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# isability in the Caribbean. A study of four countries: a sociodemographic analysis of the disabled

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**Statistics and Social Development Unit** 

Port of Spain, June 2008





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# **Abstract**

With the adoption of the Convention of the Rights of Persons with Disabilities in December 2006 and its entry into force in May 2008 ECLAC considered it timely to conduct a study on disability in the Caribbean.

The present paper presents an overview of definitions and concepts applied by the United Nations and further describes different concepts and methodologies that are available to quantify and measure disability. The results of a desk-review on policies and programs in the region revealed that much more needs to be done to sufficiently address the wide scope of needs of the disabled. In order to fill the knowledge-gap on disability, the focus of this paper is to present the findings of an empirical four country study using recent census data. The data for Antigua and Barbuda, Saint Lucia, St. Vincent and the Grenadines and Trinidad and Tobago revealed rather common trends. It was found that the primary cause for disability were life-style related diseases that affected mainly elderly persons and among those more women than men. Males, on the other hand, experienced higher rates of disability in childhood and youth since they were much more susceptible to genetic diseases than young females. Also, as young men in their late teens and twenties partook in more risk-taking behaviors, such as driving and aggressive drinking than young women, they were also more likely to become disabled as the result of an accident than young women.

The study further looked into the accessibility of assistive devices, living arrangements and social activities of those affected by these ailments. However, in order to better understand the situation of the disabled also in the wider Caribbean, more information would be needed on the prevalence, the epidemiology of various types of ailments and disabilities as well as on particular initiatives undertaken by Governments and civil society to meet the needs of those affected.

# Introduction

The World Health Organization (WHO) estimates that presently nearly 600 million people are living with disabilities worldwide. The organization also projects that the number of disabled is on the rise, due to aging populations, escalating rates of chronic diseases among the elderly and injuries sustained from violence, vehicular accidents and workplace-related incidents. Nearly 80 per cent of the disabled are found in low-income countries. They live in poverty and have quite often very limited access to the basic health and social services they require. Much of the literature on disability in developing countries also notes that the disabled are often poorer than the rest of the population and that those living in poverty are more likely to become disabled.

To aid in improving conditions for the disabled worldwide, the United Nations General Assembly approved the Convention on the Rights of Persons with Disabilities in December of 2006. It is hoped that the Convention will encourage countries into taking action and also raise awareness of the issues faced by the disabled. As of August 2007, the treaty had been signed by 101 United Nations member countries and seven signatories are Caribbean States.<sup>1</sup>

Caribbean signatories included: Antigua and Barbuda, Barbados, Cuba, Dominica, the Dominican Republic, Guyana and Jamaica.

As in many other parts of the developing world, little is known or written about disability in the Caribbean. Therefore the purpose of this paper is to provide the foundation for a dialogue on disability in the region by, first, providing some background information on the matters surrounding disability, including its definitions, measurements, and causes. Special attention will also be given to disability among the most vulnerable sectors of society: women, children and the elderly. This is followed by an overview of the work carried out by the United Nations to assist the disabled over the last 50 years. Then, an overview of the information found via desk-research on disability in the Caribbean is provided. Finally, an in-depth analysis of most recent census data sets (2000 census round) of four Caribbean countries: Antigua and Barbuda, Saint Lucia, St. Vincent and the Grenadines and Trinidad and Tobago, is presented. This analysis focuses exclusively on census data and looks at various aspects of disability, such as age- and gender-specific prevalence rates, causes for these ailments, access to assistive devices and living conditions of those whose lives are affected by such debilitating circumstances.

Along with the newly adopted Convention on the Rights of Persons with Disabilities, it is hoped that this first thorough multiple-country study on disability can inspire the countries in the region to strengthen their efforts towards recognizing the needs of all disabled persons in their countries to improve their lives at present and in the future.

# I. Definitions and concepts

Numerous definitions of disability exist in the literature<sup>2</sup> and the concept has many dimensions with both subjective and objective characteristics.<sup>3</sup> The definitions often rely on the perception of "normal activity" and what is perceived as normal can vary. Disability is also difficult to observe, as it involves the subjective evaluation and verification of both the individual in question and the individual's peers.<sup>4</sup>

Some of the literature argues that the lack of consensus is reflective of the multifaceted nature of the concept and should not be perceived as something negative. Developing a definition for disability, however, is not merely a matter of semantics. Changing the theoretical definition can have serious political, economic and social consequences. It can, for example, have far-reaching implications for the design of government programmes and access to these programmes by the disabled. Moreover, as will be discussed in a later chapter, the manner in which the concept is defined also directly affects its measurement.

11

Thomas, Philippa. "Disability, Poverty and the Millennium Development Goals: Relevance, Challenges and Opportunities for DfID." Department for International Development of the United Kingdom, June 2005.

Government of Canada, Human Resources and Social Development Canada Site, available from http://www.hrsdc.gc.ca/asp/gateway.asp?hr=/en/hip/odi/documents/Definitions/Definitions003.shtml&hs=hze; accessed 8 February 2007.

Wan, Ann. "Poverty and Disability: A Survey of the Literature." Social Protection Discussion Paper Series, No. 9932. World Bank, December 1999.

itra, Sophie. "The Capability Approach and Disability." Journal of Disability Policy Studies 16 no. 4, Spring 2006.

<sup>&</sup>lt;sup>6</sup> Government of Canada.

The twentieth century saw an evolution in the perception of disability.<sup>7</sup> Traditionally, disability had been perceived as an abnormality or a health problem that resided within an individual's mind or body. The disabled individual was seen as having an unwanted condition that forced him/her into the role of being abnormal or sick. During the last century, with the recognition that disability was more than a set of medically defined limitations, the definition of disability evolved. It was recognized that disability was also characterized by the manner in which individuals perceived and reacted to their limitations and by how others influenced an individual's limitations through their expectations and reactions.<sup>8</sup> It was also understood that the disabled were "disadvantaged not only because of their impairments, but also as a result of the limitations imposed on them by social, cultural, economic and environmental barriers." Contemporary perspectives on disability hold that disability does not originate on individual's physical or mental health, but in the societal restrictions faced as a consequence thereof.<sup>9</sup>

# A. WHO and disability classification

In response to the need for a universal definition and classification system for disability, the WHO published the International Classification of Functioning, Disability and Health (ICF) in 2001. <sup>10</sup> The guide is an attempt "to provide a coherent view of different perspectives of health from a biological, individual and social perspective." Its primary purpose is to provide a standardized language for classifying a large variety of information on issues related to health, including disability.

See Annex 1 for a full description of the most prominent theoretical models concerning disability.

<sup>8</sup> Ibid.

Albert.

See Annex 1 for further explanation of the ICF manual.

<sup>&</sup>lt;sup>11</sup> WHO, 2001: 20, cited in Mitra, p. 238.

# II. United Nations and disability

The United Nations World Programme of Action for Disabled Persons and the Standard Rules on the Equalization of Opportunities for Persons with Disabilities stresses that disability is a socially created problem, as opposed to an attribute of the individual. The United Nations Convention on the Rights of Persons with Disabilities states that "disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others." <sup>12</sup>

Adopted by the General Assembly in 1971, the Declaration of the Rights of Mentally Retarded Persons was the first treaty to pass through the United Nations specifically concerning disability. It provided a "framework for protecting the rights of the mentally retarded through national and international action," and emphasized the need for adequate medical care, education, protection from exploitation, and equal access to legal procedures for the mentally disabled. In 1975, the General Assembly passed the Declaration on the Rights of Disabled Persons. The treaty recognized the need to reaffirm the political, social, legal, and economic rights of the disabled. The following year, the General Assembly designated 1981 as the International Year of Disabled Persons. The foremost purpose of the

United Nations Enable web site, Secretariat for the Convention on the Rights of Persons with Disabilities, available from http://www.un.org/esa/socdev/enable/, accessed 10 February 2007.

United Nations Enable web site, Secretariat for the Convention on the Rights of Persons with Disabilities, available from http://www.un.org/esa/socdev/enable/, accessed 10 February 2007.

year was to bring attention to the challenges faced by the disabled, especially the equalization of opportunities, rehabilitation and the prevention of disabilities. Among the principal outcomes was the creation of the World Programme of Action Concerning the Disabled. This document called for the development of long-term, national strategies to prevent disability, rehabilitate the disabled, promote the ability of the disabled to participate in life and their communities, and promote their economic, social, legal and political equality.

In order to encourage governments to act promptly in implementing the activities proposed by the World Programme of Action, the General Assembly designated 1983 to 1992 to be the Decade of Disabled Persons. During the decade, US\$1.1 million was spent on data collection, research, training, and advocating for the rights of the disabled. The General Assembly marked the close of the decade by passing the Standard Rules on the Equalization of Opportunities for Persons with Disabilities in 1993. This document was meant to provide guidelines for the creation of policies regarding the disabled and to serve as a foundation for technical and economic cooperation among States, international organizations, and government agencies. It also encouraged policies to prevent disability, rehabilitate the disabled and to equalize opportunities of the disabled.

Specifically, the rules called for:

- The collection and distribution of information on the living conditions of persons with disabilities.
- The inclusion of disability issues in relevant policies and national plans.
- The creation of economic policies that create equal opportunities for the disabled.
- The involvement of disabled persons and organizations of persons with disabilities in the creation of local, regional and national legislation and policies affecting the disabled.
- The monitoring and evaluation of national legislation, services and programmes.
- Technical and economic cooperation between the United Nations, States and other organizations.

A Special Rapporteur on disability was nominated to provide a biannual report on the state of the rights of the disabled and the implementation of the *Standard Rules* to the Sub-Committee on the Prevention of Discrimination and Protection of Minorities.<sup>14</sup>

In 2001, the General Assembly established an ad hoc committee to consider the creation of an international convention regarding the protection and promotion of the rights of the disabled. In December 2006, the General Assembly reviewed and adopted the *Convention on the Rights of Persons with Disabilities.* <sup>15</sup> The treaty provides detailed stipulations concerning the rights of the disabled. The primary principles of the document are:

- Respect for independence, dignity, and individual autonomy of disabled persons.
- Non-discrimination.

• Equal participation and inclusion.

- Respect for and acceptance of persons with disabilities as part of human diversity and humanity.
- Access to equal opportunity.

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<sup>&</sup>lt;sup>14</sup>. United Nations Enable web site, Secretariat for the Convention on the Rights of Persons with Disabilities, available from http://www.un.org/esa/socdev/enable/, accessed 10 February 2007.

United Nations Enable web site, Secretariat for the Convention on the Rights of Persons with Disabilities, available from http://www.un.org/esa/socdev/enable/, accessed 10 February 2007.

- Accessibility.
- Equality between the sexes.
- Respect for the development and identities of children with disabilities.

The treaty also acknowledges that achieving equality for the disabled involves changing negative attitudes and stigmas associated with disability. Importantly, it assists the international community in pressuring governments to improve their policies regarding the disabled. An optional protocol was also created which gives individuals and groups that have been subjected to discrimination the right to petition a committee 16 on the rights of the disabled once they have exhausted all legal options available in their country. Countries began ratifying and signing the treaty in March 2007. 17

Not yet established.

Ibid.

# III. Quantifying disability

There is limited knowledge about the prevalence or epidemiology of disability in developing countries. According to most literature on the topic, the dearth of information is a result of a combination of factors. Interest in the topic is generally low and those most affected often do not have a voice and are faced with stigmatization. The political and economic concerns related to disability prevalence are also factors. The lack of information about disability in developing countries has serious consequences, as it is only with solid factual data that appropriate programmes, political action, advocacy, and improvement of services and general conditions of the disabled can be undertaken.

Definitional and measurement problems have also contributed to the low quality of data. Despite efforts to identify and implement a universal definition and classification system for disability, such as the ICF framework, most States continue to use a variety of definitions and classifications. The manner in which disability is defined, classified and measured carries serious implications for the statistical analysis of the issue.<sup>20</sup>

<sup>18</sup> Elwan

Washington Group on Disability Statistics. Final Report of the First Meeting of the Washington Group on Disability Statistics. Washington D.C., February 2002, available from http://www.cdc.gov/nchs/data/citygroup/WCGFinRep.pdf; accessed 20 January 2007.

Numerous instruments of measurement exist. They can encompass at least six areas of function, including mobility, cognition, participation, self-care, and social and occupational responsibilities that can be measured by a variety of scales. The measurement of disability can also become a political issue, especially where disability insurance is concerned.<sup>21</sup> A study of 13 countries<sup>22</sup> found large variations in the number of recipients of disability benefits and proposed that nearly all of these variations were linked to inherent incentives in the various domestic disability insurance programmes.<sup>23</sup> Cultural and language barriers also stand in the way of developing a common framework in censuses and surveys, as sometimes even the corresponding words of different languages do not imply the same underlying concepts. The use of assistive devices can lead to underreporting. Researchers found that many of those using assistive devices did not perceive themselves as having limitations. Therefore, they were not recorded by surveys or censuses, which defined disability through limitations and contained no questions regarding device use.<sup>24</sup> Negative social attitudes and stigmas associated with disability terminology can also lead to underreporting.

Questions used by most surveys and censuses, furthermore, do not allow for the differences that exist between disabled children and adults. Questions used to identify the severity and occurrence of disability are not appropriate for both adults and very young children, as these groups inherently do not have the same capabilities. Some activities, like running, are necessary for a child to participate in normal daily life within a community, but not for an adult. In turn, activities which would be part of an adult's normal daily life within a household, such as cleaning or cooking, may not be duties expected of a child. Also, the types of behavioural problems afflicting children are different from those affecting adults.<sup>25</sup>

Semantic, cultural, political and economic issues often make domestic data on disability difficult to collect and of low quality. Country variations in definitions, concepts and methodologies make cross-national comparisons of data impossible. International attempts to solve these issues and to unify definitions, classifications, and instruments of measurement are currently under way. Foremost among these is the Washington City Group on Disability Statistics, established at the United Nations International Seminar on Measurement of Disability in 2001. 26 The Group has developed a set of questions intended primarily for use in census formats.

The United Nations Statistics Division has also published two reports to assist States in the collection of disability statistics. The first report, Manual for the Development of Statistical Information for Disability Programmes and Policies, was published in 1996. It was created for those working specifically with the collection and use of statistics in the implementation, monitoring, and evaluation of policies and programmes. The manual focuses on the principal uses of statistics in planning and evaluating disability programmes. Recommendations are given for the production of statistics, as well as how to obtain and use the information when faced with complex circumstances, such as refugee relief and emergency situations. The second report, Guidelines and Principles for the Development of Disability Statistics, builds on the first report as well as a section on disability in the Principles and Recommendations for Population and Housing Censuses. The publication is meant to provide statisticians with principles and guidelines on the production and dissemination of disability statistics. It also provides examples from developing and developed countries.

the United States, Argentina, Chile, the United Kingdom, the Netherlands, Sweden, Norway, Germany, Austria, Switzerland, Poland, Latvia, and Hungary.

Aarts et al., 1999, cited in Elwan, p.3.

Madans et al. "Exploring the Impact of Assistive Device Use on Disability Measurement." PowerPoint presentation presented at the first meeting of the Washington Group on Disability Statistics, Washington D.C., February 2002, available from http://www.cdc.gov/nchs/ppt/citygroup/madans\_rasch\_altman.ppt.

Meltzer, Howard. "Disability among Children: a Statistical Perspective." Paper presented at the fourth meeting of the Washington City Group on Disability Statistics, October 2004.

As of 2006, the Group had hosted six meetings to discuss various methodological issues in disability measurement, including the purposes of measurement, the ICF model, cultural issues, and the affect of device use on disability measurement.

Several United Nations agencies have also attempted to estimate the global prevalence of disability. In 1981, the WHO projected the number of disabled persons to be somewhere between 7 and 10 per cent of the total population of each country. A 1992 report from the United Nations Development Programme (UNDP) states that the figure is probably lower than the WHO estimate, approximating the number of moderately to extensively disabled persons to be around 5 per cent.<sup>27</sup>

As part of their activities in connection with the International Year of Disabled Persons in 1981, the United Nations Statistics Division collected data from 63 national censuses, registration systems, and surveys of 55 countries. These data were released in 1988 in the United Nations Disability Statistics Database (DISTAT – 1) and an analysis was published in 1990 in the United Nations Disability Statistics Compendium. The statistics available in the compendium indicated that the prevalence of disability ranged from 0.2 per cent to 20.9 per cent. <sup>28</sup>

In 1990, the WHO carried out the first Global Burden of Disease Study: "(i) to decouple epidemiological assessment of the magnitude of health problems from advocacy by interest groups of particular health policies or interventions; (ii) to include in international health policy debates information on non-fatal health outcomes along with information on mortality; and (iii) to undertake the quantification of health problems in time-based units that can also be used in economic appraisal producing estimates of global disease and injury rates." From the data collected, an indicator the Disability Adjusted Life Years (DALYS) was derived to calculate the number of years of good health lost to premature death or years living with a disability. One DALY is the equivalent of one lost year of 'healthy' life. A component calculation of the DALY is the Years Lived with Disability (YLD). Disability incidence, disability duration, age of onset, and distribution by severity class are some of the data required to calculate the YLD. According to the 2002 WHO report on the global burden of disease, the leading causes of premature death and years lost to disability in developed and developing countries were heart disease, Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS) and unipolar depressive disorders.<sup>30</sup>

Mathers et al. "Global Burden of Disease in 2002: data sources, methods and results." Global Programme on Evidence for Health Policy Discussion Paper No. 54. World Health Organization, December 2003.

Ibid. See Annex 2 for WHO charts on DALYs and YLDs.

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Elwan. The UNDP estimates the disability prevalence to be 9.9% in High Human Development (HHD) countries, 3.7% in Medium Human Development (MHD) countries and 1% in Low Human Development (LHD) countries. UNDP, 1997.

See Annex 1 for further information on DISTAT.

# IV. Causes of disability

According to the WHO report, *Global Burden of Disease in 2002: data sources, methods and results*, globally, the primary cause of disability is neuropsychiatric conditions that account for over 37 per cent of all YLDs for the adult population. Visual impairment, hearing loss, and HIV/AIDS are the other major causes of YLDs in developing countries with high mortality rates. In developed and developing countries with low mortality rates, the majority of disabilities among adults are caused by visual impairment, hearing loss, musculoskeletal disease, chronic obstructive pulmonary disease, and other non-communicable diseases such as stroke.<sup>31</sup>

The report also found that the populations of developing countries not only have lower life expectancies, but also face living a larger proportion of their lives in disability. Strikingly, more than 80 per cent of global non-fatal health conditions transpire in developing countries. Populations of developing countries also have a much higher incidence of disability as a result of preventable illnesses, such as cardiovascular disease, chronic respiratory diseases, long-term outcomes of communicable diseases and nutritional deficiencies.<sup>32</sup>

According to the data analyzed in a subsequent section of this report, the primary cause of disability in the Caribbean is lifestyle-related illness. These illnesses principally affect the elderly, especially women, and are the result of poor nutrition and lifestyle choices as well as a lack of adequate healthcare and access thereof.<sup>33</sup> Accidents,

<sup>31</sup> Mathers et al.

<sup>32</sup> Ibid

See pages 8 through 10 for more information regarding disability in women and the elderly.

most likely as a result of dangerous working, driving and living conditions, are also a cause of disability, especially among younger men.<sup>34</sup>

Rapid changes in diets and lifestyles recently occurred as a result of industrialization, urbanization, economic development and market globalization. These changes have significant implications on the health and nutritional status of large numbers of the population in most developing countries. Food availability and variety has increased and consumption of energy-dense diets high in fat, particularly saturated fat, and low in unrefined carbohydrates has become increasingly popular. This has been coupled with a decline in energy expenditure from the use of motorized transport and of mechanized devices in the home and in the workplace, as well as devoting leisure time to physically undemanding activities, such as watching television. In addition, crime and dangerous road conditions can also discourage people from participating in sports and other outdoor activities. These trends have caused a rise in diet-related and lifestyle-related chronic diseases, especially among the poor. Obesity, diabetes, cardiovascular disease, hypertension, stroke, and some types of cancer become increasingly prevalent causes of disability in many parts of the world.<sup>35</sup>

Lack of adequate health care can exacerbate the consequences of disease and transform temporary impairments into long-term disabilities. Specifically, opportunities to prevent diseases through education and early detection are missed. Among the factors contributing to the low accessibility of health care in developing countries are economic restrictions, the lack of adequately trained professionals and health infrastructure and increasing demand and, in some instances, the consequence of a failed approach to health sector reforms.<sup>36</sup>

Those living in developing countries are generally more likely to work in hazardous or demanding environments. The inferior environmental standards which exist can lead to dangerous levels of exposure to toxic products, such as asbestos and chemical pesticides. Safety standards on construction sites are frequently much lower and workers tend to have longer working hours and are often not required to wear protective clothing.<sup>37</sup>

Dangerous road conditions are also a leading contributor to disability in developing countries. A 2003 WHO report on road traffic injury prevention estimates that 20 to 50 million people worldwide are injured or disabled in road traffic each year. The report concludes that the poorer populations of developing countries comprise the majority of casualties and lack long-term care in the event of serious injuries. Furthermore the cost of long-term care and the loss of income because of a disabling injury, furthermore, can push a family into poverty. Developing countries also often have lower safety standards for vehicles, less enforcement of existing vehicle standards and traffic codes, and inferior road infrastructure. Recent growth in the number of motor vehicles on the roads is a primary factor in unsafe road conditions.<sup>38</sup>

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See Annex 1 for further information on the global causes of disability.

Joint WHO/FAO Expert Consultation on Diet, Nutrition and the Prevention of Chronic Diseases. "Diet, Nutrition, and the Prevention on Chronic Diseases." WHO Technical Report Series, Geneva 2003.

Koot, Jaap. "Accessibility to Health Care in Developing Countries," available at http://www.phc-amsterdam.nl/artikelen/accessibility.pdf., accessed 3 February 2007.

Elwan, p. 23

Peden et al., ed., "World Report on Road Traffic Injury Prevention." World Health Organization. Geneva, 2004.

# V. Disability in children, women and the elderly

#### A. Children

A United Nations Children's Fund (UNICEF) report on the state of the world's children in 2006 estimates that 150 million children worldwide live with disability.<sup>39</sup> The majority of these children live in developing countries.<sup>40</sup> According to the WHO, DALY rates for children aged 0 to 4 are three times higher in developing regions with low mortality rates and six times higher in developing regions with high mortality rates than those for the same age group in developed regions. Children with disabilities are generally excluded from normal activities within the home and do not participate in community life. Families often shun or mistreat their disabled children and frequently adequate care is not provided. Most have little or no access to healthcare, rehabilitation or other support services and are deprived of the opportunity for formal education. When provisions are made for disabled children, they are often isolated in institutions or special schools.<sup>41</sup>

<sup>39</sup> Moccia et al.

<sup>40</sup> Elwan

<sup>41</sup> Moccia et al.

### B. Women

Literature on disability in both developed and developing countries concurs that disabled women are far more disadvantaged by their condition than disabled men. Disabled women contend with multiple disadvantages and quite often experience discrimination as a result of both their gender and their disability. Disabled women are less likely to have a job or business than disabled men. Disabled girls are less likely to go to school and those who do receive schooling are less likely to be employed, earn lower wages and have fewer chances to participate in post-secondary training or education. A study conducted by the United Nations Economic Commission for Asia and the Pacific (ESCAP) found that discrimination against disabled girls often starts at birth. They are given less food and care, are frequently subjected to mental, physical, and sexual abuse and they may be left out of family activities. A report on the experiences of disabled girls in the Middle East concluded that there is a general reluctance among heads of households to allow their disabled daughters access to tangible and intangible resources, thereby undermining their already slim chances of improving their lives.

Women with disabled family members are also more likely to be their primary caregivers. A study of living arrangements among children with disabilities in the United States affirms that "women shoulder a disproportionate share of the unpaid carework for children with disabilities". Their time spent in this work contributes to already existing gender inequalities and the general challenges women face by devaluing their labour and limiting their access to the labour market. Mothers of children with disabilities are also more likely to divorce and less likely to marry or remarry, and disabled children of unmarried parents are five times more likely to live with their mothers than with their fathers. Another study on healthcare conducted recently in the United States found that women with disabilities experienced limitations in access to care and medication compared with non-disabled women.

Disability rates are generally higher for women than for men. Women and men are exposed to different risks in varying frequencies. Also prevalence rates of disability differ for men and women depending on the questions used to assess their conditions. For example, when impairment questions are used to screen for disabilities, resulting rates for men are generally higher. When activity-limitation questions are used, however, the disability prevalence rates are either similar for both sexes or occasionally higher for women.<sup>48</sup>

Causes of disability vary between the sexes.<sup>49</sup> Women are less likely to become disabled as a consequence of an injury, but are more likely to become disabled as a result of chronic illnesses. As a result of increased longevity and increasingly unhealthy lifestyle choices, middle-aged and elderly women are seriously affected by such diseases.<sup>50</sup> Diseases such as arthritis, hypertension, and diabetes cause sight disabilities and impairments in the lower extremities. Women are also more affected by mental conditions, especially unipolar depressive disorders, anxiety and somatic complaints. Depressive disorders comprise nearly 41.9 per cent of disability from neuropsychiatric

Jans and Stoddard. "Chartbook on Women and Disability in the United States." U.S. Department of Education, National Institute on Disability and Rehabilitation Research: Washington D.C. 1999.

46 Cohen and Petrescu-Prahova. "Gendered Living Arrangements among Children with Disabilities." Journal of Marriage and Family: 68, August 2006.

See, for example, Thomas, Elwan, and Yeo.

<sup>43</sup> Thomas

<sup>45</sup> Abu-Habib, 1997, cited in Elwan, p. 29.

<sup>&</sup>lt;sup>47</sup> Parish and Huh. "Health Care for Women with Disabilities: Population-Based Evidence of Disparities." Health and Social Work: 31.1, February 2006.

<sup>48</sup> Han, Chol-O. "Engendering Disability Statistics." PowerPoint presentation presented at the first ESCAP workshop on improving disability statistics, May 2004.

Han, Chol-O. "Engendering Disability Statistics." PowerPoint presentation presented at the first ESCAP workshop on improving disability statistics, May 2004.

Jans and Stoddard.

disorders among women, but only 29.3 per cent among men worldwide. The gender-specific risk factors for common mental disorders include gender-based violence, socioeconomic disadvantage, (including income inequality and low income), inferior social status and continuous responsibility for the well-being of others. Sexual violence perpetrated against women and the high prevalence of Post Traumatic Stress Disorder which can follow such acts makes women the largest group affected by such condition.<sup>51</sup>

Research on the status of disabled women in the Caribbean is not available. More needs to be done to understand their condition and the challenges they face. According to the census data analyzed in a latter section of this report, elderly women seem to be the most affected by disabilities in the region. The data also indicate that their disabilities are most likely the result, in the majority, of lifestyle-related diseases brought on by poor nutrition and sedentary lifestyles.

# C. The Elderly

According to estimates published by WHO in 2000, there are nearly 600 million people over the age of 60 worldwide and it is expected that the number will double by 2025. Developing countries are home to nearly two thirds of all older people today and by 2025 three fourths of all older people will be living in those countries.<sup>52</sup> The majority of disabled persons worldwide are elderly. The elderly and disabled are some of the most vulnerable members of society. Both disabled and non-disabled elderly persons frequently face severe poverty in developing countries as a result of a lack of access to paid work, basic services and social networks.<sup>53</sup> This is significant as the prevalence of disability among the elderly is also directly related to socio-economic status.<sup>54</sup>

Chronic disease is the main cause of disability among the elderly.<sup>55</sup> Causes of disability and disabling diseases include cognitive, sensory and physiological impairment, inappropriately treated diseases, depression, cigarette, alcohol and drug addiction, a sedentary lifestyle, poor dietary habits, weight problems, and inadequate social support.<sup>56</sup> Other causes include gender and genetic factors.<sup>57</sup> Often a combination of these factors makes matters worse.

Accessing services and programmes which might assist the elderly in preventing, curing or coping with disability is often difficult, and the breakdown of traditional family networks that could otherwise be a primary source of care, makes the elderly and disabled even more vulnerable.<sup>58</sup>

As mentioned above, elderly women seem to represent the majority of all cases of disability in the Caribbean. According to the data, a significant number of these women seem to be living with extended family members, who then most likely become their primary source of support and care. While census data provide a good view of the general conditions of the disabled, including the elderly, more research on the vulnerabilities of the elderly and disabled in the region needs to be conducted to provide the empirical knowledge necessary to create appropriate policies, legislation and support programmes.

58 Barrientos et al.

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World Health Organization, Mental Health Site, "Gender and Women's Mental Health," available from http://www.who.int/mental\_health/prevention/genderwomen/en/, accessed 13 February 2007.

World Health Organization, Ageing and Life Course Site, "The world is fast ageing – have we noticed?" available at http://www.who.int/ageing/en/, accessed 12 February 2007.

Barrientos et al. "Old Age Poverty in Developing Countries: Contributions and Dependence in Later Life." World Development: 31.3, 2003.

World Health Organization. "What are the main risk factors for disability in old age and how can disability be prevented?" Regional Office for Europe's Health Evidence Network, September 2003.

<sup>55</sup> WHO, 2003.

Burden of Disease Network Project, The Finnish Centre for Interdisciplinary Gerontology. "Disability in Old Age: Final Report,
 Conclusions and Recommendations." Jyväskylä University Press, Finland, 2004.

<sup>&</sup>lt;sup>57</sup> WHO, 2003.

# VI. Disability in the Caribbean

Very little has been written on disability in the Caribbean, thus it has been difficult to draw any conclusions on overall trends in disability in the region. Though some general information regarding disability was available from various islands, the most detailed information came from the census data of four countries: Antigua and Barbuda, Saint Lucia, St. Vincent and the Grenadines, and Trinidad and Tobago. <sup>59</sup>

For the countries from which the information was available, disability prevalence rates ranged from 2.2 to 8.4 per cent of the total population. Most rates hovered somewhere between 4 and 5.3 per cent. This adheres to the global estimate given by UNDP. <sup>60</sup> A desk review of laws protecting the disabled from discrimination showed that 5 out of 13 countries had such legislation in place. <sup>61</sup> A review of the Human Rights Country Reports for the Caribbean issued by the United States State Department found that some countries did have legislation mandating access for the disabled to public buildings and transportation. Though most countries had a ministry or a department within a ministry that dealt with disability issues, there was not much information available on programmes targeting the disabled. <sup>62</sup>

See Annex 3 for further information on laws and legislation regarding disability in Caribbean countries.

See Annex 4 for the census questionnaires for all countries.

<sup>60</sup> See UNDP, 1997.

<sup>62</sup> United States Department of State Site, "2006 Country Reports on Human Rights," available from http://www.state.gov/g/drl/rls/hrrpt/2006/, accessed 3 March 2007. See Annex 3 for more information concerning disability in the Caribbean, including legislation and policies.

According to a survey conducted by UNICEF on the status of children and adolescents with disabilities in the Caribbean (Barbados and the Eastern Caribbean countries), it was found that significantly more boys than girls suffered from disabilities, mainly in the form of learning, hearing and speech impediments. The report asserts that the gender disparity may be due to a higher propensity for work-related injuries and risk-taking behavior among young males, such as aggressive driving, substance abuse and unprotected sex. The study also argues that the gender disparities could also be a result of differences in parental perceptions of disabilities, family size, and poverty levels. According to the findings of the study, an average of 20 per cent of the disabled children and adolescents were receiving some form of help from government of civil society, however with considerable differences among the countries surveyed. Countries in which the disabled seem to be getting the most support were St. Kitts and Nevis, Suriname, Barbados, Antigua and Barbuda and Grenada. The report recommends the establishment of home- or community-based rehabilitation programmes, and the inclusion of disabled children into regular schools to enhance their inclusion into mainstream society from early on.

The four-country census analysis<sup>64</sup> revealed several common trends for all countries reviewed. The findings of the data confirm that disability levels for the countries to be in the range of other studies mentioned earlier. However, the data point at considerable age and gender differences in disability prevalence rates. That the heaviest burden of disability is carried by the elderly over age 60 and among those by elderly women who suffer mainly from lifestyle-related chronic diseases and disabilities. In the younger age-groups men were found to be more prone to disabilities either of a congenital nature<sup>65</sup> early in life or later as a consequence of adverse lifestyle-related behaviour.

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<sup>63</sup> UNICEF Caribbean Area Office. "An Assessment of the Status of Children and Adolescents with Disabilities in the Caribbean," December 2000. (Remark: The UNICEF Caribbean Area office covers Barbados and the Eastern Caribbean States).

The census questionnaire used by the three member countries of the Organization of Eastern Caribbean States (OECS) was identical, while the census questionnaire used in Trinidad and Tobago, differed to a considerable extent from the survey instrument used in the OECS countries (see Annex 3 for more details on the respective census questionnaires used).

<sup>65</sup> See Annex 1 for further explanation.

# VII. Country studies

This chapter presents the main results of the analysis of the 2000 census round data of four Caribbean countries: Antigua and Barbuda, Saint Lucia, St. Vincent and the Grenadines and Trinidad and Tobago. 66

# A. Antigua and Barbuda

#### 1. General Trends in the Data

According to the 2001 census data for Antigua and Barbuda, 5.1 per cent of the population surveyed reported suffering from a disability. This finding conforms to figures from other sources (see chapter III) on this topic. A first look at age and gender specific disability data shows (table 1) that generally more women than men seem to be affected. The data also confirmed earlier observed global and regional trends insofar as disability rates for both sexes increased considerably beyond age 60.

<sup>66</sup> The selection of these four countries was determined by the fact that these are the only countries that have provided ECLAC full access to their census micro-data.

TABLE 1
DISABILITY IN ANTIGUA AND BARBUDA, BY SEX
AND SELECTED AGE GROUPS

	Disal		
Age Group	Yes	No	Total
Male			
0-4 Years	0.6%	99.4%	100%
5-19 Years	2.1%	97.9%	100%
20-39 Years	2.7%	97.3%	100%
40-59 Years	5.6%	94.4%	100%
60 Years and over	20.0%	80.0%	100%
Total	4.4%	95.6%	100%
Female			
0-4 Years	0.8%	99.2%	100%
5-19 Years	2.2%	97.8%	100%
20-39 Years	3.0%	97.0%	100%
40-59 Years	8.1%	91.9%	100%
60 Years and over	23.6%	76.4%	100%
Total	5.7%	94.3%	100%

Source: 2001 Census, ECLAC analysis.

# 2. Causes of disability

The findings also point at considerable gender differences (table 2) concerning the causes of disability. The majority of all disabilities in the country seem to be as a consequence of illness. The second most important cause of disability appears to be congenital disorders that seem to have caused almost every sixth disability in Antigua and Barbuda, with considerable gender differences. Accidents were found to be the third most important cause of disability. Conditions that trigger disabilities seem to be gender specific with generally more males experiencing disability from birth or as a consequence of accidents in younger years, while more females became disabled as a result of illness or other causes later in their lives.

TABLE 2
CAUSE OF DISABILITY AMONG MALES AND FEMALES
IN ANTIGUA AND BARBUDA

Origin of Disability	Male	Female	Total	Male	Female	Total
Illness	618	1 027	1 645	47%	53%	51%
From birth	230	254	484	17%	13%	15%
Accident	237	127	364	18%	7%	11%
Other	244	516	760	18%	27%	23%
Total	1 329	1 924	3 253	100%	100%	100%

Source: 2001 Census, ECLAC analysis.

#### 3. Diseases

The census also included questions on chronic diseases.<sup>67</sup> While not all respondents who indicated that they suffered from a chronic disease are disabled, lifestyle-related chronic diseases, such as hypertension, diabetes and arthritis are known to be the cause of many debilitating disabilities that occur later in life. And this seems also to be the case in Antigua and Barbuda. The data show that women experienced considerably higher prevalence rates for almost all chronic diseases listed in the census questionnaire with nearly twice as many women than men being affected by hypertension, arthritis, diabetes, sickle cell anemia, carpal tunnel syndrome and lupus.<sup>68</sup> Women were also found to have higher overall rates of asthma and heart disease (figure 1).

Hypertension
Heart Disease
Diabetes
Arthritis

0 500 1000 1500

Number of Persons Affected

FIGURE 1
PREVALENCE OF LIFESTYLE RELATED DISEASES AMONG THOSE AGED 60
AND OLDER IN ANTIGUA AND BARBUDA

Source: 2001 Census, ECLAC analysis.

Elderly men had higher rates of stroke, cancer, and kidney disease as compared with women of the same age group. These higher prevalence rates of cancer could signify a high rate of prostate cancer among older males in Antigua and Barbuda. Generally, the majority of the diseases listed in the census affected the elderly, with the exception of asthma and sickle cell anemia which were more common among children and youths of both sexes.

# 4. Forms of disability

The census data for Antigua and Barbuda revealed that the five most common disabilities observed included hearing and vision impediments, joint problems and/or the loss of upper or lower limbs and speech impediments<sup>69</sup>. However, the data showed considerable age and gender disparities. The largest proportion of the disabled population comprised women in older age groups who suffered mainly from disabilities resulting from chronic illness as discussed earlier, such as

Since lifestyle-related diseases affect mainly the elderly population, the present analysis will only focus on this age-group. The absolute numbers of persons with disabilities other than the ones displayed in the chart are small for both sexes, thus only the prevalence of the major chronic diseases is displayed in the chart. These figures do not reflect individual cases but incidences, since individuals report suffering from more than one chronic disease.

<sup>68</sup> See Annex 1 for further information on sickle cell anemia, carpal tunnel syndrome and lupus.

These data do not reflect the number of persons with a disability, but reflects incidences, since one person can suffer from more than one disability.

loss of vision and degenerative joint diseases and/or loss of upper and lower limbs (figure 2). Outstanding are the gender disparities with regard to vision impediments with nearly twice as many women than men being affected. With respect to behavioural problems, the findings go along with global trends that show generally higher prevalence of illnesses such as anxiety disorders and senile dementia among elderly women.<sup>70</sup>

FIGURE 2

PREVALENCE OF DISABILITIES AMONG THOSE AGED 60 AND OLDER IN ANTIGUA AND BARBUDA Sight Hearing Speech Disability ■ Females ■ Males Upper Limb Lower Limb Behavioural 0 100 200 300 400 500 **Number of Persons Affected** 

Source: 2001 Census, ECLAC analysis.

Significant findings regarding disability among the young were the higher rates of vision impediments for girls and young women, and in the case of boys and young men the higher prevalence of learning, hearing and behavioural disorders as well as handicaps related to upper and lower limb impediments (figure 3). The explanation for the latter could be higher rates of involvement of boys and young men in traffic- and work-related accidents. On a general note, rates of genetic diseases surveyed and of asthma were considerably low and thus they are not reflected in the chart.

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Mathers et al. "Global Burden of Disease in 2002: data sources, methods and results." Global Programme on Evidence for Health Policy Discussion Paper No. 54. World Health Organization, December 2003.

Sight Hearing Speech Disability ■ Females Upper Limb ■ Males Lower Limb Learning Behavioural 0 50 100 150 200 250 300 350

**Number of Persons Affected** 

FIGURE 3
PREVALENCE OF DISABILITIES AMONG THOSE AGED 5 TO 39
IN ANTIGUA AND BARBUDA

Source: 2001 Census, ECLAC analysis.

# 5. Activity and participation among the disabled

Overall, almost all disabled persons in the country reported having problems with working and going out and, only to a lesser extent, difficulties getting dressed and learning. As women had a higher rate of disability, more women than men experienced problems with learning, dressing, going out, and working (figure 4).

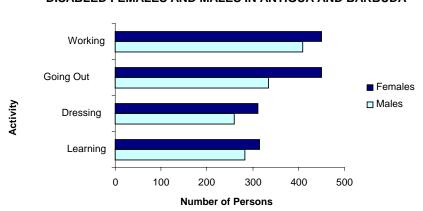


FIGURE 4
ACTIVITY AND PARTICIPATION AMONG THE
DISABLED FEMALES AND MALES IN ANTIGUA AND BARBUDA

Source: 2001 Census, ECLAC analysis.

#### 6. Uses of assistive devices

Overall, barely one third of the total disabled population was found to have access to any assistive device. The census data show the rather inadequate access to assistive devices other than canes and walkers and the limited use of crutches, wheelchairs or even prostheses. Less than one per cent of the total disabled population of Antigua and Barbuda could benefit from prostheses, orthopedic devices, braillers or adapted cars. And, as might be expected, the majority of wheel chairs, walkers, and canes belonged to women over age 60.

## 7. Living arrangements

The study shows considerable gender disparities in living arrangements of the disabled. Disabled minors of both sexes live in the majority with their families. However, the data show considerable gaps in the living arrangements of adults and, among those, particularly older disabled persons. Marriage patterns seem not be influenced by disability, simply due to the fact that lifestyle-related disabilities mainly occur later in life, generally after the years of marriage and family formation. Consequently, the marital status of particularly older disabled persons is by far more determined by demographic factors, such as gender-gaps in the age of couples, to the effect that men generally tend to marry younger women with the consequence that women often outlive their spouses. With regard to the position of the disabled within the household, the results show four times more women than men living in the household of a son or a daughter. The position of these women is especially precarious as the majority are elderly and most likely incapable of caring for themselves should they be unable to stay on with their families.

#### B. Saint Lucia

#### 1. General Trends in the Data

The general trends observed in the census data for Saint Lucia were similar to those found in Antigua and Barbuda. Almost 5 per cent of the population reported suffering from a disability with slightly more women than men with a physical or mental handicap. As already observed in Antigua and Barbuda, disability rates for both sexes peaked after age 60. Further, the data also confirm known trends for the region (table 3) in so far as elderly women seem to be the most affected by such conditions.

TABLE 3
DISABILITY IN SAINT LUCIA, BY SEX
AND SELECTED AGE GROUPS

	Disal		
Age Group	Yes	No	Total
Male			
0-4 Years	1.4%	98.6%	100%
5-19 Years	2.6%	97.4%	100%
20-39 Years	3.1%	96.9%	100%
40-59 Years	6.0%	94.4%	100%
60 Years and over	17.5%	82.5%	100%
Total	4.7%	95.3%	100%
Female			
0-4 Years	1.5%	98.5%	100%
5-19 Years	2.3%	97.7%	100%
20-39 Years	2.9%	97.1%	100%
40-59 Years	6.3%	93.7%	100%
60 Years and over	19.9%	80.1%	100%
Total	5.1%	94.9%	100%

Source: 2001 Census, ECLAC analysis.

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More details on living arrangements of the elderly can be found in the ECLAC study 'Population ageing – a four country study: Socio-demographic analysis of recent census data', Port of Spain, 2007, LC/CAR/L.128.

# 2. Causes of Disability

Observable trends in the causes of disability for males and females are similar to those observed in the data for Antigua and Barbuda (table 4). Disabilities in females and males were found to be mainly a result of illness and birth defects. While illness as a cause is more predominant in women, birth defects seem to be a more outstanding factor in the case of men. Also accident-related disabilities affected males more often than females.

TABLE 4
CAUSES OF DISABILITY AMONG MALES AND FEMALES IN SAINT LUCIA

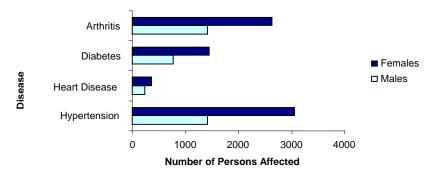
Origin of Disability	Male	Female	Total	Male	Female	Total
Illness	1 686	2 349	4 035	46.7%	57.2%	52.3%
From birth	825	764	1 589	22.9%	18.6%	20.6%
Accident	649	337	986	18%	8.2%	12.8%
Other	450	659	1 109	12.5%	16%	14.4%
Total	3 610	4 109	7 719	100%	100%	100%

Source: 2001 Census, ECLAC analysis.

#### 3. Diseases

Not surprisingly, also in Saint Lucia, the majority of disabilities seem to be related to lifestyle-related chronic conditions, such as hypertension, arthritis, diabetes and heart diseases and, to a lesser extent, to cancer, stroke, carpal tunnel syndrome and lupus. Again, women, and particularly women in older age-groups, seem to be the most affected by these conditions with almost 60 per cent of all cases with hypertension, arthritis and diabetes (figure 5). Men experienced higher rates of kidney diseases, possibly as a consequence of gender-biased substance abuse. Asthma and sickle cell anemia, on the other hand, were mainly observed in children and youth, since asthma is generally outgrown in adulthood and life-expectancy for patients with sickle-cell anemia is generally less than 40 years.<sup>72</sup>

FIGURE 5
PREVALENCE OF LIFESTYLE RELATED DISEASES AMONG
THOSE AGED 60 AND OLDER IN SAINT LUCIA



Source: 2001 Census, ECLAC analysis.

Absolute incidence of diseases other than displayed in the chart were rather small, thus they were not displayed in the chart.

Carpal tunnel syndrome, lupus, HIV and AIDS had very few reported cases and again, women were found with higher rates of all four conditions. There were only 11 reported cases of HIV/AIDS, which most likely signifies considerable underreporting<sup>73</sup> which could be explained by the social stigma still associated with the disease in the country.

# 4. Forms of disability

The five most prevalent forms of disabilities found in the census data included vision impediments and upper and lower limb impairments and amputations, along with behavioural disorders. As already observed in Antigua and Barbuda, disabilities also in Saint Lucia were more prevalent in women, with elderly women carrying the main burden (figure 6). The fact that, among the elderly, the majority of disabilities impact on vision and physical mobility (upper and lower limb impairments and amputations) suggests that these handicaps are mainly a cause of lifestyle-related chronic diseases as discussed earlier in this study.

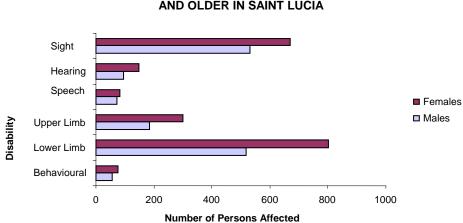


FIGURE 6
PREVALENCE OF DISABILITIES AMONG THOSE AGED 60
AND OLDER IN SAINT LUCIA

Source: 2001 Census, ECLAC analysis.

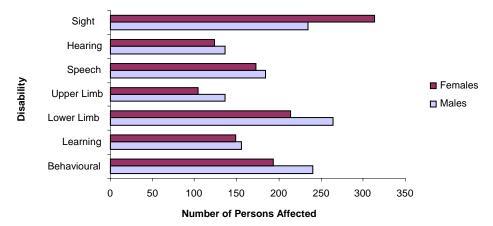
While younger women were over-proportionally affected by vision impediments, younger men take stand out in almost all categories other categories (figure 7). Of importance are the higher rates of learning, speech and behavioural impediments<sup>74</sup> in young boys as well as their significantly higher rates of physical impediments, possibly a result of accidents on the road or at the workplace.

This adheres with international trends. Young males are more likely to have learning, behavioural and speech disparities than young females.

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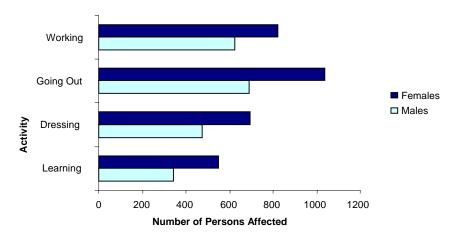
UNAIDS estimates that there were about 300,000 adults and children living with HIV in the Caribbean in 2005. UNAIDS Site, 
"AIDS Epidemic Update: December 2005 – Caribbean," available from http://www.unaids.org/epi/2005/doc/
EPIupdate2005\_pdf\_en/Epi05\_08\_en.pdf, accessed 22 May 2007.

FIGURE 7
PREVALENCE OF DISABILITIES AMONG THOSE AGED 5 TO 39 IN SAINT LUCIA



Source: 2001 Census, ECLAC analysis.

FIGURE 8
PROBLEMS WITH ACTIVITY AND PARTICIPATION AMONG THOSE
AGED 60 AND OLDER IN SAINT LUCIA



Source: 2001 Census, ECLAC analysis.

#### 5. Use of assistive devices

Generally, as already observed in Antigua and Barbuda, accessibility to assistive devices other than canes and walkers was also limited in Saint Lucia. As expected, the main users of such appliances were older women to help them overcome physical impediments resulting from physical degeneration of joints or the loss of a limb due to amputations. As already observed in Antigua and Barbuda, more males than females used crutches and prostheses in Saint Lucia, and among those more males in the younger age group.

## 6. Living arrangements

The study shows considerable gender disparities in living arrangements of the disabled in the country. Disabled minors of both sexes live, as is also common in other parts of the more and less developed world, mainly with their families. However, the data show considerable gaps in the living arrangements of disabled adults, and among those, particularly, older disabled persons. Marriage patterns seem not be influenced by disability, most probably due to the fact that lifestyle-related disabilities mainly occur later in life, generally late after the years of marriage and family formation. Consequently, the marital status particularly of older disabled persons is by far more determined by demographic factors, such as gender gaps in the age of couples and female longevity. With regard to the position of the disabled within the household, the results show four times more women than men living in the household of a son or a daughter.<sup>75</sup>

## C. St. Vincent and the Grenadines

#### 1. General trends in the data

The trends regarding the prevalence of disability found in the census data for St. Vincent and the Grenadines were similar to those found for Antigua and Barbuda and Saint Lucia. A little less than 5 per cent of the total population reported suffering from a disability with slightly higher prevalence rates for women than for men. Also, the earlier observed positive correlation between age and disability prevalence is reflected in this data set (table 5) with the highest prevalence rates observed in the age group 60 years and over. And, again, older women are over-proportionally affected by these ailments.

TABLE 5
DISABILITY IN ST. VINCENT AND THE GRENADINES,
BY SEX AND SELECTED AGE GROUPS

	Disal	oility	
Age Group	Yes	No	Total
Male			
0-4 Years	0.8%	99.2%	100%
5-19 Years	2.3%	97.7%	100%
20-39 Years	3.2%	96.8%	100%
40-59 Years	6.0%	94.0%	100%
60 Years and over	15.7%	84.3%	100%
Total	4.3%	95.7%	100%
Female			
0-4 Years	0.7%	98.3%	100%
5-19 Years	2.0%	98.0%	100%
20-39 Years	2.5%	97.5%	100%
40-59 Years	6.1%	93.9%	100%
60 Years and over	19.2%	80.8%	100%
Total	4.6%	95.4%	100%

Source: 2001 Census, ECLAC analysis.

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A more detailed analysis of the living arrangements of the elderly can be found in: Population ageing – a four country study: Socio-demographic analysis of recent census data, ECLAC, 2007, LC/CAR/L.128.

## 2. Causes of disability

The causes of disability in St. Vincent and the Grenadines were similar to those found in the other countries discussed earlier in this report. Again, females were more likely to have become disabled as a consequence of lifestyle-related diseases, while males were more likely to have had a disability from the time of birth or to have sustained a disabling injury resulting from an accident (table 6).

TABLE 6
CAUSES OF DISABILITY AMONG MALES AND FEMALES
IN ST. VINCENT AND THE GRENADINES

Origin of Disability	Male	Female	Total	Male	Female	Total
Illness	859	1 227	2 086	37.6%	50.5%	44.2%
From birth	571	445	1 016	25.0%	18.3%	21.5%
Accident	435	239	674	19.0%	9.8%	14.3%
Other	42	521	941	18.4%	21.4%	19.9%
Total	2 285	2 432	4 717	100%	100%	100%

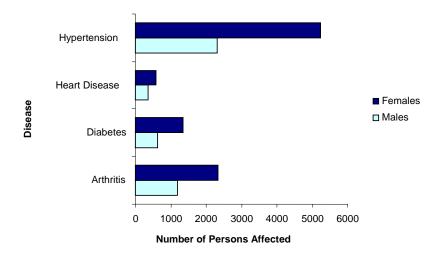
Source: 2001 Census, ECLAC analysis.

#### 3. Diseases

As in the other countries presented in this report, chronic lifestyle-related illness was mainly prevalent in the older age-groups and notably again in older women. Older women accounted for more than 60 per cent of all cases of hypertension, diabetes, heart disease and arthritis (figure 9). <sup>76</sup>

Children and youths again represented the majority of cases of asthma and sickle cell anemia. Asthma was more prevalent among young males than females of the same age. There were few reported cases of carpal tunnel syndrome, lupus, HIV and AIDS. The prevalence of HIV and AIDS was most likely underreported because of the social stigma associated with the disease.

FIGURE 9
PREVALENCE OF LIFESTYLE RELATED DISEASES AMONG THOSE AGED 60
AND OLDER IN ST. VINCENT AND THE GRENADINES



Source: 2001 Census, ECLAC analysis.

<sup>76</sup> Since the majority of chronic diseases is experienced by the elderly and the incidences of other disabling chronic ailments are rather small, only the major trends in chronic diseases that affect the elderly are reflected in the chart.

## 4. Forms of disability

Also in St. Vincent and the Grenadines, elderly women suffered most from disabilities. Characteristically the data displayed similar age and gender disparities as observed in the countries studied earlier. Disabilities as a consequence of lifestyle-related chronic diseases were mainly prevalent in the older age groups (figure 10), whereas congenital disabilities, behavioural, learning and hearing disorders along with accident-related impediments in upper and lower limbs were more prominent in younger men (figure 11).

Sight Hearing Speech ■ Females Disability ■ Males Upper Limb Lower Limb Behavioural 0 10 20 300 400 500 60 700 **Number of Persons Affected** 

FIGURE 10
PREVALENCE OF DISABILITIES AMONG THOSE AGED 60
AND OLDER IN ST. VINCENT AND THE GRENADINES

Source: 2001 Census, ECLAC analysis.

Also behavioural disorders seemed to be more prevalent in young men and in older women. With regard to disabilities leading to physical constraints, similar patterns than in the other islands were found since more older women then men reported suffering from upper and lower limb disorders and loss of vision, most probably due to lifestyle-related diseases discussed earlier.

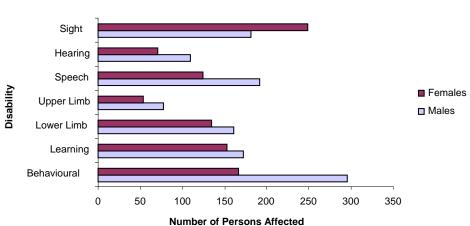


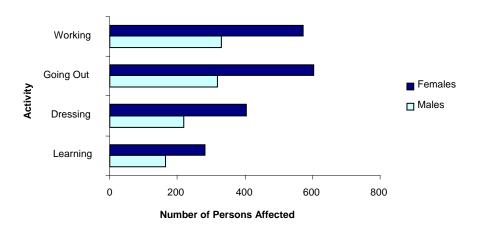
FIGURE 11
PREVALENCE OF LIFESTYLE RELATED DISEASES AMONG THOSE AGED 60
AND OLDER IN ST. VINCENT AND THE GRENADINES

Source: 2001 Census, ECLAC analysis.

## 5. Activity and participation among the disabled

As elderly women represented the majority of those affected by disabilities in the country, they were also found to be the group that had experienced the highest rates of activity and participation impediments (figure 12). Older women in particular seemed to be suffering most from exclusion from various activities inside and outside their homes.

FIGURE 12
PREVALENCE OF ACTIVITY AND PARTICIPATION DIFFICULTIES AMONG
THOSE AGED 60 AND OLDER IN ST. VINCENT AND THE GRENADINES



Source: 2001 Census, ECLAC analysis.

#### 6. Use of assistive devices

The trends in the data regarding accessibility to assistive devices in St. Vincent and the Grenadines remained the same as those in the other countries studied. Generally there seems to be limited access to such devices and the most popular were canes and walkers and, to a far lesser extent, wheelchairs and crutches. Elderly women are also the main users of such appliances, as a consequence of their higher rates of disability. Only a few individuals reported having access to more sophisticated items, such as orthopedic devices, braillers or adapted cars.

# 7. Living arrangements

The study shows considerable gender disparities in living arrangements of the disabled. Disabled minors of both sexes live, as elsewhere, mainly with their families. However, the data show considerable gaps in the living arrangements of adults, and among those, particularly older disabled persons. The majority of the disabilities are a consequence of lifestyle-related diseases that become manifest later in life, generally after the years of marriage and family formation. Consequently, the marital status of particularly older disabled persons is by far more determined by demographic factors, such as gender gaps in the age of couples and female longevity. With regard to the position of the disabled within the household, the data show four times more women than men living in the household of a son or a daughter.<sup>77</sup> The position of these women is especially precarious as the majority are elderly and most likely incapable of caring for themselves should they be unable to

A more detailed analysis of the living arrangements of the elderly can be found in: Population ageing – a four country study: Socio-demographic analysis of recent census data, ECLAC, 2007, LC/CAR/L.128.

stay on with their families. Unlike the other islands, however, there were more disabled male than female relatives living with their extended families.

# D. Trinidad and Tobago

#### 1. General Trends in the Data

The results of the census conducted in Trinidad and Tobago diverged slightly from those of the other islands presented since the survey instrument differed to a certain extent from the questionnaire used in the countries of the Organisation of Eastern Caribbean States (OECS) (see annex 3). Issues such as the causes of disability, activity and participation of the disabled and access to assistive devices were not covered by the census. The questions concerning disabilities used different categories and thus the results were only to a certain extent directly comparable with the analysis of the OECS countries. However, in spite of the use of different categories, the overall prevalence rates for disabilities along with the age and gender specific disparities follow similar patterns as observed in the other countries in the study. Overall 4 per cent of the population reported a disability with few gender disparities but a similar bias towards the elderly, as noted earlier.

TABLE 7
DISABILITY IN TRINIDAD AND TOBAGO, BY SEX AND
SELECTED AGE GROUPS

	Disal		
Age Group	Yes	No	Total
Male			
0-4 Years	0.7%	99.3%	100%
5-19 Years	1.7%	98.3%	100%
20-39 Years	2.6%	97.4%	100%
40-59 Years	5.4%	95.6%	100%
60 Years and over	15.6%	84.4%	100%
Total	4.0%	96.0%	100%
Female			
0-4 Years	0.6%	99.4%	100%
5-19 Years	1.4%	98.6%	100%
20-39 Years	2.1%	97.9%	100%
40-59 Years	5.4%	94.6%	100%
60 Years and over	17.7%	82.3%	100%
Total	4.2%	95.8%	100%

Source: 2000 Census, ECLAC analysis.

#### 2. Diseases

With the exception of HIV and AIDS, which, according to the data, affected men and women to the same extent, the majority of all other diseases surveyed by the census were more prevalent in women than in men. Again, it can be assumed that HIV/AIDS rates observed do not reflect the real prevalence rates due to social stigma and fear of possible discrimination. Again, the elderly, and among those women, were more often significantly affected by chronic diseases than any other

sector of the population (figure 14). Children and youth once again had higher rates of asthma and sickle cell anemia 78.

Heart Disease

Hypertension

Diabetes

Arthritis

0 10000 20000 30000 40000

Number of Persons Affected

FIGURE 13
PREVALENCE OF LIFESTYLE RELATED DISEASES AMONG THOSE
AGED 60 AND OLDER IN TRINIDAD AND TOBAGO

Source: 2000 Census, ECLAC analysis.

# 3. Forms of disability

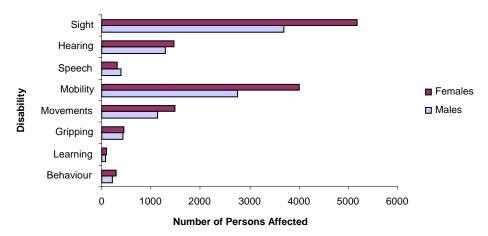
The census conducted in Trinidad and Tobago did not include disabilities related to upper and lower body part impediments that were surveyed in the censuses of the other countries studied. But, unlike the census for the OECS countries, Trinidad and Tobago included questions regarding mobility<sup>79</sup>, movement<sup>80</sup> and gripping. With regard to age and gender disparities, the date showed similar trends than observed in the other countries in the region. Generally more elderly than young people reported being affected by disabilities and among the group of the elderly, women suffered demonstratively more than men from vision and hearing impediments and from loss of mobility (mobility and movements) (figure 15). The latter might be an indicator of handicaps affecting upper and lower limbs, and thus allows for comparison with the results in the OECS countries which collected direct information on such impediments. Also, elderly women again displayed higher incidences of behavioural disorders, a trend already observed in the OECS countries and in other parts of the world.

Since the incidence of chronic diseases other than those displayed in the chart is rather limited, and the majority of the chronic diseases are affecting the elderly, only the major chronic ailments affecting this age-group are displayed.

Defined in census as "walking, standing, and climbing stairs".

Defined in census as "reaching, crouching and kneeling".

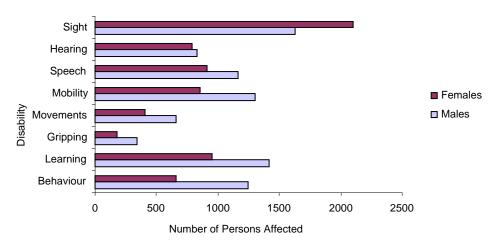
FIGURE 14
PREVALENCE OF DISABILITIES AMONG THOSE AGED 60
AND OLDER IN TRINIDAD AND TOBAGO



Source: 2000 Census, ECLAC analysis.

With regard to disabilities observed in younger age groups, young men stand out – following similar patterns as already observed in the OECS countries included into this study – with their higher prevalence of mobility impediments (mobility and movements) and learning, speaking and behavioural disorders (figure 15).

FIGURE 15
PREVALENCE OF DISABILITIES AMONG THOSE AGED 5 TO 39
IN TRINIDAD AND TOBAGO



Source: 2000 Census, ECLAC analysis.

Reported constraints in physical movements could be considered an indicator of handicaps affecting upper and lower limbs, as already pointed out in the discussion of disability for the elderly, and could thus serve as a proxi-indicator for disabilities affecting upper and lower limbs.

Should this be the case, the results also of this census would become reasonably comparable to those observed in Antigua and Barbuda, Saint Lucia and St. Vincent and the Grenadines. Young women again seem to be much more affected by vision impediments than younger men, a trend also observed in other countries of the region.

## 4. Living arrangements

The study shows considerable gender disparities in living arrangements of the disabled. Disabled minors of both sexes generally live with their families and only to a limited extent with non-related persons or in homes. However, the data show considerable gaps in the living arrangements of disabled adults, and among those particularly of older persons. Marriage patterns seem not be influenced by disability, simply due to the fact that lifestyle-related disabilities mainly occur later in life, generally long after the years of marriage and family formation. Consequently, the marital status of particularly older disabled persons is by far more determined by demographic factors, such as gender-gaps in the age of couples and female longevity. With regard to the position of the disabled within the household, the results show four times more women than men living in the household of a son or a daughter. The position of these women is especially precarious as the majority are elderly and most likely incapable of caring for themselves should they be unable to stay on with their families.

A more detailed analysis of the living arrangements of the elderly can be found in: Population ageing – a four country study: Socio-demographic analysis of recent census data, ECLAC, 2007, LC/CAR/L.128.

# VIII. Summary and conclusions

The census data analysis for the four Caribbean countries on disability has revealed a number of critical observations common to all countries observed. Two main patterns with regard to age and gender disparities are outstanding: The first is the fact that disability in the Caribbean mainly affects elderly women as a consequence of lifestyle-related chronic diseases that lead to joint disorders, upper and lower limb impediments and loss of vision. The second observation made in all countries is the fact that in the younger age-groups, however at a considerably lower incidence level, boys and young men experience higher rates of disabilities than girls and young women. School-age boys and male youth were generally found with higher rates of learning, speech and behavioural disabilities than girls of the same age-groups.

In total, only one third of all disabled persons reported having access to assistive devices, which are mainly canes and walkers and, to lesser extent, wheelchairs and crutches. Special devices such as prosthesis, braillers or even modified vehicles seemed to be only available for very few disabled individuals.

As is the case for disabilities, chronic diseases follow distinct age and gender patterns. Generally, the elderly, and among those women, were much more prone to lifestyle-related chronic diseases than the younger population. However, in most countries, men were found to have slightly higher rates of prostate cancer and kidney diseases, with generally higher rates of substance abuse as a cause for kidney disorders in men. As elsewhere, congenital diseases are mainly observed in the younger population, since the life expectancy for individuals carrying such diseases in generally short, not exceeding 40 years at most. Asthma also commonly afflicts the young, but is

typically outgrown in adolescents and adults. Reported cases of HIV/AIDS were definitely lower than observed by other sources for the Caribbean. However, social stigma and fear of discrimination, marginalization and social exclusion most probably prevented those infected from reporting their condition.

With regard to living arrangements and support systems for the disabled, the study has shown that since the majority of disabilities are lifestyle-related and thus occur only later in life, marriage and family formation seem not to be impacted by these conditions. Disabled youth generally live with their immediate family and only to a very limited extent with other persons or in homes.

While this census data analysis could shed some light on various aspects of disability the limitations of census data need to be kept in mind. While such data provide a first insight into the prevalence of chronic diseases and disabilities, census data might underreport certain conditions that are stigmatized or under-diagnosed, such as HIV/AIDS or mental illnesses. Also since physical impediments are generally easier to report, it is more difficult to get thorough data on less visible and less obvious illnesses, such as hypertension, heart diseases or mental and psychological disorders, particularly in cases when they have either not yet been recognized as such and/or not yet been diagnosed or bear a social stigma. Consequently, it can be assumed that such ailments are underreported in census data and therefore the real prevalence rates can be expected to be higher than reported in such surveys. Also, to draw significant conclusions from the data analysis for small populations is limited due to the rather small numbers in some instances, particularly regarding certain ailments and disabilities that only occur in rather small numbers. This is also the reason why the tables and figures only present the results concerning the main trends observed in the analysis of various variables.

To better understand the situation of the disabled not only in the countries studied, but also in the wider Caribbean, more information is needed on the prevalence as well as on the epidemiology of ailments and disabilities, particularly of those ailments that are underreported in census enumerations. Also, more needs to be known on living arrangements, educational opportunities and access to social and economic security for disabled young children and youth. Finally, a more thorough study of various types of disabilities by age and gender and their impact on the socioeconomic well-being of those directly and indirectly affected would be needed to develop adequate policies and programmes to appropriately address the needs of the most destitute. Access to health-care, public transportation and other facilities that would enhance the quality of life of those affected by these conditions need to be studied more thoroughly.

The desk-research on policies and programmes targeted to the disabled of all ages in the Caribbean has shown that very few specific programmes do exist and that most services for the disabled seem to be provided within the general basic health and social assistance frameworks. Programmes addressing early education of youth and young children suffering from various physical and/or mental disabilities are scarce and in the majority of the countries in the region non existent. Even less support is available for disabled out-of-school youth and adults. Issues of economic security, financial independence and social inclusion of persons with various forms of disabilities need to be addressed with utmost urgency.

As a consequence of the fact that most disabled persons in the Caribbean are older women who suffer the dire consequences of unhealthy lifestyles, early education on the prevention of such chronic diseases along with the promotion of healthy lifestyles should become a cross-cutting theme in all public education programmes. The promotion of affordable healthy diets along with encouraging physical activities should be at the forefront of all public and private health promotion initiatives.

While the prevention of lifestyle-related disabilities is of critical importance, more needs to be done for those who are presently suffering from other non-lifestyle-related disabilities. Special programmes for children and youth with congenital handicaps and learning and behavioural disabilities and the provision of assistance and reintegration programmes particularly addressing the needs of young men who have become disabled is of utmost importance. Of critical importance are the special needs of boys and young men suffering from learning disabilities and behavioural disorders. Addressing these conditions early in life might be one avenue to ensure their education and integration into mainstream society and possibly curbing the growing tendency among boys to become delinquent in rather young age. Efforts to curb accident-related disabilities are much more difficult to realize. However, law enforcement regarding drunken and aggressive driving along with educational campaigns on the negative impact of alcohol and drug abuse on driving could contribute to reducing vehicle-related accidents. Enhancement of security at the workplace along with the provision of protective gear could contribute to the reduction of workplace-related accidents in males.

Also, the great knowledge gaps on disability in the public but also in regional government circles unfortunately perpetuate ignorance, prejudice and social stigma concerning those directly affected and their families. This leads to a call for information campaigns to raise public awareness about disability. Most importantly, however, more countries need to implement legislation to protect the legal, social, political and economic rights of the disabled. This would be an essential step toward improving the lives of the disabled and their families. As the United Nations Convention on the Rights of Persons with Disabilities is legally binding for those countries which sign and ratify it, the Convention could assist countries in creating a comprehensive approach to disability, especially in ensuring non-discrimination, equal recognition before the law, liberty, security, accessibility, mobility, independent living, health, employment, education, and participation in political and cultural life for the disabled.

While the data reflect the particularities of the four countries studied, due to the historic, cultural and socio-economic similarities it can be assumed that the trends observed also speak for the wider Caribbean, particularly for the other English- and the Dutch-speaking countries and territories in the region.

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# **Annexes**

# ANNEX 1 CONCEPTS AND DEFINITIONS

#### 1. Disability

#### 1.1 International Classification of Functioning, Disability and Health

According to the International Classification of Functioning, Disability and Health (ICF) manual, (WHO, 2001), disability begins as a health condition that creates impairments. The impairments result in restrictions and limitations on activity and participation within contextual factors. Empairments are defined as "problems in body function or structure such as a significant deviation or loss." Activity is defined as an action or task carried out by an individual and participation is defined as an individual's involvement in life. Contextual factors refer to environmental circumstances, such as social attitudes, legal systems, and physical barriers, and personal circumstances, such as social background, gender, and age. The ICF uses two scales of 0 to 9 to assess an individual. A *capacity qualifier* determines the individual's capacity to carry out tasks or actions in a "standard environment," and a *performance qualifier* determines the experience of the individual in their personal and environmental context. When assessing capacity, a standard environment is required to counteract the impact of varying environments on the capacity of the individual. This can include: "(a) an actual environment commonly used for capacity assessment in test settings; (b) an assumed environment thought to have a uniform impact; or (c) an environment with precisely defined parameters based on extensive scientific research." 83

#### 1.2 United Nations Disability Statistics Database

An updated version of the DISTAT database (DISTAT -2), covering 179 national studies, was released in 2001. Though the range of disability prevalence did not change, data from DISTAT -2 demonstrated that there was a noteworthy increase in the number of countries which included disability in their population censuses during the last two decades. <sup>84</sup>

#### 1.3 Theoretical Models of Disability

The twentieth century saw an evolution in the perception of disability. Theoretical models of the concept were created based on prevailing perspectives. Existing definitions of disability are based on these theoretical models.

<u>Impairment Perspective</u>. The impairment perspective represents the traditional perception of disability. From this perspective, disability is an abnormality or a health problem that resides in an individuals' mind or body. It is best embodied by the *medical model*. This theoretical model considers disability "a problem of the individual that is directly caused by a disease, an injury, or some other health condition and requires medical care in the form of treatment and rehabilitation." The individual is perceived as having an unwanted condition that forces them into the role of being abnormal or sick. The medical model is principally normative. A person is considered disabled if they are not able to function as a "normal" person would. Expression of this model assert that by classifying disability as a problem residing with the individual, disabled people perceive themselves and are perceived by others as damaged or as "objects for a variety of rehabilitative interventions."

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<sup>82</sup> Mitra, p. 238.

<sup>83</sup> World Health Organization. International Classification of Functioning, Disability and Health. Geneva, 2001.

Mbogoni, Margaret. "Disability Census Questions – the Perspective of Developing Countries." Paper presented at the first meeting of the Washington City Group on Disability Statistics. Washington D.C., February 2002.

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<u>Functional Limitations Perspective</u>. The functional limitations perspective was developed as a response to these criticisms. It was an attempt to incorporate the non-medical aspects of disability into the medical model. However, the idea that disability originated in the impairments in the individual's body or mind remained the foundation for this perspective and disability was still defined by comparing an individual against a normative standard. <sup>87</sup>

The *Nagi model* became part of the functional limitations perspective. Sociologist Saad Z. Nagi associated disability with limitations on normal daily activities, such as holding a job or caring for a child, rather than with medically tested limitations, such as lifting weight. Disability, furthermore, was not only defined by the nature of an individual's impairments, but also by the manner in which individuals perceive and react to their limitations and by how others influence an individual's limitations through their expectations and reactions.<sup>88</sup>

<u>Ecological Perspective</u>. The ecological perspective evolved in the 1970s as a result of the criticisms of both the impairment and functional limitations perspectives. It did not gain mainstream recognition until the 1990s. Central to this perspective is the *social model*. <sup>89</sup> There are at least nine sub-models of the social model, <sup>90</sup> but each is based on the concept that disabled people are "disadvantaged not because of their impairments, but as a result of the limitations imposed on them by social, cultural, economic and environmental barriers."

#### 1.4 Causes of Disability

Malnutrition. Malnutrition is a cause of disability and a contributing factor in illnesses which increase vulnerability to disabling diseases. Access to food with high nutritional value, awareness and access to information on dietary and food preparation guidelines is lacking in most developing countries. More than half of all childhood deaths globally are caused by malnutrition. Those who survive, however, are often physically and psychologically crippled and vulnerable to disease and intellectual disabilities. In 1998, the WHO estimated that approximately two hundred and thirty million children of developing regions were stunted because of malnutrition. Furthermore, the World Bank 1993 World Development Report notes that "in 1990 alone, the worldwide loss of social productivity caused by four overlapping types of malnutrition - nutritional stunting and wasting, iodine deficiency disorders and deficiencies of iron and vitamin A - amounted to almost 46 million years of productive, disability-free life."

Maternal Healthcare. Maternal healthcare is essential in preventing disability in mothers and their children. As can be seen in Section 4 Table 1, perinatal conditions are one of the top three contributors to DALYs in both high and low mortality developing countries. Likewise, perinatal and maternal conditions are part of the top 10 contributors to YLDs for both men and women. The United Nations Population Fund (UNFPA) estimates that more than eight million women suffer life-long health conditions as a result of complications during pregnancy and delivery. Health care during delivery and the neonatal period is extremely important in preventing and treating the vesicovaginal fistulas that can form as a result of obstructed labour. This condition can result in severe social consequences for the women who suffer from it, such as divorce, exclusion from religious activities, family separation, worsening poverty, and malnutrition. Access to proper information regarding proper prenatal nutrition, furthermore, can assist in preventing mental and

89 Government of Canada.

<sup>87</sup> Government of Canada.

<sup>88</sup> Ibid.

<sup>90</sup> Mitra.

<sup>91</sup> Elwan.

Rasheed, Sadig. "Major Causes and Consequences of Childhood Disability." *Education Update*, UNICEF, 2.4, October 1999.

<sup>93</sup> Glasier et al. "Sexual and reproductive health: a matter of life and death." The Lancet 2006; 368.

physical disabilities in babies. Recent studies also suggest a link between maternal depression and ill health and disability among their offspring. In rural Pakistan, for example, infants of depressed mothers have a four times higher risk of being underweight or stunted at six months than children whose mothers are not depressed. Children of depressed mothers also have higher rates of diarrhea and are less likely to be immunized. These studies also show that depression during pregnancy is linked to low birth weight.<sup>94</sup>

<u>Hygiene and Sanitation</u>. According to the WHO, nearly 6 per cent of cases of disability worldwide is caused by diseases related to poor sanitation, water supply, and personal and domestic hygiene. There are several parasitic conditions that could be avoided by improving sanitation and hygiene that continue to cause significant morbidity and disability, such as schistosomiasis, lymphatic filariasis, trachoma, trypanosomiasis and chagas disease. Trachoma, for instance, is responsible for 15 per cent of the world's blindness. <sup>96</sup>

<u>Violence</u>. During an armed conflict, not only soldiers are at risk of disabling injuries. Civilians are threatened by landmines, unexploded ordnance, shootings, and shelling.<sup>97</sup> The maiming of civilians has also become commonplace, especially in ethnic conflicts. The approximate ratio of people injured to those killed is 1.9 to 13.0.<sup>98</sup>

The victims of war are also more likely to experience psychological consequences and studies indicate that psychological conditions are more prevalent than physical injuries among adults who have experienced conflict situations. A World Bank report on mental health and conflict estimates that 40 to 70 per cent of refugees suffer from post-traumatic stress disorder and acute clinical depression. Refugees are also become susceptible to debilitating diseases during their journeys or time spent in crowded camps. It is difficult for those already disabled to move from conflict zones and they are less likely to be assisted by relief workers.

During conflicts, furthermore, health care and other social systems are disrupted leaving those already disabled vulnerable to further deteriorating health. Those who contract health conditions or sustain injuries which might not otherwise result in disability are also more likely to become disabled. Private and government programs meant to prevent illness, such as immunization and perinatal services, are also often interrupted.<sup>101</sup>

Landmines and unexploded ordinance which are left long after a conflict has ended pose a particular threat to civilians. Approximately two thirds of the sixty five countries which sustained casualties from landmines explosions between 2002 and 2003 had not suffered active conflict during the period. According to the WHO, they have also increasingly been used specifically to target civilians "in an attempt to isolate them or force them from their communities by depriving them of access to farmlands, roads, and even necessities such as drinking-water and firewood." Landmines

United Nations Children's Fund. "State of the World's Children 2006." New York, 2005.

Rahman, Atif. "For the sake of the child, look after the mother." ID21: Insights. Issue 6, January 2005. available at http://www.id21.org/insights/insights-h06/insights-issh06-art03.html. accessed 3 February 2007.

<sup>95</sup> WHO, World Water Day Site, available from http://www.worldwaterday.org/wwday/2001/thematic/control.html. accessed 5 February 2007.

Royal National Institute of the Blind, Public Site, available from http://www.rnib.org.uk/xpedio/groups/public/documents/Public Website/public\_rnib003680.hcsp. accessed 10 February 2007.

<sup>97</sup> Elwan

Murray et al. "Armed Conflict as a Public Health Problem." British Medical Journal:524. 9 February 2002. available from http://gking.harvard.edu/files/armedph.pdf.

Baingana, Florence. "Mental Health and Conflict." Social Development Notes. World Bank. October 2003. available from http://siteresources.worldbank.org/DISABILITY/Resources/Conflict-Prevention-and-Reconstruction/Mental\_Health\_and\_ Conflict.pdf. accessed 12 February 2007.

Elwan and Murray et al.

main or kill 15,000 to 25,000 people each year. Civilians comprise approximately 80 per cent of these cases. 103

#### 2. Genetic Disorders

Due to differences in genetical predispositions, males are more vulnerable to genetic diseases than females in cases where diseases are caused by mutations of the X chromosome. Such diseases become much more often manifest in males than in females. The reason is that in the case of females, the second X chromosome that does not carry the disease can compensate for the defect, which makes a female a carrier of the disease, but she herself will not be affected by it. In the case of a male who only has one X chromosome, there are no compensatory mechanisms and thus, the disease will become manifest. Examples of such diseases are: Duchenne muscular dystrophy, a progressive degeneration of muscle tissue; fragile-X syndrome, a common form of mental retardation in boys; and hemophilia, a disease in which a deficiency in one of several blood-clotting factors causes uncontrollable bleeding. <sup>104</sup>

#### 3. Chronic Diseases

- 3.1 Sickle Cell Anemia. The red blood cells of those who are afflicted with sickle cell anemia change shape, usually becoming crescent-shaped, upon deoxygenation of the blood. The bending damages the membrane of the red blood cells. It can also cause them to become stuck in blood vessels, thus depriving the downstream tissues of oxygen. This can cause ischaemia and infarction, which can lead to organ damage. The disease is chronic and lifelong. Individuals do not have continuous symptoms, but experience periodic painful attacks and those who are afflicted have an average lifespan of 40 years. The disease occurs usually in people, or their descendants, from regions where malaria is or was common. 105
- <u>3.2 Carpal Tunnel Syndrome</u>. Carpal tunnel syndrome occurs when the median nerve in the wrist in compressed. The condition leads to pain, paresthesias, and muscle weakness in both the hand and forearm. A common cause of carpal tunnel symptoms is intense, repetitive hand use or activity.<sup>106</sup>
- 3.3 Lupus. Lupus is a chronic autoimmune disease in which the immune system attacks the body's cells and tissue. This leads to inflammation and tissue damage. It can affect any part of the body. The heart, joints, skin, lungs, blood vessels, liver, kidneys and nervous system, however, are the most commonly afflicted. The disease can occur at any age, but is most *common in women*. Generally, females are 10 times more likely than males to contract Lupus. Most of these cases occur between the ages of 15 and 45 years of age. 107

Walsh and Walsh. "Rehabilitation of Landmine Victims - the ultimate challenge." Bulletin of the World Health Organization 81.9.
WHO 2003

<sup>104</sup> Cardiff University Site, available from http://www.cardiff.ac.uk/medicine/medical\_genetics/study/year\_1\_medical\_teaching/year\_1\_medical\_teaching/x\_chromosome\_and\_sex\_linked\_inheritance.htm, accessed 20 March.

Medline Plus Site, provided by the United States National Library of Medicine and the National Institutes of Health, available at http://www.nlm.nih.gov/medlineplus/sicklecellanemia.html, accessed 20 March 2007.

National Institute for Neurological Disorders and Stroke Site, available at http://www.ninds.nih.gov/disorders/carpal\_tunnel/detail\_carpal\_tunnel.htm, accessed 20 March 2007.

Medline Plus Site, provided by the United States National Library of Medicine and the National Institutes of Health, available at http://www.nlm.nih.gov/medlineplus/lupus.html, accessed 20 March 2007.

#### 4. Disability Adjusted Life years and years lived with Disabilities

#### Leading global causes of DALYs and YLDs

Disability Adjusted Life Years (DALYS) represents the number of years of good health lost to premature death or years living with a disability. One DALY is the equivalent to of one lost year of 'healthy' life. A component calculation of the DALY is the Years Lived with Disability (YLD). Disability incidence, disability duration, age of onset, and distribution by severity class are some of the data required to calculate the YLD.

TABLE A.1
LEADING CAUSES OF BURDEN IN DEVELOPED AND DEVELOPING COUNTRIES, 2002 (WHO)

	Developed countries	% total DALYs		Developing low mortality countries	% total DALYs
1	Ischaemic heart disease	9.1%	1	Unipolar depressive disorders	6.0%
2	Unipolar depressive disorders	7.3%	2	Perinatal conditions	5.9%
3	Cerebrovascular disease	6.4%	3	Cerebrovascular disease	5.0%
4	Alcohol use disorders	3.6%	4	Road traffic accidents	3.7%
5	Hearing loss, adult onset	2.8%	5	Ischaemic heart disease	3.3%
6	Chronic obstructive pulmonary disease	2.6%	6	Chronic obstructive pulmonary disease	3.1%
7	Road traffic accidents	2.5%	7	Lower respiratory infections	2.6%
8	Trachea, bronchus, lung cancers	2.4%	8	Tuberculosis	2.4%
9	Alzheimer and other dementias	2.3%	9	Diarrhoeal diseases	2.4%
10	Self-inflicted injuries	2.3%	10	Cataracts	2.4%
	Developing high mortality	% total			

	Developing high mortality countries	% total DALYs
1	HIV/AIDS	9.2%
2	Lower respiratory infections	8.5%
3	Perinatal conditions	8.0%
4	Diarrhoeal diseases	5.8%
5	Malaria	5.1%
6	Maternal conditions	3.1%
7	Unipolar depressive disorders	3.1%
8	Ischaemic heart disease	2.9%
9	Measles	2.8%
10	Tuberculosis	2.7%

Source: Mathers et al. "Global Burden of Disease in 2002: data sources, methods and results." Global Programme on Evidence for Health Policy Discussion Paper No. 54. World Health Organization, December 2003.

TABLE A.2 LEADING CAUSES OF YLD IN MALES AND FEMALES, GLOBAL ESTIMATES 2002 (WHO)

	Males	% total YLD		Females	% total YLD
1	Unipolar depressive disorders	9.6%	1	Unipolar depressive disorders	13.9%
2	Alcohol use disorders	5.8%	2	Maternal conditions	6.4%
3	Hearing loss, adult onset	4.8%	3	Cataracts	4.9%
4	Cataracts	4.5%	4	Hearing loss, adult onset	4.4%
5	Schizophrenia	2.8%	5	Osteoarthritis	3.1%
6	Perinatal conditions	2.8%	6	Vision disorders, age- related and other	2.7%
7	Bipolar affective disorder	2.5%	7	Schizophrenia	2.7%
8	Asthma	2.3%	8	Perinatal conditions	2.6%
9	Vision disorders, age- related and other	2.3%	9	Bipolar disorder	2.4%
10	Cerebrovascular disease	2.2%	10	Migraine	1.9%

Source: Mathers et al. "Global Burden of Disease in 2002: data sources, methods and results." Global Programme on Evidence for Health Policy Discussion Paper No. 54. World Health Organization, December 2003.

#### **ANNEX 2**

The following table provides an overview of information on disability available for various Caribbean countries

Country	Prevalence Rate	Ministry	Legislation	Programs	Organization/s Working with Disability Issues
Anguilla	5.3% 108	*	*	Social Security is paid to the disabled who have a history of work.      Education programs for disabled are administered under the Special Needs Services Program.	*
Antigua & Barbuda	5.1%	Ministry of Health, Sports and Youth Affairs	- Signed the Convention on the Rights of the Disabled  - The constitution contains some antidiscrimination provisions, but there are no specific laws protecting the disabled from discrimination.	*	Antigua & Barbuda Association for Persons with Disabilities
The Bahamas	2.3% 110	Ministry of Social Services and Community Develop- ment	- There are no laws specifically protecting the disabled from discrimination.	- The Government works with the Bahamas Council for Disability to provide services through both government and private residential and nonresidential institutions. These services included education, training, counseling, and job placement services for adults and children with both physical and mental disabilities.	The Bahamas Council for Disability
Barbados	4.6% 111	Ministry of Social Transfor- mation	- There are no laws specifically protecting the disabled from discrimination against persons with disabilities, other than constitutional provisions asserting equality for all.  - In April of 2005, a National Advisory Committee on the Rights of Persons with Disabilities was established. Their mandate was to coordinate government efforts to fully integrate persons with disabilities into society. The committee has not yet held a meeting.	- In April of 2005, the government opened the Harambee House, a resource and community center for persons with disabilities.	Barbados Council for the Disabled Barbados National Organization for the Disabled

Halcrow Group Limited, Decision Economics, Willms and Shier, University College London, and the National Assessment Team of Anguilla. "Country Poverty Assessment Report: Anguilla, Vol. 1." Caribbean Development Bank, December 2002.

All information on legislation and programs in this chart has been taken from the United States Department of State Site, "2006 Country Reports on Human Rights," available from http://www.state.gov/g/drl/rls/hrrpt/2006/, accessed 3 March 2007.

Inter-American Development Bank Site, "Data on Disability," available from http://www.iadb.org/sds/soc/site\_6215\_e.htm, accessed 3 March 2007.

Inter-American Development Bank Site, "Data on Disability," available from http://www.iadb.org/sds/soc/site\_6215\_e.htm, accessed 3 March 2007.

British Virgin Islands	4.0%112	Ministry of Health and Welfare	*	- Social Security is paid to the disabled who have a history of work.	British Virgin Islands Friends of the Blind  Virgin Islands Advocacy Center  Virgin Islands Resource Center for the Disabled <sup>113</sup>
Cuba	*		- There are no laws specifically protecting the disabled from discrimination against persons with disabilities.  - A Labour Ministry resolution gives persons with disabilities the right to equal employment opportunities and equal pay.	- The Ministry of Education supervises education and training programs for children with disabilities.  - The Ministry of Labour and Social Security administers an employment program for the disabled.	Asociación Nacional de Ciegos y Débiles Visuales  Asociacion Cubana de Limitados Fisicos-Motores  Asociacion Nacional de Sordos de Cuba
Dominica	18.0% 114	*	- Signed the Convention on the Rights of the Disabled.  - There are no laws specifically protecting the disabled from discrimination against persons with disabilities.  - Labour laws permit employment of persons with disabilities for less than the minimum wage in order to increase employment opportunities for the disabled.	- Welfare and pension benefits are provided to the disabled.	Dominica Association of Disabled Persons
Dominican Republic	5.0%	*	- Signed the Convention on the Rights of the Disabled The law prohibits discrimination against persons with disabilities.	- The Ministry of Public Health recently gave a subsidy to the Dominican Association for Rehabilitation, which has seventeen branches around the country, to provide rehabilitation assistance to the disabled.	Asociacion Dominicana de Rehabilitacion  Asociacion Nacional de Sordos de la Republica Dominicana  Circulo de Mujeres con Discapacidad

Figure represents number of households with disabled or individuals with long-term illnesses. Halcrow Group Limited, Decision Economics, Willms and Shier, University College London, and the National Assessment Team of the British Virgin Islands. "Country Poverty Assessment: British Virgin Islands, Vol. 1." Caribbean Development Bank, May 2003.

The Virgin Islands Advocacy Center and the Virgin Islands Resource Center for the Disabled are located in the US Virgin Islands, but also serve the British Virgin Islands.

Halcrow Group Limited, Decision Economics, Willms and Shier, University College London, and the National Assessment Team of Dominica. "Government of the Commonwealth of Dominica Country Poverty Assessment, Vol. 1." Caribbean Development Bank, June 2003.

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Grenada	*	*	- There are no laws specifically protecting the disabled from discrimination against persons with disabilities.	- The government has made provisions for disabled children in regular schools, but most parents have chosen to send their disabled children to one of Grenada's three special education schools.	Grenada National Council for the Disabled
Guyana	2.2% (% disabled among working age population census 2001)	Ministry of Health*	- The constitution mandates that the state "take legislative and other measures designed to protect disadvantaged persons and persons with disabilities."  - No legislation exists, however, to assist the disabled in contesting discriminatory acts.	A National Commission on Disability has begun drafting legislation to protect the disabled.      The Commission also undertook a study in 2005 to survey the status of the disabled in Guyana.	Guyana Coalition of Citizens with Disabilities
Jamaica	6.2%115	Ministry of Labour and Social Security; Ministry of Health	- Signed the Convention on the Rights of the Disabled.  - There is a National Disability Policy, enacted in 1999, which provides guidelines for cooperation between government and civil society in addressing the equalization of opportunities for persons with disabilities.  - There are no laws, however, specifically protecting the disabled from discrimination.	- There are several government ministries which provide services and programs to various groups of persons with disabilities There is, however, no government agency specifically charged with assisting persons with disabilities.	Jamaica Council for Persons with Disabilities Combined Disabilities Association
Netherlands Antilles	8.4% <sup>116</sup>		- The government passed an act in 2004 guaranteeing equal treatment and banning discrimination in employment, education, and public transportation.  - A committee was established to accept complaints.	*	Caribbean Association on Mental Retardation and Other Developmental Disabilities (Curacao)
St Kitts & Nevis	*	Ministry of Social and Community Development and Gender Affairs	- Laws in St Kitts and Nevis prohibit discrimination, but they do not specifically mention discrimination against the disabled.	*	St Kitts and Nevis National Association of Disabled Persons
Saint Lucia	5.1%	Ministry of Health	- There are no laws specifically protecting the disabled from discrimination against persons with disabilities.	- The Ministry of Health operates a community-based rehabilitation program in residents' homes.  - There are schools for the deaf and the blind up to the secondary level. There also was a school for persons with mental disabilities.	National Council of and for Persons with Disabilities

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Inter-American Development Bank Site, "Data on Disability," available from <a href="http://www.iadb.org/sds/soc/site">http://www.iadb.org/sds/soc/site</a> 6215 e.htm, accessed 3 March 2007.

Government of the Netherlands Antilles, Central Bureau of Statistics, available from http://www.cbs.an/census/antd1.asp, accessed 3 March 2007.

St. Vincent & the Grenadines	4.4%	Ministry of National Mobilization, Social Development, NGO Relations, Family, Gender Affairs and Persons with Disabilities	- Laws prohibit discrimination against persons with physical and mental disabilities.	- The government partially subsidizes a school for persons with disabilities, which had two branches.  - It also supports a small rehabilitation center which has the capacity to treat approximately five persons a day.	National Society for Persons with Disabilities
Suriname	*	Ministry of Social Affairs; Ministry of Education; Ministry of Health	- Signed the Convention on the Rights of the Disabled There are no laws specifically protecting the disabled from discrimination against persons with disabilities.	- The Ministry of Education administers twenty-one elementary- level schools and eleven secondary-level schools for students with special education needs.  - Early detection programs are administered by the Ministries of Education and Health.  - Thirteen institutions are providing long-term care to the disabled.  - The government also operates a small number of vocational training programs.	Caribbean Association for Mobilizing Resources and Opportunities for People with Developmental Disabilities
Trinidad & Tobago	4.5%	Ministry of Social Develop-ment	- There are no laws specifically protecting the disabled from discrimination against persons with disabilities	- The government enacted a national policy on persons with disabilities in 2005.  - The government provides a monthly grant to those that have been diagnosed by a medical professional as permanently disabled. Grants are also available to the parents of disabled children.  - The Ministry of Education administers special education programs.  - The government also provides geriatric inhome care to the disabled in Tobago.	National Center for Persons with Disabilities

#### **ANNEX 3**

# 1. Relevant Questions from the Census Questionnaire for Organization for Eastern Caribbean States (OECS) Member States

Does .... suffer from any long-standing illness, disability or infirmity?

Caribbean States (OECS) Member States						

- 1. Yes
- 2. No
- What was the origin of the disability?
- 1. Illness
- 2. From Birth
- 3. Accident
- 4. Other
- What type of disability or impairment does ....have?
- 1. Sight (even with glasses if worn)
- 2. Hearing (even with hearing aid if used)
- 3. Speech (talking)
- 4. Upper Limb (arm)
- 5. Lower Limb (leg)
- 6. Neck and spine
- 7. Slowness at learning or understanding
- 8. Behavioural (mental retardation)
- 9. Other, please specify .....
- 10. Not stated
- Was .....'s disability/major impairment ever diagnosed by a medical doctor?
- 1. Yes
- 2. No
- 3. Not stated
- Because of a physical, mental or emotional condition lasting <u>6 months or more</u>, does this person have any difficulty in doing any of the following activities?
  - o Learning, remembering, concentrating?
    - 1. Yes
    - 2. No
  - o Dressing, bathing or getting around inside the home?
    - 1. Yes
    - 2. No
  - o Going outside the home alone to shop or visit a doctor's office?
    - 1. Yes
    - 2. No
  - o Working at a job or business?

(Answer if person is 15 YEARS OLD OR OVER)

- 1. Yes
- 2. No

- Are you required to use any of the following aids? (more than one oval may be filled)
- 1. Wheelchair
- 2. Walker
- 3. Crutches
- 4. Brailler
- 5. Adapted Car
- 6. Cane
- 7. Prosthesis/artificial body part
- 8. Orthopedic shoes
- 9. Other, please specify
- 10. None
- Does ....suffer from any of the following illnesses?
- 1. Sickle Cell Anemia
- 2. Arthritis
- 3. Asthma
- 4. Diabetes
- 5. Hypertension/High blood pressure
- 6. Heart disease
- 7. Stroke
- 8. Kidney disease
- 9. Cancer
- 10. HIV
- 11. AIDS
- 12. Lupus
- 13. Carpal tunnel syndrome
- 14. None
- 15. Other, please specify
- 16. Not stated
- What is the ....'s relationship to the head of household?
- 1. Head
- 2. Spouse/partner
- 3. Child
- 4. Son/Daughter-in-law
- 5. Grandchild
- 6. Parent/Parent-in-law
- 7. Other Relative
- 8. Non-relative

#### 2. Relevant Questions from the Census Questionnaire for Trinidad and Tobago

- Does (N) suffer from any longstanding disability that prevents him/her from performing an activity?
- 1. Yes
- 2. No
- 3. Not stated
- Does (N) have difficulties in
- 1. Seeing (even with glasses if worn)
- 2. Hearing (even with hearing aid if used)
- 3. Speaking (talking)
- 4. Moving/Mobility (walking, standing, climbing stairs)
- 5. Body movements (reaching, crouching, kneeling)
- 6. Gripping
- 7. Learning
- 8. Behavioural
- 9. Other
- 10. Not stated

#### (multiple responses can be checked)

- Does (N) suffer from any of the following illnesses?
- 1. None
- 2. Arthritis
- 3. Asthma
- 4. Diabetes
- 5. Hypertension
- 6. Heart disease
- 7. Kidney disease
- 8. HIV/AIDS
- 9. Lupus
- 10. Sickle Cell Anemia
- 11. Other
- 12. Not stated
- What is (N's) marital status?
- 1. Never married
- 2. Married
- 3. Widowed
- 4. Legally separated
- 5. Divorced
- 6. Not stated



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