, the Declaration has strongly affected development of the Inter-American Convention on the Elimination of All Forms of Discrimination Against Persons with Disabilities. Promulgated in 2000 by the

¹ UN General Assembly Resolution 2,856 (XXVI), On the Declaration on the Rights of Mentally Retarded Persons, New York, 1971; UN General Assembly Resolution 3,447 (XXX), On the Declaration on the Rights of Disabled Persons, New York, 1975.

Organization of American States (OAS), the Convention's goal, in keeping with the WPA principles and Standard Rules, is to promote the full integration of persons with disabilities into society (OAS 1991).

Ramifications for National Policies

This study reviewed national disability policies currently in force across the LAC region to determine the effects of the international policies and regional initiatives described above. A snapshot of disability legislation by country, including the types of legal instruments in existence, was assembled (Annex). Data was obtained primarily from an informal survey that the Inter-American Development Bank (IDB) conducted across all countries in the region, as well as the Pan American Health Organization (PAHO 1997), Canadian Association for Community Living (CACL 1997), and thorough review of available literature.

Direct effects of international principles and regional initiatives on national policies can be seen in the legislation of Costa Rica (Ley 7,600 de Igualdad de Oportunidades para las Personas con Discapacidad), Brazil, Guatemala, and Peru.² Moreover, many countries (e.g., Chile, Costa Rica, Dominican Republic, El Salvador, Honduras, and Uruguay) have ratified various international resolutions, conventions, and declarations.

Most of the instruments identified in this review address single-disability issues, such as education, labor, human rights, health, or accessibility. Some address media, building codes, and import-tax exemption on special vehicles. Others address the establishment of disability organizations or registries (e.g., CONAPREM in the Dominican Republic and the National Registry of Persons with Disabilities in Peru). Still others address the issue of support (mostly financial) or special assistance programs (e.g., allocating a percentage of tax on cigarettes to special activities in Costa Rica or special subsidies to assist homebuyers in Chile).

Certain countries have designated special days to increase public awareness of persons with disabilities. For example, in 1993, Colombia designated December 3 National Day of Persons with Disabilities. (This decree parallels the UN's designation of December 3 as International Day of Disabled Persons.)

Various general instruments reportedly address disability concerns, including the Code of Children and Adolescents in Honduras, National Commission on Human Rights in Honduras, and laws against domestic violence in Costa Rica. In addition, national constitutions refer specifically to persons with disabilities (e.g., Brazil 1988 and Venezuela 2001) (Annex).

While it is not feasible here to analyze the content and effectiveness of all disability-related instruments in the region, researchers have noted the global and regional inadequacy or nonexistence of policy implementation and enforcement (Helander 1995; CACL 1997). Specific examples can be found in Bolivia and Venezuela.³ For example, in Bolivia, the United States Agency for International Development (USAID) noted that Law 1,678 of 1995 "has not been properly operationalized or enforced; in fact, since it was passed by the Bolivian congress, only a few, mostly private organizations and the disabled themselves have been aware of it." (USAID 2000). In Venezuela, The National Council for the Integration of Persons with Disabilities noted the inadequacy of its 1994 law (CONAPI 2000). Referring to Central America, the CACL (1997) noted that

² Rodrigo Jimenez notes that the paradigm of aid and protection (i.e., persons with disabilities present a problem and should therefore be protected for having disabilities) is now nearly nonexistent as a basis for policy. This change has occurred mainly through the repeal of existing policies (e.g., Dominican Republic, Paraguay, and Venezuela).

³ In its analysis of health components of disability policies, PAHO, 1997, noted that the policies of most of the countries studied (Argentina, Chile, Costa Rica, Guatemala, Honduras, Mexico, Nicaragua, and Venezuela) lack well-defined coordination mechanisms, clear explanations of who will pay, and specific recommended actions.

problems in implementation create a widening gap between legal enfranchisement of persons with disabilities and their marginalized status.

In identifying underlying causes and potential solutions for the inadequate implementation and enforcement of disability policies and regulations, Helander (1995) suggests that 1) governments do more to inform citizens of their rights and duties; 2) governments create adequate administrative, political, and services structures to ensure the implementation and enforcement of relevant policies; and 3) efforts be made to clearly define general political objectives so that policies related to people with disabilities are consistent and better integrated.

Disability Statistics

Difficulty in establishing a consistent definition of disability has contributed to statistical unreliability and unavailability. Variations in survey methods and studies have compounded the problem, making valid data comparisons across countries or regions nearly impossible.⁴ Before 1990, few studies were carried out in the LAC region.⁵ Since then, however, a number of surveys and studies have been conducted at both local and national levels. Given the current difficulties in making cross-country comparisons, this study focuses mainly on national studies, using local surveys to provide illustrative detail.

Disability Prevalence

The most often cited estimate of global disability prevalence is the 1976 WHO figure of 10%. Based on the data available in 1976, this figure included a relatively large number of people with slight and reversible disabilities. Recently, the author of the 10% estimate revised the percentage downward to a global rate of 5.5%, which is an aggregate of 8.5% for more developed regions and 4.8% for less developed ones (Helander 1999). Some organizations now refer to this revised figure, while others maintain that the 10% figure is too low (Metts 2000). Since the 10% figure has been recognized for so long, it is still widely considered the official WHO estimate and is often cited. In 2000, the IDB conducted an informal survey across the LAC region on disability statistics, causes, and policies. Of the 25 countries surveyed, 20 have responded to date. Of these, 5 used the WHO 10% estimate of prevalence because they had not conducted any formal survey or census. Data based on the WHO estimate was not used in this review.

Disability prevalence, as reported in household surveys, ranges from 1.2% in Colombia to 13.1% in Peru (Table 1). Of the countries that lack prevalence data, six (Argentina, Bolivia, Brazil, Honduras, Trinidad and Tobago, and Venezuela) will include disability questions in their national surveys or censuses for the first time within the next year.

⁴ It is beyond the scope of this study to discuss the problems inherent in disability-related statistics. For a review of statistical issues, see UN, 1988 and 1996. The latter work is a comprehensive manual covering both the use of existing statistics and the development of future statistical information. Anticipated publications on disability statistics include a detailed study on disability surveys by Helander; results of a 2001 UN-sponsored seminar on disability statistics; and findings from the ICIDH-2 field trials.

⁵ For a review of disability statistics before 1990, including an examination of the UN statistical database, see PAHO, 1990.

Country	Prevalence (%)	Source for IDB Survey Response	Year
Chile	4.3	National Socioeconomic Household Survey (CASEN)	1996
Colombia	1.2	National Administrative Department of Statistics (DANE)	1993
Costa Rica	9.3	Multipurpose Household Survey	1998
Ecuador	13.2	National Institute of Statistics and Censuses	1996
El Salvador	1.6	General Directorate of Statistics and Censuses	1992
Mexico	2.3	XII General Population and Housing Census	2000
Nicaragua	12.3	Technical Report on Disabilities in Latin America (using data from Household Survey)	1995
Paraguay	1.0	National Population and Housing Census	1992
Peru	13.1	National Population (IX) and Housing (IV) Census	1993

Table 1. Prevalence of Disability in Selected Countries of LAC(% of Total Population)*

* Note: Cross-country comparisons are not possible due to variances in methods and disability definitions.

Even though figures are collected using official instruments, estimates can vary widely within countries. In Colombia, for example, the National Administrative Department of Statistics (Departamento Administrativo Nacional de Estadística or DANE) calculated that 2.1% of the population had some form of disability, according to the country's 1993 census. Then, in 1997, the National System of Information reported that 23.8% of the population had a disability. Two years later, the Department of

Health reported that 12% had a physical, mental, or sensory disability. The current government, in its National Plan for Disability, uses the figure of 18% (Corporación Síndrome de Down 2001).

The IDB survey also attempted to estimate the regional distribution of disability prevalence by location (whether rural or urban), gender, and age. Wide variations in survey results argue for further research that will facilitate better cross-country comparisons (Box 2).

Box 2. Disability Distribution Across the LAC Region

Below are results from the IDB 2000 survey on the distribution of disability by location (rural or urban), gender, and age (those under the age of 18). Statistics for each category are estimated proportions of the total population with disabilities (Elwan 1999).

Rural/Urban. Of the two countries that reported information on the distribution of persons with disabilities—Mexico and Paraguay—neither showed significant differences in rates between rural and urban areas. Worldwide, arguments have been made for higher rates in both areas. Thus, further research on the nature of rural/urban distribution is needed to better inform policies on services distribution.

Gender. No significant differences were reported in the percentage of women and men with disabilities, except for Uruguay (60% men, 40% female), where a self-selection bias is likely because of the nature of the sample. Worldwide, health conditions in certain countries may cause more frequent instances in one gender; however, overall incidence does not appear to differ (Helander 1999). One major factor that can affect the overall numbers is life expectancy. Since women tend to live longer than men, the female population, including women with disabilities, is larger. In other cases, a cultural bias toward boys increases the mortality rate of girls with disabilities (Duncan and Berman-Bieler 1998).

Children and Youth. Of the six countries that reported on the percentage of persons with disabilities under the age of 18, data varied widely (7.2% in El Salvador, 19.6% in Chile, 21.4% in Costa Rica, 23.2% in Paraguay, 43.9% in Peru, and 60% in Colombia). One reason for such wide variance may be differences in underlying age structure (if a population has more people under the age of 18, then higher proportions of the population with disabilities may be under 18). Another reason may be that questionnaire responses were limited to data on the proportion of people with disabilities who were children, meaning that specific data on disability prevalence *within* the child population would require further research. Worldwide, it has been noted that the proportion of children with disabilities is higher in developing countries than in more developed ones (Elwan 1999). Yet, in some cases, prevalence may be lowered by a high mortality rate for those born with disabilities and/or lack of early diagnosis (Helander 1999).

Table 2 provides an overview of the percentages of disability types for those who reported having a disability; however, this information is illustrative, not definitive, since the populations within each category may vary between For example, a visual-disability countries. category in one country may be specified as blindness in one or both eyes in a second country and may include another type of visual impairment in a third country, which greatly increases the percentage reported. In certain countries, mental disability might include those with mental retardation, a learning disability, people with and perhaps psychiatric impairments.

Thus, the need to create a common language and methodology for collecting and analyzing

disability statistics should be emphasized.⁶ Reliable national information is essential for policy and program development, and reliable local information is necessary for developing effective services (Amate 1993). In the interim, currently available data is useful primarily in facilitating a dialogue on disability in the region.

⁶ In response to the challenges involved in collecting disability information, PAHO developed guidelines for collecting disability data in household surveys. Using these guidelines, based mainly on the ICIDH method and questions, a country can obtain estimates for the number of persons with impairments, disabilities, and handicaps. Peru was the first country to follow these guidelines in its 1993 survey, the report of which analyzes the data and makes recommendations for future surveys using this method.

Country	Visual	Auditory and Speech	Physical	Mental	Other	Source
Barbados	23.8	14.1	26.1	12.9	28.3	BARNOD
Chile	26.9	32.9	21.2	13.1	5.9	MIDEPLAN
Colombia	48	31.7	24	17	NA	Down Syndrome Corporation
Costa Rica	26.5	4.8	18.9	8.1	41.7	National Council of Rehabilitation and Special Education
El Salvador	22.2	21	29.4	16.2	NA	Salvadoran Institute of Disability Rehabilitation (ISRI)
Mexico	28.6	21	44.9	14.6	0.7	XII General Population and Housing Census
Nicaragua	63.1	14.1	8.5	4.0	9.6	National Autonomous University of Nicaragua
Paraguay	11	20.2	19.5	13.2	36.1	Ministry of Public Health and Social Well-being
Peru	9	20	49	22		CONADIS
Uruguay [*]	11.6	16	45	19	NA	National Commission of Disability

Table 2. Overview of Disability Types

* Based on a sample of 500 people enrolled in the National Registry of Persons with Disabilities of the National Commission of Disability. While this sample is not large enough to estimate prevalence for the country, the data provide interesting information on other aspects of disability.

Note: Cross-country comparisons were not possible due to variances in methods and disability definitions.

Causes of Disability

In discussing causes of disability, one must distinguish between direct causes or proximate determinants of impairment, such as disabling diseases; congenital causes; accidents and injuries; and underlying or indirect factors, many of which are linked to poverty. Causes of disability, which may vary greatly within and between countries, are affected by level of development, standards of public health services, age structure, and lifestyle.

In LAC, as in much of the developing world, detailed knowledge about causes of disability is

limited. Figures are sketchy, restricted largely by divergent estimates based on a few census and survey results that do not permit cross-country comparisons. Such differences between countries reflect the great changes they have been undergoing in recent decades and their varying stages of development.⁷

⁷ Sources that deal with the concept of demographic transition include the World Bank's *1984 World Development Report*, as well as demographic textbooks.

In the early stages of economic and demographic transition, relatively low income levels and living standards tend to be associated with high mortality and fertility levels. Moreover, a larger proportion of ill health is caused by communicable, childhood, and child-bearing diseases, as well as those related to unsanitary or unsafe living or working conditions. WHO notes that the major causes of disabling impairments in developing countries are malnutrition, communicable diseases. low quality of perinatal care, and accidents (including violence) (WHO 1981). In more developed societies, characterized by relatively low levels of mortality and fertility, a larger proportion of the population is older and subject to cancer, heart disease, and arthritis. The causes of disability in a population are influenced by these disease patterns; however, congenital diseases cause а significant proportion of disabilities, regardless of the other disease patterns.⁸ Although much progress has been made in the LAC region, there is still great potential for disease prevention and reduction of causes of impairment. In 1993, it was estimated that more than half of the region's population with disabilities would have become disabled by the end of the century as a result of lack of preventive measures (Amate 1993).

Poverty-related Causes

Risk of infection, associated with many communicable diseases, is higher for poor families because inadequate sanitation increases exposure to harmful pathogens. Inadequate shelter is conducive to disease vectors (such as mosquitoes) and overcrowding increases transmission. Poor living conditions and nutrition can also decrease individual resistance to disease; in poor areas, preventive measures, such as vaccinations, are often inadequate. People in low-income countries, who tend to work in physically-demanding labor environments, are more prone to accidents and injuries than workers in high-income countries. Lack of adequate, timely health care and rehabilitation services often exacerbate disease outcomes, turning impairments into chronic disabilities.

Malnutrition in its various forms can function simultaneously as a direct cause of disability and as a factor that increases susceptibility to other disabling diseases.⁹ Babies of poor mothers often have low birth weights and risk contracting debilitating diseases. A 1992 review points out that accurate birth measurements play an important role in identifying high-risk children and that LAC has the necessary hospital infrastructure to obtain reliable birth data of this kind (Perez-Escamilla and Pollitt 1992). Recently, much knowledge on the various forms of malnutrition and their effects on health and disability have been acquired (Ebrahim 1983; UNICEF 1998). 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 (Khan and Durkin 1995).

In developing countries, major disabling, communicable diseases include poliomyelitis, trachoma, onchocerciasis (river blindness), measles, and leprosy (Doyal 1983; Despouy 1993). HIV/AIDS is also a growing concern. The spread of trachoma, polio, and schistosomiasis (a debilitating disease estimated in the early 1980s to affect some 850 million people) is related to inadequate sanitation.

Much progress has been made toward eradicating polio and measles, largely through widespread immunization programs; by late 1994, global vaccine coverage for these two

⁸ Most respondents of the 2000 IDB questionnaire identified this category of causes as the most important or second most important. However, caution should be taken in interpreting results or making comparisons as the categories also included underlying, as well as direct, causes.

⁹ Micronutrient deficiencies can have severe direct consequences; for example, lack of vitamin A can cause eye disorders and even blindness. Globally, however, micronutrient deficiencies are rapidly diminishing because of large-scale interventions; this trend is also likely for the LAC region.

diseases was 78% (Helander 1995). The last confirmed case of acute, paralytic poliomyelitis in the Western Hemisphere occurred in Peru in 1991. Measles not only kills children, but is one of the main causes of blindness, deafness, and mental defects (Despouy 1993). Communicable eye diseases, such as river blindness and trachoma, have already been largely reduced. Of particular relevance to the LAC region is the rapid progress in combating Chagas disease, a WHO notes that its sleeping sickness. transmission through vectors and blood transfusion has either been eliminated or is close to elimination in Argentina, Brazil, Chile, and Uruguay, which will lead to reduced incidence for more than 70% of the region (Moncayo 1997). Other disabling, but largely preventable, diseases in the LAC context include malaria.¹ leishmaniasis,¹¹ tuberculosis,¹² and mumps.

Accidents and Injuries

Injuries are among the world's leading causes of disability and death. Those associated with road traffic are the most common. Injuries affect mostly young people, often causing long-term disability (Krug et al. 2000). A 1992 study notes that accident-related death rates for children under 15 years of age in many LAC countries are higher than those in the United States; in addition, attention and resources devoted to the prevention of such accidents are not commensurate to their importance as a public health concern (Francisco 1992). Work-

related accidents also cause a significant proportion of disability in the region.¹³

Longevity and Lifestyle

Patterns of disease can change dramatically in association with increased longevity and changing lifestyles. Non-communicable diseases have become the main cause of chronic ill health in Caribbean countries, where it is estimated that more than 70% of persons with disabilities are adults. Chronic disability is a growing problem. Leading contributors are hemiplegia (paralysis of one side of the body resulting from stroke); blindness; and diabetes, a growing disability that affects 12-15% of the adult population aged 35 and over.

Lifestyle is considered to be strongly associated with diabetes, as a large proportion of diabetes sufferers are overweight (Hagley 1990). A study of hospital patients in Trinidad and Tobago showed that 56% of surviving stroke patients were severely disabled at the time of discharge. The study noted that, for most stroke cases, risk factors were subject to modification (for example, hypertension), and that effective preventive strategies needed to be developed (Mahabir, Bickran, and Gulliford 1998).

Mental Conditions

One must distinguish between the diagnosis of mental conditions and the measurement of resulting disability needs. Epidemiological classifications inadequately capture such recently recognized phenomena as mild mental retardation, which is thought to result from the under-stimulation of children in disadvantaged

¹⁰ As USAID, 2000, notes, repeated bouts of cerebral malaria are associated with significant, permanent reduction in cognitive ability; malaria may also lead to low birthweight and permanent stunting of growth.

¹¹ Leishmaniasis is a parasitic disease; in South America, symptoms include lesions of oral and nasal mucous membranes.

¹² USAID, 2000, notes that tuberculosis, left untreated, can lead to long-term disabling disease or even paralysis. Bolivia has one of the highest incidence rates in the LAC region.

¹³ In the IDB survey responses, rankings of workrelated accidents were only slightly lower than those of traffic accidents. In 1981, for example, it was estimated that some 8% of registered workers in Brazil were affected by industrial accidents each year (Moyes, cited in Doyal, 1983).

societies (Khan and Durkin 1995).¹⁴ UNICEF (1998)also links impaired intellectual development to child malnutrition. Global prevalence of mental retardation has been estimated at 1-3% of the world's population (Sen 1992). However, detailed estimates of mental handicaps, including mental retardation, vary widely, often differing within countries. Causes of such variations include differences in definition, age groups sampled, sociocultural influences, and measurement tools. Thus. further research on the relationship between psychiatric disease and disability is warranted.

Armed Conflict

Information on disabilities resulting from armed conflict is scarce, and estimates are unreliable. With few exceptions,¹⁵ prevalence estimates are only educated guesses because of widespread absence of surveys and registration programs and unreliable population estimates. In current types of prevalent conflict, characterized by guerilla warfare and shifting alliances, civilians risk disabling injuries from sniping, shelling, contact with unexploded ordinance and landmines, and various other forms of active hostility. They may also become the victims of violent excess. For example, in El Salvador, Guatemala, and Nicaragua, thousands of people are reported to have suffered mutilation, while suffered psychological others have and emotional after-effects of conflict (CACL 1997).

Refugees of conflict are vulnerable to potentially disabling diseases because of the conditions they experienced while traveling or in refugee camps. During armed conflict, health-care and socialassistance systems break down. Preventive programs are also disrupted, causing normally treatable conditions to become disabling. Those already disabled and those who become disabled during armed conflict are particularly vulnerable. Existing estimates of people with conflict-related disabilities are likely to underestimate the psychological disabilities brought on by conflict-related trauma, which often remain undiagnosed and unrecorded.

¹⁴ It has been estimated that less than one-third of mildly retarded individuals show evidence of organic impairment and that, in most cases, retardation is caused by an impoverished social environment; see Sen, 1992.

¹⁵ Several sources refer to a relatively high proportion of Nicaraguans who became disabled as a result of war.

The 2000 Inter-American Convention rightly rejects the notion that persons with disabilities constitute a burden, emphasizing, instead, that only disabilities, not people, impose costs. A study of the integration of people with disabilities into Central America's workforce points out the damaging effects of the view that people with disabilities impose a burden on society, noting that "the cost is not only that people with disabilities are not included in social institutions, like regular education. Equally important is that other members of society, nondisabled children in the classroom, for example, do not develop capacities to include persons with disabilities and to recognize their contributions" (CACL 1997).

Much of the traditional analysis considers costs in terms of lost earnings equivalent to days worked. For example, the global gross domestic product (GDP) lost annually as a result of disability has been estimated, using disability and unemployment rates (Metts 2000). Such estimates depend on accurate wage data in a functioning labor market. In 1990, the Global Burden of Disease (GBD) study aimed to capture the number of years lived with disability and the relative severity of disability for a given population using a single indicator, the Disability Adjusted Life Year (DALY) (Murray and Lopez 1994).¹⁶ For childhood disability, days of restricted activity or days missed from school are sometimes estimated. Number of days hospitalized and physician visits have also been considered in the context of disability costs (Berggren, Ewbank, and Berggren 1981).

Use of Cost-benefit Analysis

Researchers also consider the economic benefits of increasing the functional capacities of people

with disabilities, measured primarily in terms of income gains following rehabilitation and other interventions that reduce levels of disability associated with impairments. A recurring research theme in high-income countries is analysis of the costs and benefits of rehabilitation and employment, which centers on the adequacy, equity, and efficiency of formal compensation and assistance schemes (Manton, Stallard, and Corder 1998; Haveman et al. 1995).

Cost-benefit analysis has also been used to prevent impairments caused by disease or accidents; that is, studies of the typically low costs of vaccinations and other disease prevention programs, when compared to the costs of treatment and rehabilitation. There is still a great deal of scope for prevention through relatively simple interventions; where this is the case, interventions are typically cost-effective. For example, prior to the tremendous progress made to reduce transmission of Chagas disease, large economic losses were incurred as a result of disability and early mortality; in 1995, the economic losses from Chagas disease equaled 2.5% of the continent's external debt (Moncavo 1997). The costs of control measures, by comparison, were extremely small.

Traditional cost-benefit analysis, which relies on comparing the costs of a project or program with those of an alternative, is not necessarily appropriate for analyzing certain contemporary programs aimed at reaching people with disabilities. For example, if community-based approaches to rehabilitation are preferred to institutional approaches because of their basis in the rights of their constituencies to community comparisons with institutional access, approaches may be irrelevant because the programs' objectives differ. Moreover, where community-based approaches have been initiated because traditional approaches have not reached a large proportion of the population, cost-benefit analysis is inappropriate because

¹⁶ Metts et al., 1998, notes the GBD study's problems with defining disability and methods for estimating the relative severity of disabilities.

there is no alternative on which to base comparative costs.

Traditional cost-benefit analysis also may be inappropriate for contemporary programs that have multiple objectives. Such programs may use a variety of interventions to achieve several types of outcomes that are non-measurable in economic terms. The framework for their economic evaluation is therefore limited largely to cost-effectiveness analysis. In other words, evaluation involves considering whether the program's range of objectives is being achieved with an efficient use of resources.

A study on disease-vector control in rural communities of Paraguay is one of LAC's few examples of analyzing the use of costeffectiveness. In that country, three interventions for controlling Chagas disease vectors were tested. While results for the three methods were comparable, costs of the spraving method amounted to 4% of the costs of the other two interventions (Rojas de Arias et al. 1999). As a result of this analysis, large-scale spraving of rural homes played a critical role in controlling Chagas disease in six South American countries, and efficient use was thereby made of scarce resources (Schofield and Dias 1999).

Costs to Households and Individuals

The three major economic costs of disability to persons with disabilities and their families are:

- Costs directly related to the disability;
- Costs incurred by caregivers of the individual with the disability; and
 - Income forgone, either by the individual with the disability or his or her caregivers, as a result of the disability.

Direct costs include medical expenses, equipment (such as crutches and wheelchairs), housing adaptations, and specialized services. In some societies, medical expenses for persons with activity limitations can exceed four times those for people without limitations (Trupin, Rice, and Max 1995; Avery 1983).

A large proportion of people with disabilities require assistance in carrying out one or more daily tasks, the costs of which are borne by persons with disabilities, their caregivers, and state or local authorities (as part of welfare systems). In developing countries, which lack the types of income-maintenance programs found in higher-income countries, people with disabilities usually become the responsibility of their families, whose support can be critical (Neufeldt and Albright 1998).

It is generally estimated that 25% of community members are affected by a disability, including the persons with disabilities, their families, and other caregivers. A survey in rural Chile found that two-thirds of people with disabilities required assistance in their daily life (Silva and Baechler 1989). A 1993 survey in Peru found that family assistance covered more than half of the expenses of people with disabilities, while 33% came from working and 6% from official programs.

Costs to caregivers are both economic (e.g., loss of employment and earnings) and non-economic (e.g., social marginalization). Studies have shown that mothers of children with disabilities are less likely than other mothers to have paid employment (Baldwin and Glendinning 1981); in addition, raising a child with a severe disability costs significantly more than raising a child without a disability (Dobson and Employed mothers of Middleton 1998). children with disabilities tend to work fewer hours and at lower pay rates than their controlgroup counterparts (Glendinning and Baldwin 1988; Baldwin 1985). In terms of non-economic costs, one recent study suggested that elderly, spousal caregivers in the United States experience associated strain that can lead to higher mortality risk than non-caregivers (Schulz and Beach 1999). Changes in household structure can affect care-giving For example, in Africa, as a arrangements. result of rural-to-urban migration, people with disabilities are increasingly being left in rural communities to survive on subsistence farming

and irregular remittances (Ingstad 1995). Other non-economic include negative costs psychological and social effects of marginalization, exclusion from social services and community activities, and disruption of family routine. In the Latin American Independent Living Survey of 2000, respondents from several countries noted discrimination and exclusionary attitudes toward people with disabilities.

Poverty and Disability

Disability and poverty are inextricably linked; as mentioned earlier, conditions of poverty increase the risk of becoming disabled, while disability can lead to impoverishment of particularly vulnerable groups.

Access to Services

Limited access to rehabilitation services reduces opportunities of people with disabilities to receive the education and training they may need to contribute productively to their households and communities, thereby increasing their chances of sinking into poverty. Access problems are usually more severe in rural areas, where higher illiteracy rates and longer distances to service locations compound the difficulties of accessing information and health-care and rehabilitation services. A 1992 CACL study noted the limited availability of rehabilitation services to people with disabilities in Central America, particularly in rural areas, where less than 1% of those with disabilities receive services (CACL 1997).

The costs associated with disabilities can be particularly devastating for poor households. Where outside support is unavailable, the additional family time and resources required can negatively affect household well-being. In cases where the person with the disability is responsible for all or part of the household's income or subsistence, the effect can be devastating.¹⁷ In cases where a household's economic base is already fragile, socioeconomic deprivation is associated with a higher risk of impairment and a higher risk of a treatable impairment becoming a disability, although these associations have not been adequately recognized.¹⁸

Most middle- and high-income countries have programs that cover a portion of the risk of work-related disability (resulting from accidents and occupational diseases) and non-work-related In many low-income countries, disability. however, state rehabilitation programs may not be an option for those outside the formal labor People with disabilities in agrarian market. societies or urban dwellers in the informal sector may have to depend more on themselves or their families and communities than on the formal labor sector. One study of people with disabilities in Oaxaca, Mexico found that, while most respondents with disabilities in the urban capital reported receiving some rehabilitation or financial assistance, only 13% of those from the surrounding mountainous areas did (Marshall et al. 1998).

Access to Education and Training

On average, people with disabilities receive less education and are more likely to leave school with fewer qualifications than their non-disabled peers (Neufeldt and Albright 1998; Neufeldt and Mathieson 1995). One study in Central America

¹⁷ Evans, 1989, notes the effects of onchocerciasis (river blindness) on rural households in Guinea, describing the downward spiral precipitated by the deteriorating vision of the household head, diminishing cultivation of land and production of food, increasing dependency ratio within the family, and household destitution.

¹⁸ Acton, 1983, notes that "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 lifelong incapacity" have not been adequately recognized.

notes that special-education services are provided to only 3% of school-age children with disabilities (participation rates vary between 2% and 15%). Preliminary results from household surveys in Brazil, Costa Rica, and Nicaragua indicate that, for all three countries, the proportion of people with disabilities who have no schooling is higher than for those without disabilities (Montes and Massiah 2002). In Costa Rica, 13.8% school-age children with disabilities receive secondary-level education. The proportion decreases for those who have reached the eleventh grade, and decreases again for those who receive higher education. However, this trend appears to be changing, as more efforts are made to improve access of people with disabilities to secondary and higher education.¹⁹

Access to Employment

The little existing data from developing countries shows that people with disabilities are less likely to be engaged in economic activity than the rest of the population.²⁰ The ILO notes that unemployment rates for people with disabilities can be two or three times higher than for those without disabilities (ILO 1984). A CACL study on integration of people with disabilities into the workplace in Central America notes that "rates of labor force participation and employment of persons with disabilities have not been collected for the most part," but "high rates of unemployment in the Central American countries, and the correlation between poverty and disability indicate that labor force participation of people with disabilities is lower than that of the population as a whole" (CACL 1997). Worldwide, the

proportion of people out of the labor force is higher for those with disabilities than for those without; in addition, employed people with disabilities tend to be under-employed relative to their levels of training (Neufeldt and Albright 1998; Elwan 1999; Glendinning and Baldwin 1988).

Education, training, and physical access are linked to employment, as the following examples illustrate:

- ➢ In Argentina, study of 100 а rehabilitation training-course and graduates with disabilities found that beneficial been training had in facilitating entry into the labor force. Moreover, incomes of employed graduates with disabilities who had received training did not differ significantly from their peers without disabilities who had similar jobs (Blasco de Aufiero et al. 1991).
 - In Mexico, a study of people with disabilities in Oaxaca found that more than half of adult respondents with disabilities were unemployed and that most unemployed people with disabilities had no education (Marshall et al. 1998).

Access to Income and Assets

people with high-income countries. In disabilities have lower incomes than those without disabilities. Compared to people fewer people with without disabilities. disabilities own their own homes or have substantial assets, pensions, or other welfare benefits, despite the additional claims of disability-related expenses on income (Laplante et al. 1996). Other studies from high-income countries show that elderly people with disabilities are more likely to have incomes below the poverty line, even after standardizing for age and household composition (Townsend 1979).

¹⁹ Communication from S. Chavarria, University of Costa Rica.

²⁰ However, preliminary survey results indicate that, for Nicaragua, the differences between the proportion of employed people with and without disabilities may be small, although they appear slightly larger for Costa Rica; the greatest differences are found in Brazil (see Montes and Massiah, 2002).

Studies show that, in high-income countries, women with disabilities are slightly more disadvantaged than men with disabilities. Indicators on income, education. and employment levels of people with disabilities show consistent, but not necessarily large, gender differentials. These differences can be significantly larger in developing countries. For example, one study in Oaxaca, Mexico found that about 33% of adult, female respondents with disabilities were employed, compared to more than 50% of male respondents with disabilities (Marshall et al. 1998).

Because a disability affects an entire family, other family members may also be at risk. Women, more than other family members, are more likely to function as caregivers for children with disabilities. This often means that they are unable to invest in themselves. In its response to the 2000 IDB survey, Colombia noted that, in most cases, the wife or mother is responsible for the care, rehabilitation, and education of a child with a disability and that female heads of households are particularly vulnerable (Corporación Síndrome de Down 2001).

Children and women with disabilities, the elderly, and those with severe or multiple disabilities are particularly vulnerable to the adverse effects of welfare changes. The United Nations Children's Fund (UNICEF) notes that, worldwide, some 150 million children with disabilities lack access to childcare services, schools, recreation, and other social services. Consequently, they are likely to remain illiterate, untrained, and, ultimately, unemployed.

Inclusive Policies and Strategies

If LAC is to uphold regional and national commitments to equalizing opportunities for people with disabilities, a coordinated effort based on greater understanding of disability will be required. Coordinated and integrated policies and strategies must be put in place to eliminate or mitigate the personal, social, and environmental barriers identified in the ICIDH-2, while empowering as many people with disabilities as possible to maximize their social and economic contributions.

To this end, policies and strategies must be designed and coordinated to facilitate the passage of people with disabilities through three distinct, but interrelated, stages of physical and social integration:

- 1. Adapting to the disabling condition and maximizing functional capacity,
- 2. Interacting with community and society, and
- 3. Gaining access to social and economic activities that give life meaning and purpose (e.g., contributing to family and community, actively participating in society, and becoming productively employed).

During the **first stage**, policies and strategies must provide physical and mental restoration, physical therapy, assistant technology, prosthetic devices and appliances, personal assistance, information, advocacy, and training in all activities associated with adapting to the disabling condition and maximizing functional capacity.

Second-stage strategies must be designed to provide mobility training; assistant technology; and access to housing, education, transportation, and recreation. Complementary social and institutional measures include removal and prevention of architectural and design barriers and removal of social and economic barriers (such as negative stereotyping) that restrict people with disabilities from fully participating in their families, communities, and societies.

The **third stage** must provide access to education, training and recreation, and support for employment and social participation. Complementary institutional measures include policies and strategies to reduce discrimination that restricts access of people with disabilities to social and economic opportunities (e.g., education, training, and employment).

Piecemeal interventions are unlikely to be costeffective because their beneficial effects cannot be fully realized unless their beneficiaries have maximized their functional capabilities and gained access to the full range of social and economic opportunities. Therefore, national governments and international organizations must develop and implement comprehensive, multifaceted policies and strategies based on the following inclusive principles:

- Adoption and promotion of inclusive policies and practices. Inclusive policies and practices are those that foster the inclusion of people with disabilities and a concern for their rights and needs in all aspects of an institution, community, or society. At the institutional level, such commitments are expressed through mandates to recruit and employ people with disabilities and to design, implement, and evaluate all policies, practices, and activities in ways that take their needs, rights, and concerns into account.
- \triangleright Removal and prevention of architectural and design barriers. People with disabilities face a multitude of architectural and design barriers that prevent them from achieving access to vital aspects of society, including public education: public physical transportation; and the infrastructure associated with mainstream vocational, political, and civic activities. Removal of such barriers and prevention of

creating new ones are critical elements in any successful inclusive policy or strategy.

- \triangleright Reduction of stigma and discrimination. People with disabilities are often subjected discrimination. whose negative to consequences are particularly severe in resource-poor countries. Discrimination results in being denied equal access to social and economic opportunities and benefits. It also reinforces a climate of low expectations and negative stereotyping, which further limits potential. Such handicaps can be overcome only through public education and affirmative actions aimed at empowering people with disabilities and ensuring them a place in mainstream society.
- Support for and constructive engagement \geq with organizations of people with disabilities. People with disabilities and their families are the most qualified and best equipped to support, inform, and advocate on behalf of themselves and other people with disabilities. They are also the most qualified and motivated to speak about the need for appropriate design and implementation of policies and strategies to facilitate their contributions to society. Therefore, support for and constructive engagement with organizations of people with disabilities are the most cost-effective investments available to nations and international organizations wishing to increase the socioeconomic participation of people with disabilities.
- Cost-effective, assistant technology. Because disabilities involve functional limitations, it is often difficult or impossible for people with disabilities to interact with their communities and societies without specialized assistance or technology.

Whether customized (e.g., Braille writers, prosthetic devices, wheelchairs, and hearing aids) or mainstream (e.g., personal computers, electronic mail, and the Internet), assistant technologies are vital in

giving people with disabilities access to social and environmental opportunities.

Mainstream technology is often more cost-effective than customized versions. For example, electronic mail has revolutionized the communications capacity of the hearing impaired at a fraction of the cost of customized communications; personal computers and the Internet have increased the social access of those with impaired verbal capacity in a similarly costeffective way.

In any large population, a certain percentage will continue to incur severe disabilities that prevents it from passing through all three stages of physical and social integration, even within the context of the comprehensive policies and strategies outlined above. This subgroup of people with disabilities will require lifelong support services (e.g., ongoing personal assistance) to remain capable of making social and economic Others might require contributions. specialized support services at certain times in their lives in order to overcome specific obstacles (e.g., specialized training, rehabilitation, or housing and workplace modifications).

To be cost-effective and commensurate with the global commitment to equalizing opportunities for people with disabilities, these services must be:

- Designed to facilitate access to the social and economic mainstream, wherever possible;
- Provided in mainstream institutional settings, wherever possible; and
- Provided within the context of the comprehensive, inclusive principles outlined above.

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Annex. Legislation on Disability in Latin America and the Caribbean, 1985–Present

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Note: Each letter represents the existence of at least one of that type of legal instrument.

C = Constitution L = Law

Law R = Regulation

Type of instrument unknown

D = Decree P = Policy Res = Resolution * = No data

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