

# Escaping Stigma and Neglect

## *People with Disabilities in Sierra Leone*

Mirey Ovadiya  
Giuseppe Zampaglione



THE WORLD BANK



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Washington, D.C.

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# Abbreviations and Acronyms

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|         |   |
|---------|---|
| CHYAO   | Italian Trust Fund for Children and Youth in Africa                   |
| CRPD    | United Nations Convention on the Rights of Persons with Disabilities  |
| CSO     | Civil Society Organization  |
| CWD     | Children with Disabilities  |
| DFID    | Department for International Development, UK                          |
| DPO     | Disabled People's Organizations                                       |
| ESP     | Education Sector Plan   |
| FHM     | Family Homes Movement   |
| GLRA    | German Leprosy and TB Relief Association                              |
| HDI     | Human Development Index   |
| HI      | Handicap International  |
| HRC Act | Human Rights Commission of Sierra Leone Act                           |
| ICCPR   | International Covenant on Civil and Political Rights                  |
| IGA     | Income-Generating Activity  |
| INGO    | International Nongovernmental Organizations                           |
| MEST    | Ministry of Education, Science, and Technology                        |
| MFA     | Missionaries Friends Association                                      |
| MOHS    | Ministry of Health and Sanitation                                     |
| MSWGCA  | Ministry of Social Welfare, Gender, and Children's Affairs            |
| NaCSA   | National Commission for Social Action                                 |
| NaSSIT  | National Social Security Insurance Trust                              |
| NCRPD   | National Committee for the Rehabilitation of People with Disabilities |
| NRC     | National Rehabilitation Center  |
| NSAP    | National Social Action Project  |
| PRSP    | Poverty Reduction Strategy Paper                                      |
| PTSD    | Post-Traumatic Stress Disorder  |
| SGBV    | Sexual and Gender-Based Violence                                      |
| SLIHS   | Sierra Leone Integrated Household Survey                              |
| TDR     | Tropical Diseases Research  |
| TRC     | Truth and Reconciliation Commission                                   |
| UNIOSIL | United Nations Integrated Office for Sierra Leone                     |
| WHO     | World Health Organization   |



# Foreword

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Everyone deserves the opportunity to succeed in life, whether she lives in a remote village in Africa or hails from an affluent city in the developed world. Everyone deserves a chance at a bright and prosperous future, whether he was forced to fight in a bloody conflict or is fortunate enough to have never heard the sound of a gunshot. Everyone deserves to live a healthy life, whether one is disabled or not.

Unfortunately, though we all deserve a chance to succeed, people with disabilities lack access to basic social services and economic opportunities. Anyone who has ever seen a man whose legs have been deformed by polio sitting on the ground and begging knows that people with disabilities deserve more. Anyone who has ever witnessed a blind woman being led by a small boy through busy streets to collect spare change knows the odds are stacked against people with disabilities in the developing world.

People with disabilities represent a large share of the population in the developing world, one that is consistently among the most vulnerable. They are marginalized, excluded, isolated, and dependent on others.

In conflict and postconflict countries, people with disabilities are more prevalent and have even less access to basic services and economic opportunities. Sierra Leone is one such country. In 2002, Sierra Leone ended an almost decade-long and extremely violent civil war. While the effects of the war still plague the country, Sierra Leone has shown remarkable signs of development, particularly in the domain of supporting and protecting people with disabilities. Sierra Leone has signed the UN Convention on the Rights of Persons with Disabilities, and its national human rights strategy includes safeguards for people with disabilities. Now, it must put what it has promised in international conventions and in its own constitution into practice. The World Bank is supporting this process.

Development strategies for the education, health, and employment sectors should include components that address the needs of the physically and mentally disabled. With access to appropriate health care, education, and social protection services, people with disabilities will be given those coveted opportunities that we all deserve. They will have a chance to participate in productive activities and be successful, not only for themselves, but for the further development of their countries.

This working paper is a diagnosis on the extent to which Sierra Leoneans are affected by disability and an analysis of current public policies in support of people with disabilities in Sierra Leone. The note also provides some direction to policy makers on possible reforms and measures to enable all people with disabilities, regardless of how and when they were disabled, to live better lives.

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# Overview

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The objective of this policy note on people with disabilities in Sierra Leone is to: (i) provide a diagnosis on the scale and nature of the problem, (ii) analyze current public policies in support of people with disabilities, (iii) review public and private programs, and (iv) propose some policy options to policy makers and development partners.

Disability and poverty go together. Case studies from low-income countries suggest that people with disabilities are overrepresented among the poorest and have limited access to basic services and economic opportunities. They are therefore less likely to get out of poverty compared with other groups. Marginalization and exclusion from services, community activities, and productive opportunities increase the risk that people with disabilities will stay in or fall into poverty and extreme-poverty groups. Studies also suggest that among people with disabilities, children, and women are the most disadvantaged and face the highest economic and social risks.<sup>1</sup>

Sierra Leone remains among one of the poorest countries in the world. Although extremely rich in natural resources (diamonds, gold, and other minerals) and with considerable agricultural potential, Sierra Leone remains among the poorest countries in the world. The proportion of the population below the poverty line is estimated at 70 percent and some 26 percent is classified as extremely poor.<sup>2</sup> Moreover, life expectancy is 37 years while health and education indicators are among the lowest in the world. Participatory poverty assessments conducted during the preparation of the 2005 Poverty Reduction Strategy Paper (PRSP) define “the poorest” in Sierra Leone as “often physically (and psychologically) challenged” in addition to not being able to meet basic needs.

The war has inflicted a heavy toll on human capital. Eleven years of civil war have left approximately 20,000 people dead, 2 million people displaced, and thousands of individuals amputated and injured. The war toll is even higher if one considers the indirect impact on people who did not have access to health services and nutrition during the conflict. This in turn led to an increase in mortality, morbidity, and disability. The conflict ended in 2002, when a peace agreement was signed in Accra, Ghana, between the government and rebel factions. A general census conducted in 2004 estimated that there were nearly 130,000 people with disabilities in Sierra Leone, with a prevalence of 2.4 percent of the total population. As recorded by the census, the majority of people with disabilities were only indirectly affected by the conflict, while the number of people disabled by a direct act of violence was relatively small (9.5 percent of total disabled). However, other estimates, sector studies, and experience in other countries and in post-conflict countries<sup>3</sup> suggest that the number of people with disabilities in Sierra Leone could be as much as five times higher than the official

figures,<sup>4</sup> and that the number of people who were permanently disabled by the conflict is much higher than what was recorded by the census.<sup>5</sup>

A national policy on people with disabilities is yet to be updated and approved. A draft National Policy Paper on People Living with Disabilities, using a human rights-based approach to disability, was prepared in 2004–05, under the leadership of the Ministry of Health and Sanitation and the Ministry of Social Welfare, Gender, and Children's Affairs. However, the recommendations are too broad and they are neither prioritized nor costed. A new policy should be devised with input from people with disabilities organizations that will include the full range of rights covered in international treaties and will more fully address the needs of people with disabilities with respect to access to employment, education, health, public buildings, transportation, and sports and recreation.

Historically, support to people with disabilities has been limited. Available information indicates that assistance covers a limited number of people with disabilities compared to existing needs. The 2004 Census data indicate that about 30 percent of those classified as people with disabilities receive some type of assistance (ranging from medical, rehabilitation and counseling services, to training and financial support). Prior to the war, charitable organizations, associations of disabled people,<sup>6</sup> and national nongovernmental organizations (NGOs) provided some support to people with disabilities. Family and informal community-based safety nets have remained the main form of support to people with disabilities, especially in the rural areas. After the war, selected donors have supported amputees and other people whose disability was caused by a direct act of violence. There has been almost no donor support to people whose disability did not occur as a direct result of the conflict, and most of the informal family- and community-based safety nets have been depleted by the war.

Public programs in support of people with disabilities are limited and institutionally fragmented. The Ministry of Social Welfare is the official government administration responsible for the welfare of people with disabilities, but its resources and capabilities are very limited. In addition to the Ministry of Social Welfare, programs in support of people with disabilities have also been established under the National Commission for Social Action (NaCSA) and the National Social Security Insurance Trust (NaSSIT). In September 2006, the NaCSA was officially designated to implement the War Victims Reparations Program, under the provisions of the Truth and Reconciliation Commission (TRC) report. NaCSA has also been providing support to vulnerable communities and groups, including people with disabilities, through its existing programs, such as the World Bank-financed National Social Action Project (NSAP). The NaSSIT provides a social security scheme to the "employed." This scheme only covers those employed in the "formal sector," thus excluding most people with disabilities, as only 2.6 percent of people with disabilities are paid employees.

NGOs and United Nations (UN) agencies provide the bulk of the assistance, most of which is in the process of being phased out. National and international NGOs continue to provide the bulk of the assistance, which has primarily focused on functional rehabilitation and psychological support services. Interventions include community-based rehabilitation projects, reinforcement of networks of rehabilitation and psychological services through hospitals and established institutions, strengthening organizations for people with disabilities, and support for elaboration of

a national policy for people with disabilities. There are also several initiatives among UN agencies in collaboration with NGOs and communities to mainstream and improve education opportunities to children and youth with disabilities and their families through skills training and income-generating activities (IGAs). All nationally and internationally sponsored programs currently face some level of funding constraint.

Addressing the needs of people with disabilities is part of a broader social protection strategy. This note intends to support the government of Sierra Leone in devising policies to achieve its PRSP goal to empower the most vulnerable groups, including people with disabilities, to participate in productive activities and economic growth. This note will contribute to the broader social protection debate, which includes labor issues, pension schemes, and formal safety nets, and which will be part of the ongoing overall economic and social dialogue that the government and major stakeholders are having with partners and with the World Bank in particular. The note has been prepared on the basis of (i) existing analytical work and analysis of existing documentation, (ii) the 2004 Census data and secondary data from other surveys, (iii) a mini-survey of NGOs and interviews with various stakeholders, and (iv) analysis of reports and experiences from other countries. The audience of this policy note includes the government, the donor community, national and international NGOs, people with disabilities, and their organizations.

This note contains five chapters, the first of which is this introduction. Chapter 2 summarizes the diagnosis of the scale and nature of the people with disabilities issue by examining the prevalence, types, and causes of disability and by discussing the socioeconomic profiles of people with disabilities, particularly their access to health, education, and social protection services. Chapter 3 includes an analysis of current public policies and of the legal and institutional framework for the protection and promotion of the rights of people with disabilities in Sierra Leone. Chapter 4 provides an overview of the current public and private programs to support people with disabilities, with a focus on their objectives, costs, limitations, and impact. Most of these programs have been in direct response to the conflict and have had an emergency nature, at times disregarding some of the more structural issues concerning people with disabilities and the needs of those people whose disability is only indirectly related to the conflict. The final chapter, Chapter 5, outlines possible options to reform the overall public/private approach to people with disabilities, and explores options for inclusive policies and programs to support people with disabilities including sector interventions to improve their standard of living. The appendix includes a table with specific recommendations to boost support to people with disabilities in Sierra Leone. A bibliography is found at the end of this note.

## Notes

<sup>1</sup> Roseveare and Longshaw 2006.

<sup>2</sup> *Sierra Leone Integrated Household Survey (SLIHS)*, Freetown: Office of Statistics Sierra Leone (2004).

<sup>3</sup> Massagli and Scott 2003.

<sup>4</sup> Mont 2007.

<sup>5</sup> Inaccurate or incomplete definition or categorization of people with disabilities in such surveys has resulted in an inaccurate accounting of people with disabilities in developing countries.

<sup>6</sup> Usually organized by disability and referred to as Disabled People's Organizations (DPO).

# Diagnosis

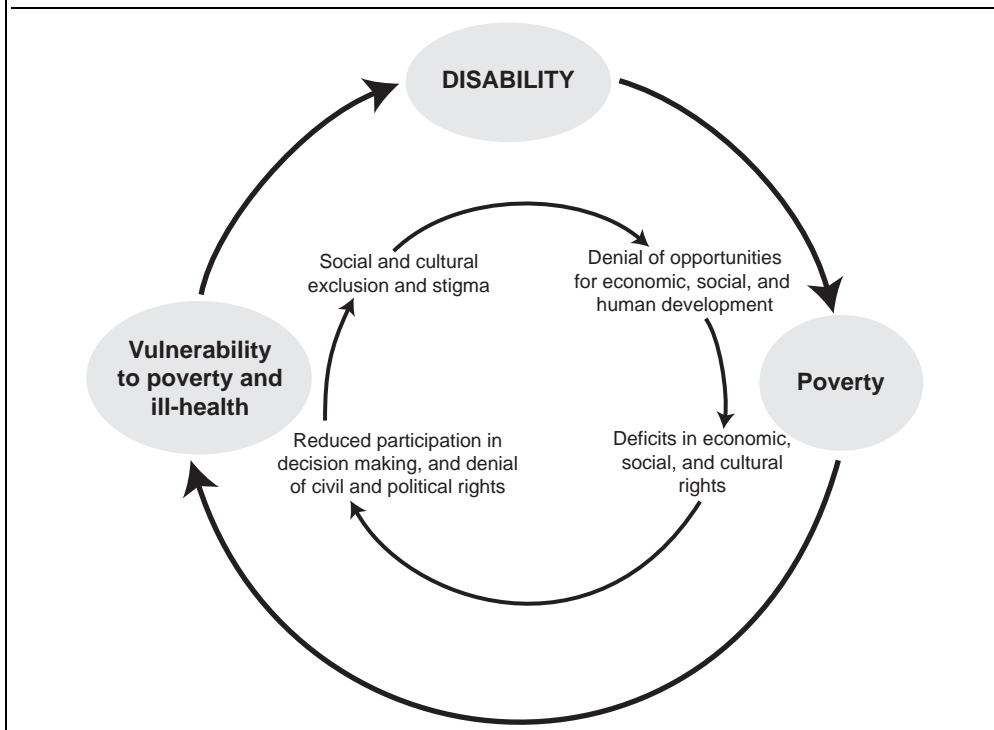
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### **Disability and Poverty**

Direct impact of disability on poverty (and that of poverty on disability). There is sufficient evidence to suggest that poverty is both a cause and consequence of disability. Poverty and disability reinforce each other, contributing to increased vulnerability and exclusion. Children with disabilities are more likely to die young, to be neglected, malnourished, uneducated, and poor. People with disabilities who are denied educational opportunities are subsequently less able to find employment, driving them deeper into poverty. People with disabilities are usually among the poorest of the poor, and their literacy rates are considerably lower than the rest of the population.<sup>1</sup> Studies indicate that disability and poverty are mutually reinforcing; poor people tend to be disproportionately disabled and disabled people are disproportionately poor.<sup>2</sup> Disability is both a cause as well as a consequence of poverty and is manifested in a complex cycle depicted in figure 1.

Sierra Leone remains among the poorest countries in the world. The inextricable link between poverty and disability is unmistakable in Sierra Leone, designated by the 2006 UN Human Development Index as the second poorest country in the world.<sup>3</sup> Some 70 percent of the population lives below the poverty line, with some 26 percent classified as extremely poor.<sup>4</sup> Life expectancy is 37 years and health and education indicators are classified as very low.<sup>5</sup> Participatory poverty assessments conducted by the World Bank as part of the PRSP process referenced people with physical and psychological disabilities as among the poorest segment of the population.<sup>6</sup>

The war has had a devastating impact on human capital. During almost a decade-long civil war that ended in 2002, the Sierra Leonean population experienced widespread human rights violations, affecting the majority of its population and resulting in permanent disability (physical, sensory, and/or psycho-social) for many. A significant number of those who lived with a disability prior to the conflict may have acquired additional disabilities. Violations of international law, including abduction, torture, and indiscriminate killings, were widespread, and mutilation as a form of community-based terror left between 1,000 and 3,000 amputee survivors.<sup>7</sup> Use of landmines has also resulted in permanent disability.<sup>8</sup> Sexual and gender-based violence (SGBV) during the conflict took the form of widespread rape, resulting in both physical and psycho-social disabilities for many survivors.<sup>9</sup> Violence against women and girls continues in the post-conflict context.<sup>10</sup> During the conflict, preventive health care measures to address communicable diseases were halted, including, but not limited to, health education (HIV/AIDS, malaria), river spraying (programs to prevent river blindness), and immunization programs.

**Figure 1. Cycle of Poverty and Disability**

Source: "Disability, Poverty and Development," UK Department for International Development (DFID), London, UK, February 2000.

### Definition of People with Disabilities

There are a number of different approaches to defining people with disabilities. The 2004 Census uses the World Health Organization's (WHO) general definition of a person with disabilities as, "one who experiences any limitation in performing a daily-life activity in a manner considered normal for a person of his or her age, because of a long-term physical condition (that is, more than six months), mental condition<sup>11</sup> or health problems." Questions asked in the context of the 2004 Census reflected a disability dimension of the issues rather than impairment or handicap approaches focused on a social rather than a medical model. The disability approach emphasizes the person's practical experience in participating in daily life activities and his or her self-positioning in relation to his or her participation or nonparticipation in them. The medical approach focuses on impairment and requires specific medical knowledge. The social model examines the relationship between people with disabilities and the social and physical environment in which they live.<sup>12</sup>

### Prevalence

The 2004 Census has comparatively low estimates of people with disabilities. According to the 2004 Census and the Sierra Leone Integrated Household Survey,<sup>13</sup> there were almost 120,000 people with disabilities in Sierra Leone (approximately



63,000 men and 57,000 women), with a prevalence rate of 2.4 percent of the total population (table 1). These statistics seem to underestimate the prevalence of disability in Sierra Leone, considering the level of poverty, historically low Human Development Index (HDI), and the social, security, and political turmoil that the country has experienced for close to two decades. Disability prevalence in neighboring Liberia, a comparably poor and conflict-affected country, is put at 17 percent by the Ministry of Health.<sup>14</sup> Based on other evidence, some sources point to a higher than 2.4 percent disability prevalence in Sierra Leone, putting the total number of people with disabilities at 250,000 or 4 percent of the total population.<sup>15</sup>

The census data could underestimate the number of people with disabilities. The census estimates, however, are likely to be limited to people with certain types of disabilities, especially those with severe ones.<sup>16</sup> For example, the census reported only 3,300 cases of mental retardation, while a 2003 study<sup>17</sup> estimated that Sierra Leone was likely to have almost 219,000 children with mild to medium forms of mental retardation in addition to 33,000 children with severe forms of mental retardation due to a nutrient deficiency among women of reproductive age. While mild mental retardation does not necessarily imply the inability to perform basic daily activities, more severe forms do.

Sierra Leone is not alone in underestimating the number of people with disabilities. Experience from other countries shows that official census estimates of the number of people with disabilities tend to underrepresent the prevalence of the phenomenon in the population, based on evidence seen or recorded by other organizations. For example, the 1991 Brazilian Census reported only a 1–2 percent disability rate, but the 2001 Census, using an improved approach, recorded a 14.5 percent prevalence of disability. Increases of three to four times from census data were later recorded by more focused surveys in countries such as Turkey and Nicaragua.

**Table 1. Number of People in Sierra Leone with Disabilities (by Rural/Urban and Gender)**

|                       | Rural       |           |                  |
|-----------------------|-------------|-----------|------------------|
|                       | Male        | Female    | Rural total      |
| With disability       | 44,195      | 40,173    | <b>84,368</b>    |
| Without disability    | 1,433,194   | 1,561,644 | <b>2,994,838</b> |
| Disability prevalence | 3.0%        | 2.5%      | <b>2.7%</b>      |
|                       | Urban       |           |                  |
|                       | Male        | Female    | Urban total      |
| With disability       | 18,535      | 16,357    | <b>34,892</b>    |
| Without disability    | 895,053     | 919,427   | <b>1,814,480</b> |
| Disability prevalence | 2.0%        | 1.7%      | <b>1.9%</b>      |
|                       | Countrywide |           |                  |
|                       | Male        | Female    | Total            |
| With disability       | 62,730      | 56,530    | <b>119,260</b>   |
| Without disability    | 2,328,247   | 2,481,071 | <b>4,809,318</b> |
| Disability prevalence | 2.6%        | 2.2%      | <b>2.4%</b>      |

**Table 2. Prevalence of Disability in Selected Countries by Source**

| Censuses       |      |                                       | Surveys     |      |                                       |
|----------------|------|---------------------------------------|-------------|------|---------------------------------------|
| Country        | Year | Percent of population with disability | Country     | Year | Percent of population with disability |
| United States  | 2000 | 19.4                                  | New Zealand | 1996 | 20.0                                  |
| Canada         | 2001 | 18.5                                  | Australia   | 2000 | 20.0                                  |
| Brazil         | 2000 | 14.5                                  | Uruguay     | 1992 | 16.0                                  |
| United Kingdom | 1991 | 12.2                                  | Zambia      | 2006 | 13.1                                  |
| Uganda         | 2001 | 3.5                                   | Ecuador     | 2005 | 12.1                                  |
| Mexico         | 2000 | 2.3                                   | Nicaragua   | 2003 | 10.3                                  |
| Botswana       | 1991 | 2.2                                   | Germany     | 1992 | 8.4                                   |
| Chile          | 1992 | 2.2                                   | Italy       | 1994 | 5.0                                   |
| India          | 2001 | 2.1                                   | Egypt       | 1996 | 4.4                                   |

*Source:* Mont 2007; United Nations Statistics Division; IBGE (Brazil), INEC (Nicaragua); INEC (Ecuador); INEGI (Mexico); Statistics New Zealand; INE (Spain); Census of India 2001, SINTEF Health Research (Zambia) 2006.

Further, intercountry comparison of disability prevalence, as recorded by census and surveys, shows that developing countries systematically estimate disability prevalence at a much lower rate than do developed countries (see table 2).

These differences result from at least three sources: (i) varying definitions of disability and related issues of observability,<sup>18</sup> (ii) different methodologies for collecting information on disability, and (iii) potentially different underlying rates of disability. It is probable that the main reason for the difference in prevalence rates between developed and developing countries—as is becoming apparent from recent studies—is that the data instruments in developing countries tend to only identify the most severely disabled people, and not even all of them. These countries tend to simply ask, “Do you have a disability?” instead of asking specific questions about functioning (for example, walking, seeing, hearing, self-care, and so forth). Simply asking about the presence of a “disability” tends to underestimate prevalence rates since in developing countries the word “disability” is generally taken to mean only severe limitations in functioning, and so misses mild and moderate disabilities. Moreover, people think of disability relative to their expectations of how they should be functioning, so elderly people and people who live in areas with a significant number of people in poor health will not consider themselves disabled because they do not function any differently than they would expect someone in their position to function.

The WHO estimates prevalence of disability in developing countries at around 10 percent of the population. Moreover, prevalence rates of 13.1 in Zambia, 12.1 in Ecuador, 10.3 in Nicaragua (and recent testing in about 20 countries including Kenya, Uganda and Tanzania) suggest that a 10–12 percent global prevalence rate is a reasonable estimate. For all of the above reasons, it is a sound proposition to conclude that disability prevalence in Sierra Leone is well above that suggested by the available data, as much as four times, approaching or exceeding the rough often-cited WHO global 10 percent figure. Despite this data limitation, the 2004 Census remains the most

recent and complete data source, and the information provided for the rest of this chapter is from the 2004 Census, unless stated otherwise.

**Disability at the household level.** Another way of looking at the scale of disability and its impact on society is to examine the proportion of households with at least one disabled member. In Sierra Leone, an estimated 5 percent of households have one or more disabled individuals. Formal analysis of the social and economic impact of disability at the household level is quite limited because of the dearth of information provided by the census or other studies in this respect. However, this aspect remains important as most of the coping mechanisms of people with disabilities are family-based, and thus depend on and impact the economic and social well-being of households.

### **Type, Causes, Gender**

The analysis of the census sheds some light on the types of disabilities affecting people in Sierra Leone. Notwithstanding the limitations of available disability data, some trends are apparent based on the analysis of census data. As shown in table 3, the most prevalent visible and severe forms of disability include physical and visual impairments caused by diseases, accidents, illnesses, or some combination of the three. According to the census, the most common type of reported disability is the limited use of legs (21 percent), followed by visual impairments (19 percent) and blindness (7 percent).

**Table 3. Selected Profile of People with Disabilities**

|                                   |                 | Percentage of population | Percentage of people with disabilities |
|-----------------------------------|-----------------|--------------------------|--|
| Share of people with disabilities |                 | 2.40                     | 100.00                                 |
| Type of disability*               | Physical        | 0.90                     | 37.54                                  |
|                                   | Visual          | 0.64                     | 26.69                                  |
|                                   | Hearing/speech  | 0.35                     | 14.51                                  |
|                                   | Mental          | 0.13                     | 5.25                                   |
|                                   | Other           | 0.38                     | 16.01                                  |
| Cause of disability               | Disease/illness | 1.09                     | 45.65                                  |
|                                   | Accident/injury | 0.40                     | 16.46                                  |
|                                   | Congenital      | 0.29                     | 11.93                                  |
|                                   | Aging           | 0.28                     | 11.84                                  |
|                                   | War             | 0.23                     | 9.58                                   |
|                                   | Others          | 0.11                     | 4.54                                   |
| Gender                            | Male            | 2.60                     | 52.60                                  |
|                                   | Female          | 2.21                     | 47.40                                  |

Source: 2004 Census.

\* Physical: loss or limited use of limbs or back spine; visual: blindness, sight difficulty. Hearing and speech: loss or impairment of hearing and speech. Mental: mental retardation and illness. Other: epileptic, rheumatism, others.

War-related physical disabilities account for less than 10 percent of people with disabilities. War-related mental disabilities account for less than 0.4 percent of the total. This small percentage is likely due to the underreporting of mental disability in general. A survey in Freetown following a period of intense violence in early 1999 reported that nearly all respondents indicated a high level of psycho-social impact that would meet the clinical threshold for post-traumatic stress disorder (PTSD) using Western criteria.<sup>19</sup>

Conflict takes a major toll in terms of morbidity and mortality, but even more so in terms of long-term disability due to increased risk of disease and injury, poor access to health care, and weakened social networks.<sup>20</sup> As a result of conflict, health systems and services are often disrupted and dilapidated, if not entirely destroyed.<sup>21</sup> Further, essential services, supplies, and logistics are damaged including the provision of clean water and sanitation, food, key infrastructure, as well as networks of communication. Essential preventive services such as disease control, immunization and supplementation programs, and campaign activities are thwarted. Further, as surveillance systems break down, the incidence and spread of disease cannot be tracked and treated adequately in a timely fashion. These factors lead to a higher indirect<sup>22</sup> effect of the conflict not recorded in official statistics.<sup>23</sup>

Low immunization coverage, poor access to health services, and increased incidence of injuries, trauma, malnutrition, and infectious disease place populations at serious increased risk of disease, death, and disability.<sup>24</sup> An estimated 65 percent of epidemics occur in unstable countries.<sup>25</sup> Conflict-affected populations also experience increased vulnerability to STDs, HIV/AIDS, and other infectious diseases<sup>26</sup> that are associated with increased morbidity,<sup>27</sup> mortality, and disability. In Sierra Leone, the control of onchocerciasis, which often results in blindness and significant disfigurement if left untreated, was badly disrupted during the conflict and remains a major public health concern.<sup>28</sup> Other cases of conflict and post-conflict countries have shown disease to be a significant cause of disability, though research to date is limited. A study in Kakuma Camp (Kenya) found that disease and infections were reported to be the leading causes of disability, responsible for 70.1 percent of vision cases, 77 percent of hearing cases, 69.3 percent of mental cases, and 46.8 percent of speech cases.<sup>29</sup> In Burundi, illness was the primary cause of disability, accounting for 58.9 percent (Makamba Province), 46 percent (Muyinga Province), and 61.1 percent (Bujumbura Province) of total disabilities, followed by injuries (general and war-related) with 18 percent, 18 percent, and 11.6 percent, respectively.<sup>30</sup> In Muyinga, over 75 percent of disability was caused by preventable disease, and 75 percent was due to delayed or never-sought treatment. In the case of Sierra Leone, the last census found that nearly 50 percent of disability was due to disease.

Both in absolute and relative terms there are more disabled men than women. The prevalence of disability is 2.6 percent among males and 2.2 percent among females. The male-female ratio of disability was 111 to 110, which is skewed and reversed with respect to the general male-female population ratio of 95 to 100. Most disabled are over 25 years old (70 percent), and the number of disabilities among the male population is greater than that of the female population in most of the types of disabilities, except in the case of natural illness and disability from ageing. Visual impairments (including blindness), and limited use of arms and legs were more prevalent among men than

women, while hearing impairments were more common among women than men. Loss of limbs (arm or leg) was relatively more widespread among men with disabilities than women with disabilities. In terms of causes, there were higher levels of disability among females due to accidents, occupational injuries, and war.

## **Location**

In Sierra Leone, the incidence of people with disabilities is higher in the south and east, and more pronounced in rural areas than in urban ones. People with disabilities are more concentrated in the Southern (2.9 percent) and Eastern Provinces (2.8 percent), followed by the Northern Province (2.2 percent) and the Western Area (1.7 percent). Intrastate variation is also high in both the Southern Province, where the prevalence ranges from 2.39 percent in Bo district to 3.68 percent in Bonthe district, and the Western Area, where prevalence in urban districts (1.4 percent) is less than half of that in rural districts (3.1 percent). The inter- and intra-province variations of specific disabilities are also obvious: The proportion of people with visual disability alone, for instance, reaches almost 1 percent in Bonthe, Moyamba, and Pujehun districts in Southern Province, whereas that in Western Urban district is only 0.35 percent. Nevertheless, the Western district had the highest percentage of persons suffering from loss of limbs followed by districts in the north. As indicated by a recent report based on the 2004 Census, a possible reason for this is the presence of a disability center in the Western Area.<sup>31</sup> From the analysis, there seems to be little correlation between the regional prevalence rates of people with disabilities and the impact of the conflict in such regions. In fact, the Northern region was among the most affected by the conflict and yet the prevalence rate is among the lowest. At the other extreme, the Southern region, which was among the least affected by the conflict, has the highest rate of people with disabilities. Such discrepancies can be attributed to the relatively low incidence of war as a direct cause of disabilities, at least as recorded by the census, and displacement of populations after the conflict. One other explanation may be related to the combination of two factors: (i) Only severe disabilities are being picked up by the census questions, and (ii) disabled people are more likely to die when health systems are disrupted during conflict. Thus, people with moderate and mild disabilities tend not to be counted, while people with severe disabilities may have died by the time of the census.

## **Access to Education**

Education helps people with disabilities and their families. Access to education (i) creates necessary human capital to achieve sustainable economic development and reduce poverty at the national level; (ii) improves the livelihood of family members, disabled and not disabled; (iii) helps the integration of people with disabilities into economic life, sustaining country economic growth; and (iv) helps change attitudes toward people with disabilities. The Sierra Leone New Education Policy as well as the PRSP states the need for special education for disabled and vulnerable children and youth as one of the priorities. These plans recommend inclusive education of disabled children in primary and secondary schools, providing suitable facilities for those in need, and developing different approaches to teaching and curriculum that benefit all

students, including children affected by disabilities. Such an inclusive education policy is not yet developed in Sierra Leone.

Children with disabilities (CWD) are less likely to attend school than children without disabilities. Disparity between nondisabled and disabled children and youth in school attendance (age 5 to 19 years) is 7 percentage points in the case of boys and more than 10 percentage points for girls. This gender disparity within the disparity between nondisabled and disabled children attending school increases even further with age. As shown in table 4, boys and girls with disabilities are on par for school attendance in the 0-5 year age group. The girl-boy ratio increases to 1 to 1.1 for the age group 10-14 and to 1 to 1.6 for the age group 15-19. This finding is somewhat comparable to a recent study<sup>32</sup> that shows lower school participation among disabled children in 11 countries. The need to increase access to education of disabled children in Sierra Leone emerges from a sample survey on vulnerable people in selected districts where the most frequently requested assistance by the families with disabled children is schooling for their children.<sup>33</sup>

School attendance and highest level of education attained seem to be negatively correlated with disability. Census data suggest that there is a wide disparity at all education levels between people with and without disabilities. In particular, primary, junior secondary and secondary attainment is at least 2 percentage points lower among people with disabilities.

## Health

While health care is essential to prevent disabilities and support rehabilitation, access to such services for people with disabilities is limited. While the 2002 National Health Strategy indicates that disability is one of the priority health problems in Sierra Leone, it does not prioritize among different health approaches and, in particular, it does not address the question of whether public policies should focus on prevention, cure, rehabilitation, and mitigation, and in which order of importance or combination. On the other hand, information from the Ministry of Health and NGOs points to the fact that the actual provision of health services to prevent disabilities and rehabilitate people with disabilities is inadequate. Moreover, rehabilitation, both as a means to mitigate functional limitations and to prevent secondary disabilities, needs to be a key component of health care services.

**Table 4. Proportion of Children and Youth Attending School**

| Age (year) | Male               |                 | Female             |                 |
|------------|--------------------|-----------------|--------------------|-----------------|
|            | Without disability | With disability | Without disability | With disability |
| 05-09      | 52.3               | 45.3            | 52.3               | 42.7            |
| 10-14      | 77.3               | 62.2            | 72.1               | 55.4            |
| 15-19      | 62.5               | 48.4            | 39.0               | 28.7            |
| 20-24      | 26.3               | 17.7            | 9.7                | 6.3             |

Source: 2004 Census.

Unfortunately, census data on access to health services are very limited. Based on some sector studies, there is evidence that the protracted conflict has had a negative impact on immunization and prevention campaigns. It is expected that this will have a negative medium- to long-term impact on some disabling diseases.

### **Income and Economic Activities**

There is sufficient evidence, particularly in the case of Sierra Leone, to suggest that poverty is both a cause and consequence of disability. The census provides sufficient data on income and nonincome indicators for households with people with disabilities. A comparison with data of households without people with disabilities further supports the thesis that people with disabilities are poorer than people without disabilities. Case in point: Employment rates are lower among people with disabilities than in the general population, varying by gender and disability type. While about 46 percent of the population between ages 10 and 65 years is either employed or self-employed, the same is true of only 38 percent of people with disabilities. Moreover, the proportion drops to 31 percent for female people with disabilities and 26 percent for people with mental disabilities. Differences among people with disabilities excluded from the labor force (based on type of disability) are even greater: While 25 percent of those with visual and mental disabilities are part of the labor force, only 8 percent of people with hearing/speech disabilities are employed. Average earnings and employment potential are likely to be lower for people with disabilities than for people without disabilities of the same age groups. While these findings are not surprising, especially since unemployment rates are high in Sierra Leone, they do shed light on how difficult it is for people with disabilities to make a living.<sup>34</sup>

Begging by people with disabilities is visible, especially in Freetown. At traffic lights, at the helipad, in markets, and in other public places it is very common to see large groups of disabled, often helped by young children, begging. Their number has grown significantly since the end of the conflict, or at least they are more visible than before in what seems to be a growing industry. In fact, many of them are part of well-organized networks of beggars. Moreover, anecdotal evidence shows that virtually all disabled beggars are accompanied by a nondisabled person.

The cost of excluding people with disabilities from society and the economy is high. The WHO estimates that in developing countries 25 percent of the total population is adversely impacted as a result of disabilities. The cost of disability is unequally shared, as the burden of care disproportionately falls on women. Moreover, disability negatively affects family members and their ability to attend school or perform jobs and other tasks that would strengthen the social and economic environment of the household.<sup>35</sup> In Sierra Leone, where the majority of people with disabilities are male, this trend is likely true and will present a high opportunity cost to household productivity and investments in human capital (that is, education).

### **Transportation/Accessibility**

People with disabilities often experience barriers to participation in social and economic life due to issues of mobility and accessibility.<sup>36</sup> Transportation and mobility are vital on an individual level to promote independent living and on a national level

to support economic and social development objectives, particularly through increasing access of the rural farming population and the urban poor to market centers and social and economic services. The challenge of having an inclusive transport system and access to public facilities and services will be addressed at both the policy and project levels. They should be given priority in planning, design, and construction in Sierra Leone.

The census provides no specific information on the issue of accessibility and transportation and mobility services for people with disabilities. Some information can be gathered from the work of the Truth and Reconciliation Commission under Chapter 4 of the law establishing the commission. In particular, the commission received a total of 7,700 statements from victims of the conflict. A survey of these statements revealed those needs classified as most urgent. Sixteen percent of the sample indicated that the assistance required was related to infrastructure/transportation (and 50 percent shelter, 41 percent education, and 27 percent health; multiple responses were possible).

## Notes

<sup>1</sup> DFID 2000.

<sup>2</sup> A study in the United Kingdom indicated that the poverty rate for disabled people was 23.1 percent compared with 17.9 percent for nondisabled people, but when extra expenses associated with being disabled were considered, the poverty rate for people with disabilities increased to 47.4 percent (Mont 2005).

<sup>3</sup> The HDI for Sierra Leone is 0.335, which gives Sierra Leone a rank of 176<sup>th</sup> out of 177 countries with data (United Nations Development Program (UNDP), Human Development Report 2006).

<sup>4</sup> *Ibid.*

<sup>5</sup> *Ibid.*

<sup>6</sup> *Sierra Leone PRSP* 2005.

<sup>7</sup> Also, figures on the number of amputees vary considerably, as it is believed that many cases are not reported (Christodoulou 2004).

<sup>8</sup> International Campaign to Ban Landmines (ICBL) 2006.

<sup>9</sup> Sierra Leone, Truth and Reconciliation Commission. 2004.

<sup>10</sup> During the preparation of this report, a World Bank team interviewed some women affected by polio. Most of them became pregnant because their specific medical condition prevented them from being able to defend themselves (or be defended) from intimidation and rape. As a result, many are cast out of their homes. Usually, women with polio can give birth by cesarean section only. Because of the lack of financial resources to afford a doctor and specialized surgical treatment, these women often end up in the emergency room of a public hospital, when it is usually too late and when the pregnancy is putting at high risk the life of both the mother and the child.

<sup>11</sup> As defined by the International Classification of Diseases (ICD) published by the WHO.

<sup>12</sup> This ICF model is a classification of functionality at three levels: (i) the health condition (such as functional or structural impairment at the body level such as a problem with protein metabolism or a missing leg); (ii) the body function and structure to perform activities that others perform at the personal level (such as inability to dress oneself or to drive a car) or that are related to participation in major areas of life such as parenting, employment, education, or societal integration; and (iii) the contextual level (environmental



and personal factors). Beside these distinctions, it is important to note that disability is a continuum and not a dichotomous variable or concept. Any cutoff point is academic and influences the data collection (for example, prevalence). For definitions see: World Health Organization, "International Classification of Impairment, Disabilities, and Handicaps (ICIDH)," (1980); World Health Organization at <http://www.who.int/about/en/index.html>; and specifically on disability: <http://www3.who.int/icf/intros/ICF-Eng-Intro.pdf>.

<sup>13</sup> Squire and Jamiru 2006.

<sup>14</sup> Statement of Minister of Health and Social Welfare Coleman, May 2003 (Dukully, 2003).

<sup>15</sup> FAO 2004.

<sup>16</sup> The Sierra Leone Multiple Indicator Cluster Surveys—Round 2 (MICS2), for example, includes only blindness, loss or limited use of limbs, deafness, and muteness (<http://www.childinfo.org/mics2.html>).

<sup>17</sup> Aguayo et al. 2003.

<sup>18</sup> As observed in a World Bank report on people with disabilities in India (O'Keefe 2007): "Correctly observing the existence of a disabling impairment presents many challenges ... Many impairments occur on a continuous spectrum (reduction in mobility, in eyesight, or IQ). This in turn brings about the question of at what point impairment can be considered a disability." This uncertainty emerges also in the disability approach as discussed above under the heading "Definition of People With Disabilities," as a person with a disability still performs an activity but at a much reduced level of efficiency because of the disability, and the limitation she/he originally had is now considered the normal condition.

<sup>19</sup> De Jong et al. 2000.

<sup>20</sup> For example, Dr. Alawan, Interim Health Minister, has asserted that "more Iraqis have died as a result of inappropriate health policies, sanctions and neglect of the health sector over the past 15 years than from wars and violence" (Dyer 2004).

<sup>21</sup> For application see: International Committee of the Red Cross, "ICRC Health Services: Introduction," <http://www.icrc.org/Web/eng/siteeng0.nsf/html/57JQ9W> (May 29, 2007); Alma Ata Declaration; and Zwi (2005).

<sup>22</sup> Although an individual may be affected *indirectly* (this term is not likely to mean "accidental"), the act may not be any less "deliberate." As has been observed, "rebels and government soldiers loot and destroy housing, schools and health facilities" in addition to other key infrastructure (Hoeffler and Reynal-Querol 2003; Loretto 1997).

<sup>23</sup> "Military operations target water plants and health facilities as means of deliberately hurting civilians" (Loretto 1997). And "in most wars, health facilities come under attack" (see "The impact of armed conflict on child development," [www.un.org/rights/impact.htm](http://www.un.org/rights/impact.htm)). In addition, distribution systems for safe food and water are disrupted as electricity networks are also destroyed, as is medical equipment (Neumayer and Plumper 2006). Destruction of power sources (power plants), "bringing forests under extreme pressure as trees are being cut to meet increasing energy demands," has also "led to atmospheric pollution with the use of private generators on the 'increase,' particularly in urban areas" (UNDP 2006).

<sup>24</sup> Lett et al 2006; WHO 2005.

<sup>25</sup> WHO 2005; Armstrong and Ager 2005.

<sup>26</sup> Research shows that "both the spread of HIV 1 infection in the 1980s, and the subsequent development of AIDS to its 1990 spatial pattern, are shown to be significantly and positively correlated with ethnic patterns of recruitment into the Ugandan National Liberation Army

(UNLA) after the overthrow of Idi Amin some 10 years earlier in 1979" (Smallman-Raynor and Cliff 2001).

<sup>27</sup> One form of disability is HIV/AIDS-related cognitive impairment and dementia, which is thought to take a significant toll on HIV-infected populations. HIV is "the commonest cause of cognitive dysfunction in young people worldwide," according to Justin McArthur, Vice Chairman of Neurology at JHU, who treats neuroAIDS, which makes this "a major public health issue." "Surviving AIDS can wreak havoc on the brain. Early exposure can cause developmental delays" (Neergaard 2006).

<sup>28</sup> Moreover, "the true burden of onchocerciasis has largely been underestimated." For, "infected people face physical disability and social stigma that can reduce the quality of life.... A number of former OCP countries face major challenges as a result of conflict and political instability. In these countries, civil disturbance and consequence migration have caused major disruptions in OC operations, and many of the structures and systems established by OCP have disappeared. The conflict situation has prevented continuation of control activities in Sierra Leone, Côte d'Ivoire, and Guinea-Bissau. The epidemiological situation in Sierra Leone is very alarming, as some indicators have reverted to the pre-control situation of a decade ago. CDTI alone (without any vector control operations) has been established countrywide with the support of the OCP Trust Funds and NGOs. The results of these renewed efforts are not yet known" (Fox and Liebenthal 2006).

<sup>29</sup> A study of refugees in Kakuma Camp (IRC 2003).

<sup>30</sup> In Makamba, out of 38 injuries that induced disability, 16 or 42.1 percent were violence-related, with 14 directly war-related and 2 due to rapes. In Muyinga, out of 30 injuries that induced disability, 7 or 23.3 percent were violence related. In Bujumbura, out of 45 injuries that induced disability, 25 or 55.5 percent were violence related, with 23 being directly war-related (IRIN 2003).

<sup>31</sup> Kamara et al. 2006.

<sup>32</sup> Filmer 2005.

<sup>33</sup> Squire and Jamiru 2006.

<sup>34</sup> A recent disability survey in Nicaragua found disabled people to have much lower rates of education, much higher rates of illiteracy, and much lower rates of economic activity. In Serbia, 70 percent of disabled people are poor and only 13 percent have access to employment (Roseveare and Longshaw 2006).

<sup>35</sup> Evidence from Uganda and Yemen shows significant drops in attendance of nondisabled children if there are disabled adults in the household. Evidence from Nicaragua shows significant amount of time spent on caring for disabled family members that presumably cuts into labor supply and other household production (Mont 2007).

<sup>36</sup> Draft legislation—see next chapter—clearly states the principle that persons with disabilities shall be entitled to a barrier-free environment to enable them to have access to buildings, roads, and other social amenities and assistive devices and other equipment to promote their mobility. The draft legislation also prescribes that public buildings shall be adapted to suit persons with disability and that operators of public services vehicles shall adapt such vehicles to suit persons with disability. The cost of ensuring inclusivity and accessibility during reconstruction is limited, estimated at 1–1.5 percent of the entire project cost. For a discussion on this and related issues see: <http://www.ap.buffalo.edu/~arced/lifespan00/udi/udi9.html>; and <http://www.adaptiveenvironments.org/index.php?Itemid=3&option=Content> and Universal Design handbook: <http://www.universaldesign.net/PDFs/jr199.pdf>.

# Policy Framework in Support of People with Disabilities in Sierra Leone

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A policy framework referring to the (i) legal framework and (ii) institutions and policies supporting the rights of people with disabilities in Sierra Leone and facilitating their full participation in their communities is underdeveloped at present. Key elements of this framework such as constitutional rights of disabled, legislation to secure such rights, policies, and programs to benefit the disabled, and institutions to administer and implement these policies and programs exist in varying degrees of completeness and will need to be further developed to provide a long-term framework for financing and implementation.

On its 2005–2007 PRSP, the government of Sierra Leone identified as a priority the participation of vulnerable groups, including people with disabilities, in development strategies through empowerment and mainstreaming.<sup>1</sup> Medium-term strategies include (i) integration into society and the economy through access to productive social and economic resources; (ii) short- to medium-term provision of social protection; and (iii) development of a multisectoral disability policy framework, with an emphasis on providing access to sector program interventions.

Despite the strategic priorities of the 2005–2007 PRSP, Sierra Leone has no approved national policy on disability at this time. A draft National Policy Paper on People Living with Disabilities, prepared in 2004–05 under the leadership of the Ministry of Health and Sanitation (MOHS) and Ministry of Social Welfare, Gender, and Children’s Affairs (MSWGCA), has yet to be costed, adopted, and implemented. Furthermore, the draft disability legislation does not conform to international standards on disability; for example, there is no mechanism for the coordination of the finalization of the disability policy and programming.

A few specialized institutions target a small segment of people with disabilities for the provision of support. Available data<sup>2</sup> suggest that a number of barriers inhibit people with disabilities from full participation in society and that there is little in the way of integrated and inclusive development programming to effectively include Sierra Leoneans with disabilities in an ongoing and consistent fashion in the development process.

## Legal Framework

Despite the shortcomings of the current policy framework, the 1991 Constitution and a number of key treaties and conventions that Sierra Leone has signed provide an entry point to work toward an improved policy environment in support of people with disabilities.

Chapter III of the 1991 Constitution, *The Recognition and Protection of Fundamental Human Rights and Freedoms of the Individual*, contains 15 human rights provisions focusing on civil and political rights covered in the International Covenant on Civil and Political Rights (ICCPR). However, the constitution does not mention disability as a prohibited ground for discrimination, nor does it provide implicit coverage of disability as a prohibited ground within a generic category (such as membership of a social group). Nevertheless, Article 8 of the constitution sets forth social policy objectives for the state that include “the care and welfare of the aged, young and disabled shall be actively promoted and safeguarded.”<sup>3</sup>

On the other hand, at the end of the civil war, Sierra Leone actively engaged in the international dialogue on human rights and is signatory to six of seven core international human rights conventions<sup>4</sup> that have entered into force. Furthermore, Sierra Leone has signed two new core human rights conventions that opened for signature in 2007, including the UN Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol.<sup>5</sup> While the government has signaled its commitment to human rights by participating in international human rights conventions, including the negotiation of new treaties, it has been less successful in meeting its reporting obligations to international treaty monitoring bodies or in adopting domestic legislation in order to bring its international obligations into effect. The UN Integrated Office for Sierra Leone (UNIOSIL), Human Rights and Rule of Law Section, is currently providing assistance to build the capacity of state institutions to address the root causes of the previous conflict, develop a national action plan for human rights, build the capacity of the National Human Rights Commission, and to strengthen the rule of law.<sup>6</sup>

The CRPD provides the most detailed set of international standards pertaining to the rights of people with disabilities in international law. It is a comprehensive convention consisting of 50 articles, which provide coverage of a full range of civil, political, economic, social, and cultural rights applicable to people with disabilities. It also establishes a mechanism to monitor treaty compliance at the international level. Together with the convention, an Optional Protocol was adopted at the same time, which empowers the Committee on Persons with Disabilities to “receive and consider communications on behalf of individuals or groups of individuals subject to its jurisdiction who claim to be victims of a violation by that State Party of the provisions of the Convention.”<sup>7</sup> As a signatory to the convention, Sierra Leone is obliged to avoid any action that would undermine the object and purpose of the convention. The clear intention of the drafters of the convention was to provide a detailed framework for state parties to utilize in the drafting (or amendment) of domestic disability legislation.

In observance of the CRPD and other international conventions, in 2004, Sierra Leone commenced a process to draft national disability legislation with the stated purpose of providing for the “rights and rehabilitation of persons with disabilities,”

and “to achieve equalization of opportunities for Persons with Disabilities, to establish the National Council for Persons with Disabilities (NCRPD), and for connected purposes.”<sup>8</sup> There have been several iterations of the draft legislation, the latest of which was revised by the Law Reform Commission and submitted to the Attorney General at the end of 2007 for onward submission to the Parliament. During a consultative meeting held in Freetown on June 19, 2008, it was agreed that the NCRPD would circulate the document among disabled people’s organizations (DPO) for final comments. The launch/presentation of the draft legislation would be held in September 2008. The draft legislation provides coverage of some civil, political, economic, social, and cultural rights of people with disabilities and includes major institutional measures in order to put its provisions into effect.

The draft legislation has a number of shortcomings, including the manner in which it has been developed thus far, in particular, with insufficient participation by DPO. While the draft legislation does provide coverage of many important human rights reflected in international standards, as well as model domestic disability law, it does not reflect the full range of rights covered in the CRPD, nor does it capture fully the principles and concepts considered necessary to fully define a comprehensive disability law and policy. In particular, the concepts of full and effective participation of and inclusion of people with disabilities, their acceptance in society and equality of opportunity are not adequately covered or included in the draft legislation. Civil, economic, and social rights are underdeveloped. More specifically, in the areas of employment, education, health, accessibility to public buildings, transportation, and sport and recreation, the draft legislation falls short of meeting the needs of the people with disabilities in terms of securing access to services and facilitating their integration to the economy and community.

The implementation and monitoring of the draft legislation is to be undertaken by a National Council for Persons with Disabilities. The mandate of the council is to (i) issue adjustment orders under the Act; (ii) formulate and develop disability policies regarding education, employment, sporting, recreational, and cultural activities; (iii) cooperate with the government to ensure disability inclusion in the national census; (iv) advise on international treaties relating to people with disabilities; (v) recommend measures to end disability discrimination; (vi) develop projects for self employment or sheltered employment; (vii) secure rehabilitation of people with disabilities in their communities; (viii) coordinate services for the provision of rehabilitation and other services; and (ix) register people with disabilities and their organizations. In addition, the council is tasked with the (i) provision of assistive devices; (ii) consultations with government on teaching and training curricula; (iii) suitable housing for people with disabilities; (iv) provision of public information services; and (v) other functions deemed necessary and relevant, as assigned to the council. The Secretariat of the Council would include a staff headed by an Executive Director.

The council is comprised of seven members including Ministry of Social Welfare, Gender, and Children’s Affairs, a representative of youth organizations, and a representative of disabled people’s organizations, among others. The size of the council is appropriate to administer the proposed legislation, facilitate coordination among the various main line ministries and other stakeholders, and ensure representation of people with disabilities and their organizations. Nonetheless, the representativeness of

the institution should be ensured with appropriate membership from the disabled people's community. In addition, it is of paramount concern that the draft legislation provides provisions to ensure the independence of the council. As such, it fails to meet the standards set forth in the Paris Principles, the international standards against which specialized national human rights institutions are measured.<sup>9</sup> The new council is promising, and with proper support will likely facilitate improvements in laws, policies, and programs to improve the lives of people with disabilities in Sierra Leone; in the near term, however, there will be constraints to progress given that this new institution currently has insufficient resources and an inadequately trained staff.

Finally, the draft legislation calls for the establishment of a National Development Fund for People with Disabilities, to be managed by a Board of Trustees. The resources of the fund "shall be used for the benefit of persons with disabilities." This will entail significant capacity building, oversight, and monitoring to be effective and operational. Given the significant obstacles faced already with regard to other funding initiatives, including the Special Fund for War Victims that will be managed within NaCSA, the practicality of this particular component of the draft legislation is seriously open to question.

### **Institutional Environment and Policies in Support of People with Disabilities**

The 1991 Constitution supports an institutional framework for democratic governance that provides checks and balances, as well as accountability mechanisms, including an Office of Ombudsman and Anti-Corruption Commission. Accountability mechanisms are relevant to the successful implementation of disability service provision and will be essential if a disability fund is to be established as envisioned in the draft Act. Other bodies are directly relevant to the development, implementation, and monitoring of the rights of people with disabilities and are potentially significant in light of the underdeveloped state of current law and policy on disability issues.

The Parliament has a number of functioning committees, including an active Parliamentary Human Rights Committee. The committee has received support from the UN Development Program and is generally regarded as one of the most effective oversight committees within Parliament.<sup>10</sup> The parliamentary committee is tasked with reviewing human rights legislation and will therefore play a central role in the review of draft disability legislation, as well as the ratification of the CRPD. The Inter-Parliamentary Union, in collaboration with the Office of the High Commissioner for Human Rights and the UN Department of Economic and Social Affairs, has recently developed<sup>11</sup>—as part of a series on human rights convention—a handbook for parliamentarians on the CRPD. The training of parliamentary human rights committees on international disability standards is already underway in many countries and is essential to ensuring that the ratification of CRPD and the adoption or amendment of existing disability legislation is consistent with international standards.

In 2002, a Truth and Reconciliation Commission (TRC) was established to address war crimes and to promote healing and reconciliation. The TRC concluded its work in June 2004 and the Final Report<sup>12</sup> addresses many issues of importance to people with disabilities. Specifically, Chapter 4 on reparations articulates the needs of victims and issues numerous recommendations for beneficiaries, who are identified as amputees, other war-wounded, children, and victims of sexual violence.<sup>13</sup> The TRC report

emphasizes that there is no clear government policy on people with disabilities and that available assistance has come from national and international NGOs, not the government. Specific recommendations of the TRC report are outlined in Chapter IV.

In 2004, Parliament adopted the Human Rights Commission of Sierra Leone Act (HRC Act),<sup>14</sup> which provides for the establishment of a national human rights institution for the protection and promotion of human rights. The commission is a broad-based body, to be distinguished from specialized national human rights bodies such as the Disability Commission proposed in the draft domestic disability legislation. The commission is mandated to (i) investigate and inquire on human rights complaints on its own accord or on complaint by a person alleging human rights violations; (ii) promote respect for human rights through public awareness and education, information campaigns, publication of guidelines and other materials referencing obligations of public officials, and cooperating with governmental and nongovernmental bodies; (iii) review existing legislation and compliance with international human rights obligations; (iv) advise on draft legislation that may affect human rights; (v) advise on the preparation of periodic reporting to international human rights bodies; (vi) monitor and document human rights violations; and (vii) publish an annual report on human rights in Sierra Leone.

On October 4, 2006, Parliament approved the appointment of five commissioners nominated by the president in accordance with the HRC Act. The commission is required under Article 17(1) to appoint a minimum of four subcommittees on substantive issue-areas, one of which must include a subcommittee for the promotion and protection of the human rights of women and children. There is an opportunity for DPO to work with the commission to ensure that disability issues are built into its work at the earliest stage in the development of the institution. The formation of a subcommittee on the human rights of people with disabilities is therefore a means of ensuring that the work of the HRC fully integrates disability issues into its work. Subcommittees are headed by a commissioner and other persons competent in the subject matter concerned. Other national human rights institutions endowed with the power to appoint special committees have found it advantageous to establish a disability committee. Thus, for example the newly established Egyptian Human Rights Council has appointed a subcommittee to work on draft disability legislation. The Yemen framework for a disability council is also an interesting example.

The Ministry of Social Welfare, Gender, and Children's Affairs is recognized as the main focal point for handling disability issues. Other relevant key line ministries for disability policy and programming include the Ministry of Health and Sanitation and the Ministry of Education, Science, and Technology. The lack of specialized staff and of budgeted and executed policies and programs suggest, however, that institutional support for disability issues is underdeveloped across the government. A major advantage of enacting comprehensive domestic disability legislation in line with international standards will be the revision and further development of disability policy and strengthening of specialized technical capacity across all ministries—including those with traditional responsibility for disability issues, as well as those that have not yet engaged on disability issues but are responsible for ensuring inclusive development in sectors such as transport and tourism. The following chapter provides more details on specific programs being implemented by these ministries.

The National Commission for Social Action<sup>15</sup> was established as a social fund in 2001 by an Act of Parliament. It is responsible for humanitarian coordination, reconstruction, resettlement, and rehabilitation. Among the multi-sector activities of the fund is its support of projects providing aid to people with disabilities and their representative organizations. With support from the World Bank, NaCSA is implementing the National Social Action Project (NSAP).

## Notes

<sup>1</sup> IMF and World Bank 2005 (paras. 361–364).

<sup>2</sup> National Census 2004 and interviews with people with disabilities and NGOs held during January–March 2007.

<sup>3</sup> 1991 Constitution of Sierra Leone, Art. 8.

<sup>4</sup> These include the International Covenant on Economic, Social and Cultural Rights; International Covenant on Civil and Political Rights; Convention on the Elimination of All Forms of Racial Discrimination; the Convention on the Elimination of All Forms of Discrimination against Women; Convention on the Rights of the Child. Sierra Leone has signed the CRPD as well as the International Convention for the Protection of All Persons from Enforced Disappearance, which opened for signature on February 6, 2007. These two core conventions have not yet entered into force.

<sup>5</sup> UN Convention on the Rights of Persons with Disabilities, adopted by the UN General Assembly 13 Dec. 2006, opened for signature on March 30, 2007.

<sup>6</sup> For coverage of the work of the Human Rights and Rule of Law Section of UNIOSIL, see <http://www.uniosil.org/content>.

<sup>7</sup> This provision applies after all domestic remedies have been exhausted.

<sup>8</sup> (Draft) Persons with Disabilities Bill, Preambular paragraph.

<sup>9</sup> “Principles relating to the status and functioning of national institutions for the protection and promotion of human rights” (Paris Principles), Adopted by the UN General Assembly, December 1993.

<sup>10</sup> U.S. Department of State 2006.

<sup>11</sup> This handbook was launched on October 8, 2007.

<sup>12</sup> Sierra Leone, Truth and Reconciliation Commission 2004.

<sup>13</sup> The TRC only addressed the needs of People with Disabilities directly affected by the war and not those of others.

<sup>14</sup> The Human Rights Commission Act of Sierra Leone 2004, adopted August 26, 2004. This Act amends the National Commission for Democracy and Human Rights Act, 1994.

<sup>15</sup> The official website for the NaCSA is: <http://www.nacsa-sl.org>.



# Public and Private Programs in Support of People with Disabilities

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Public and private programs have only been able to support a small number of people with disabilities compared to the need. Despite being mentioned as a priority in the government's latest PRSP (2005–07) and in key sector ministry plans such as education and health, public and private programs supporting the integration of people with disabilities into the society and productive economy are limited. The majority of people with disabilities receive care from family members within their communities, and few specialized institutions have been set up by the government. International organizations and NGOs provide the bulk of assistance to meet health, rehabilitation, housing, and other needs of people with disabilities with limited resources and outreach capacity.

Prior to the war, charitable organizations, associations of disabled people,<sup>1</sup> and national NGOs provided some support to people with disabilities. After the war, select donors supported amputees and others whose disability was caused by a direct act of violence. People whose disabilities are not a direct result of conflict have received very limited donor support, although their number is by far greater than those with war related disabilities. Family and informal community-based safety nets have remained the main form of their support, especially in the rural areas. However, most of the informal family and community-based safety nets have been depleted by the war.

### **Public Program Financing**

The overall public sector record in this area is weak. Government has very limited programs and provisions to ensure access to and use of basic social services by people with disabilities. Although several ministries have the mandate to secure free services or assistance for people with disabilities, their programming falls short of their mandate. The implementation of the existing sector plans suffers from lack of resources, capacity constraints, inadequate intersectoral coordination, and insufficient awareness of service providers with respect to the rights and entitlements of the people with disabilities.

The government has also put in place a War Victims Reparations Program, targeting war-affected people with disabilities. In September 2006, the NaCSA, which

is currently implementing the World Bank–financed NSAP, was officially designated to implement the War Victims Reparations Program, under the provisions of the TRC.

The TRC recommended, among other things, the following in relation to the designated beneficiaries: (i) provision of free physical health care, rehabilitation, and free prosthetic and orthotic services for amputees; (ii) free physical health care for “other war wounded”; (iii) physical health care, free fistula surgery, HIV/AIDS and STIs testing, and treatment for victims of sexual violence; (iv) free physical health care for children; (v) free mental health care for all beneficiaries; (vi) housing assistance for particularly needy beneficiaries; (vii) disability pensions for permanently disabled; (viii) measures to enhance access to education for beneficiaries; and (ix) expansion of skills training, microcredit, and microprojects by government. The TRC further recommended that the implementation of the reparations program and Special Fund for War Victims (referred to in Article XXIX of the Lomé Agreement) be given to the existing NaCSA, within a new unit, instead of creating a new institution. The recommendations do an excellent job of identifying with precision the needs of war-affected disabled beneficiaries. Unfortunately, the bulk of the recommendations set forth in Chapter 4 of the TRC Final Report have not been implemented due to lack of resources.

The key ministries working to increase accessibility and public support to people with disabilities include: (i) the Ministry of Education, Science, and Technology; (ii) the Ministry of Health and Sanitation; and (iii) The Ministry of Social Welfare, Gender, and Children’s Affairs. The following three sections provide a brief summary of their policies and programs.

#### *Ministry of Education, Science, and Technology (MEST)*

The draft Education Sector Plan (ESP) of the MEST for 2007–12 prioritizes improving access to education for children with mobility issues, as part of the Millennium Development Goals for 2015. One of the ESP’s main policy goals is to increase the number of vulnerable and disadvantaged children enrolling and staying in school by (i) ensuring that schools can be safely used by children with disabilities, (ii) providing special needs teacher training and training materials, (iii) increasing social support and monitoring by social workers, and (iv) skills training. MEST is also working with a number of NGOs in the preparation of an Integrated Education Program.

Although primary education is currently free, in reality, parents pay for uniforms, books, and maintenance fees. This represents a real obstacle for parents and guardians with disabilities, who tend to be poorer. MEST provides a limited number of scholarships at the tertiary level, but does not offer any special scholarships or grants for primary and secondary school level children with disabilities or from poor households. Statistics on the coverage and total amount distributed through these scholarships are not available.

MEST is beginning to improve the accessibility of school facilities, as most schools are ill-equipped to respond to the needs of students with disabilities. There are some small-scale initiatives to build disabled accessible schools—most notably the Sababu project, which has built 73 schools. MEST also provides grants to special needs schools, which appear to be inadequate with patterns of untimely disbursements.

*Ministry of Health and Sanitation*

Polio victims, amputees, the blind, the deaf, the mute, and people with diabetic retinopathy legally qualify for free primary health care services. However, this legal right is not backed up by an allocation of resources to support its provision. Moreover, discussions with people with disabilities indicate that they do not have consistent access to health services, in particular rehabilitation services, and that this continues to be a major difficulty in their lives.

There is no specific resource allocation within the ministry budget to support disability related interventions, although small pilot programs on community rehabilitation exist. The Coordinating Unit within the ministry is supported by partners such as WHO, Mercy Ships, the German Leprosy and TB Relief Association (GLRA), and others. The ministry has very limited resources, with which it supports some staff salaries and supplies for the National Rehabilitation Center (NRC)<sup>2,3</sup> and Sight Savers Division of the Connaught Hospital in Freetown. Overall, the ministry needs to address the need for long-term support to provide decentralized and accessible health care services, especially rehabilitation and management of chronic conditions. In particular, the ministry needs to address the integration of rehabilitation services currently provided by NGOs into government hospital administration and management.

*Ministry of Social Welfare, Gender, and Children's Affairs (MSWGCA)*

The MSWGCA has a mandate to provide assistance to vulnerable groups including people with disabilities. The ministry has taken the lead in drafting the National Policy, Legislation, and Strategy on Disabilities (NPLSD). Although a number of ministries have collaborated with the MSWGCA in the drafting of this document, they have been constrained by, among other factors, a stagnated legal process, the absence of a binding legislation recognizing special needs of the disabled, and a lack of budgetary resources.

*Other Public Initiatives*

The National Social Security Insurance Trust (NaSSIT) provides a social security scheme to the “employed.” This scheme only covers those employed in the “formal sector,” and thus only covers the 2.6 percent of people with disabilities who are paid employees. NaCSA has also provided support to vulnerable communities and groups, including people with disabilities, through its existing programs: the number of beneficiaries (people with disabilities) and the impact on livelihoods will be analyzed as part of this study. The 2004 Census data indicates that about 30 percent of people with disabilities receive some type of assistance (ranging from surgical, medical, rehabilitation, counseling, training, and financial). These and other data need to be further analyzed to better understand coverage of existing assistance programs through private and public sources relative to the needs of people with disabilities.

*Achievements to Date and Emerging Good Practices*

Despite resource constraints and limitations, key ministries in Sierra Leone are establishing a number of good practices. Disability desks exist in many ministries, providing an important focal point for people with disabilities to lobby on their own

behalf. These desks are tasked to promote the mainstreaming of disability issues into sector plans and budgets, but are limited due to human resource constraints. Many experts have stated that a disability desk is not sufficient, and a disability unit should be established at all levels of government to adequately address all urgent issues. Also, there has been a strategic shift in the direction of the government—possibly in response to donor demands—for inclusion of disability issues in national development plans and sector strategies. Although disability still does not occupy a prominent place, the inclusion of disability issues in such documents as the ESP yields a promising trend. Furthermore, many people with disabilities have stated that the government is responsive to their needs and regularly meets with them and listens to their concerns, mainly at the level of the Ministry of Social Welfare. There is also a strong collaboration and good standing relationship between many DPO, INGOs, (international nongovernmental organizations), and government. There does appear to be a mutual desire to work in collaboration for people with disabilities.

### *Challenges for the Future*

Four key challenges emerge based on the brief analysis of the public sector financing for programs in support of people with disabilities. The first two challenges are related to resource constraints. First, there is a scarcity of reliable long-term funding and allocation of government funds for disability issues, making comprehensive long-term programming difficult. Second, there is a lack of dedicated technical capacity. Existing strategies in education and health sectors and the draft strategy on people with disabilities are examples of cases that demonstrate that without a stronger capacity for coordination and collaboration, the policies never translate into active programs. Programs that seek to strengthen the capacity of government to assume control over people with disabilities programs are important and will yield good results in the future. Intersectoral collaboration between the private and public sector to increase capacity is important for the future. For now, the public sector appears to rely heavily on donors and INGOs, an approach that is not sustainable for the future.

A third and important challenge with immediate consequences is whether government decides to adopt an “inclusive approach” in response to disability issues. Inclusive and integrated treatment of disability issues within key service sectors such as health, education, and access to employment and credit is a less costly and administratively less cumbersome policy option. Services such as rehabilitation or developing teacher training programs and curricula that cater to disabled students can be adopted as an augmentation to the general health care and education systems.

Fourth, and perhaps the most significant challenge, is the lack of political will to address disability beyond a policy framework and execute such a framework. Disability issues continue to be “lower priority” issues in Sierra Leone, negatively affecting the speed and urgency with which policies and programs are funded and carried out. Thus far, little has been done on behalf of the public sector with respect to the recommendations made in the draft legislation and strategy. The recommendations in these drafts, although crucially important, are realistically very long-term investments that would take much time, funds, and political will to see through.

**Table 5. Support Programs for People with Disabilities by Area of Intervention and Implementer**

| Area of intervention   | NGO/association name   |
|--|--|
| Education: Inclusive education; vocational/skills training; educational support (allowance/cash transfer)  | Mercy Ships, Leonard Cheshire Disability, Sightsavers International, CAUSE-SL, FHM-AVSI, Missionaries Friends Association, COOPI, St. Joseph's School for the Hearing Impaired (Makeni), Global Forum, Norwegian Friends of Sierra Leone (SLV) |
| Health: Physical rehabilitation (including community based care); psychological/ psycho-social rehabilitation (including preventive health care) | Mercy Ships, Handicap International, COOPI, Leonard Cheshire Disability, Sightsavers International, CAUSE-SL, Global Forum   |
| Housing: foster homes; housing   | FHM-AVSI, Missionaries Friends Association, SLV  |
| Advocacy: Sensitization and awareness; advocacy; training civil society groups   | DAAG, Handicap International, CCSHRS-SL, SLV, No Peace Without Justice/AIDOS/Manifesto99   |
| Livelihood support: Microcredit; youth cooperative projects; food security/IGAs  | Missionaries Friends Association, FHM-AVSI, COOPI, Leonard Cheshire International, CCSHRS-SL   |

*Notes:* Aidos :Associazione Italiana Donne per lo Sviluppo; CAUSE SL: Christian Aid for Under-Assisted Societies Everywhere (Sierra Leone); CCSHRS: Colman Centre for Specialist Neurological Rehabilitation Services, Sierra Leone; COOPI: Cooperazione Internazionale; DAAG: Disability Access Advisory Group; FHM-AVSI: Family Homes Movement— Association of Volunteers in International Service; SLV: Norwegian Friends of Sierra Leone.

## Private Program Financing

National and international NGOs (in collaboration with UN agencies) and DPO have been providing the bulk of the assistance on functional rehabilitation, psychological, and livelihood support services. There are about 20–25 major NGOs (international and national) that are active in the areas of education, health, housing, advocacy, and livelihood support. Interventions include (i) community-based rehabilitation projects; (ii) reinforcement of the network of rehabilitation and psychological services provided through hospitals and other established institutions; (iii) strengthening organizations for people with disabilities; (iv) sensitization and awareness building activities; (v) community based socioeconomic reintegration and rehabilitation including inclusive education, youth cooperative projects, microcredit, and support for income-generating activities; (vi) vocational/technical skills training; and (vii) support for elaboration of a national policy for people with disabilities. Specific programs include SOS villages, schools for the blind, schools for the deaf and the severely handicapped, the Cheshire Homes, housing for amputees, and others. Geographically, the activities focus around the Western Area, Lunsar, Lungi, and Lokomasama, Port Loko, Bombali, Moyamba Kailahun, Tonkolili, Koinadugu, Bo, Kono, Freetown, Kabala, and Bonthe.

Information has been collected from 12 small to medium-size NGOs to complement existing secondary data on private program financing. Under the surveyed programs, beneficiary coverage is estimated to be close to 65,000 people with disabilities.<sup>4</sup> The estimated amount of financing available through major NGOs surveyed<sup>5</sup> is about US\$8 million on average per year. While studies have not yet produced specific estimates about the amounts required to meet needs, it is clear that required annual spending would need to be a multiple of what is currently available. These programs target a variety of physical and psychological disabilities but tend to

focus primarily on physical disabilities, even though psychological disabilities tend to be in higher numbers in post conflict countries, particularly in Sierra Leone. At this time, a breakdown of program information by region, implementing agency, and beneficiaries by type of disability is not available.

Even with limited information on existing programs and a possible overestimation of the number of current beneficiaries from integrated, inclusive programs and disability specific programs and expenditures, available data suggests that there is a major deficit in prevention, rehabilitation, and basic services (health, education, and other) available to people with disabilities. Based on conservative estimations using the 2004 Census figures, only half of people with disabilities appear to be benefiting from any type of assistance. If one takes the higher figure for the total number of people with disabilities, most likely, only about 25 percent of people with disabilities are able to access some type of assistance program.

#### *Achievements to Date and Promising Initiatives*

Overall, the NGO sector is implementing some effective programs in support of people with disabilities, despite limited funding and insufficient coverage with respect to number of beneficiaries and the areas of intervention. Further, INGOs have shown initiative in formulating a strategy and actively lobbying for a consultative process on the draft National Policy Paper on People Living with Disabilities (2004–05) and draft Persons with Disabilities Act (2004). Certain DPO have implemented successful and long-term projects with extremely limited funds, thus providing a good example for the public sector.

Over the past few years, a few promising initiatives have been initiated. For example, support by NGOs and bilateral donors for vocational skills training centers, training courses, and skill enhancing initiatives for the disabled have emerged across Sierra Leone. A number of NGOs (such as CAUSE SL, COOPI, AVSI) have been supporting community based socioeconomic integration focusing on skills training and

#### **Box 1. Promotion of Inclusive Education for Children with Disabilities**

***Mercy Ships*** is working very actively in 31 communities in Western, rural and urban districts, and Lunsar on issues of community-based rehabilitation and inclusive education projects. These aim to integrate people with disabilities into community life by providing services within their communities rather than creating separate institutions for special needs. The interventions focus on: (i) community sensitization, awareness raising, and interactive psycho-social support programs to families, schools, and communities; (ii) provision of school support grants to enroll in and attend mainstream schools; (iii) provision of assistive devices to facilitate mobility; and (iv) provision of training to teachers, parents/guardians, members of DPO, and other community members. Currently, the program supports an estimated 800 children with mobility disabilities in collaboration with UNICEF and Ministry of Education. Average annual program financing is about US\$700,000.

***Leonard Cheshire Disability*** is another notable NGO that implements inclusive education programs in partnership with Mercy Ships and local DPO. Their emphasis is on training of teachers on special needs issues, provision of educational support materials, construction of ramps in school buildings to improve access, and sensitization of parents and communities to disability issues and the importance of education. Currently, the programs have benefited over 1,500 people including children, parents and other community members. Their average annual financing is about US\$150,000.

vocational programs for people with disabilities particularly between the ages of 15 and 35. While independent evaluations of such programs are still ongoing, there are some promising initial results. In the COOPI program, the pilot of the literacy and numeracy training for 70 youth with disabilities was successfully completed in Kono district and is being expanded to 150 participants with topics covering business management and business planning. While programs have granted people with disabilities a sense of empowerment and self-sufficiency, these efforts require more technical assistance and government support.

Another area of success is physical and psychological rehabilitation in which Handicap International (HI) and Mercy Ships have been very active. The advocacy and joint work with the Ministry of Health and local advocacy organizations on the National Strategy on Prosthetics and Orthotics and National Disability Policy and Act have helped tremendously in raising the profile of the issue within government and among the people with disabilities community. Furthermore, the services being provided promote training and use local staff, materials, and production.

Although HI concluded its psychological support program in January 2008, this program stimulated the development of a national professional organization for psychological counselors-NECPA, which continues to partner with various organizations to provide services. HI is looking into expanding its outreach by partnering with other INGOs and local people with disabilities network organizations.

## **Box 2. Provision of Housing, Skills Training, and Health Care in a Community Setting**

**Family Homes Movement (FHM)** has over the years concentrated its activities on child recovery, protection, and upkeep through the establishment of foster homes, child-tracing, and rehabilitation centers. As the principal beneficiary and implementing partner for projects sponsored by the Association of Volunteers in International Service (AVSI) in Sierra Leone, the movement seeks to improve the capacity and livelihood of vulnerable and war-affected youths. Their programs focus primarily on youth training, education, sponsorship, and job creation. The movement over the years has sponsored over ten projects focusing on youth education, child protection, and youth capacity building. FHM—in collaboration with the Ministry of Social Welfare, Gender, and Children's Affairs and UNICEF—created and managed a Child Protection Center which catered to 3,000 war-affected children and adolescents. Currently, the movement is sponsoring and managing four skills centers for unemployed youths, foster homes for street children, secondary and primary schools, and youth cooperative projects in Bumbuna and Freetown. The movement currently supports about 200 people with disabilities and their dependents through a combination of shelter (group homes) and skills training (such as bricklaying, carpentry, metal working, and artisanal fishing) programs. The program is expected to be expanded to an additional 150 war-affected youth (of whom 60 will be youth with disabilities) with support from the Italian Trust Fund for Children and Youth in Africa (CHYAO) administered by the World Bank. FHM's current annual budget is about US\$300,000.

**Missionaries Friends Association (MFA)** has been active in Freetown and its environs in promoting rehabilitation and reintegration of disabled children and youth into communities. MFA, for the last 10 years, has worked in close partnership with Ente Nazionale Giuseppini Murialdo (ENGIM) and Norwegian Friends of Sierra Leone. MFA provides monthly allowances, school fees, shelter (in the form of foster homes, group homes, and orphanages), adult education, and skills training and runs a microcredit scheme targeting amputee women. Its programs have benefited well over 300 amputees (adults) and orphaned, abandoned, and deaf and mute children. The average annual program budget is about US\$180,000.

The Ministry of Health has expressed interest in scaling-up community-based rehabilitation programs especially in light of the dire lack of basic rural health services.

Another important area of activity is the advocacy, sensitization, and outreach work actively supported by INGOs. INGOs have collaborated with local disabled people's organizations and have been active in the NCRPD, reaching out to policy makers, people with disabilities, and communities. These efforts, albeit with limited resources, have culminated in draft legislation, the Draft Persons with Disabilities Bill, as well as in the ratification of various international conventions. However, continued support in this area will be essential to further the policy agenda and mobilize funding to scale-up emerging good practices. Key ministries and DPO highlighted "sensitization" as a top priority.

### *Challenges for the Future*

Three key challenges for the future of NGO implemented programs are emerging. The first and critical challenge is to capitalize on the lessons learned and results achieved through the various programs implemented by NGOs. Government will need to approach these interventions with a coherent strategy to mobilize resources, rationalize them, and scale them up according to priorities identified by people with disabilities. All nationally and internationally sponsored programs are facing some level of funding constraint, which is likely to increase as the donor community is set to reduce its overall support to Sierra Leone.

The second challenge appears to be the weak involvement of local advocacy and civil society organizations (CSOs) in the design and implementation of programs, and the need to continue to build capacity within local CSOs for advocacy, sensitization, and program implementation. Many local DPO feel marginalized and indicate that INGOs do not show adequate willingness to work with small local CSOs.

A third challenge is the ability of local DPO to monitor the full array of government policies and programs in order to ensure that they do not miss out on opportunities to push for more inclusive policies and programs and prevent the use of resources on noninclusive programs.

### **Notes**

<sup>1</sup> Usually organized by types of disability.

<sup>2</sup> Handicap International (HI) provides all financial, logistical and maintenance support to the facility. At present, the MOHS does not have the capacity to run the center and HI is discussing with the Ministry the development of an integration strategy for the facility.

<sup>3</sup> Two other similar facilities exist: Bo Regional Rehabilitation Center and Koidu Regional Rehabilitation Center. Both are in the process of transitioning to become part of Bo Government Hospital and Koidu Government Hospital.

<sup>4</sup> This may be an overestimation as there may be overlaps between beneficiaries of several programs.

<sup>5</sup> A mini survey among 12 mid- to large-size NGOs active in Sierra Leone was conducted while preparing applications to the CHYAO Trust Fund between February–April 2007.



# Policy Approaches

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**B**ased on the analysis in chapters 1–4, this chapter includes an outline of possible avenues to reform the overall public/private approach to people with disabilities, and explores options for inclusive policies and programs to support people with disabilities, including sector interventions to improve their standard of living.

There is a clear need to strengthen the support to people with disabilities, in terms of situation analysis, policy framework, and public and private program financing. This is because support to people with disabilities has historically been very limited. Furthermore: (i) people with disabilities are a significant percentage of the total population (from a low estimate of 2.4 percent to a high estimate of up to 10 percent); (ii) people with disabilities are among the poorest and most vulnerable groups in Sierra Leone; (iii) there is a substantial economic cost to inadequate prevention and timely treatment for the household and the overall economy; and (iv) the conflict has swept away both the informal and formal support systems of people with disabilities. The proposed strategy of involvement in the issue area can be organized around two broad pillars: (i) measures that will specifically target people with disabilities within the context of Sierra Leone’s social protection agenda; and (ii) measures that will work to mainstream disability issues through sector programs.

The recommended measures are hence grouped under three categories: (i) knowledge building and analysis, (ii) strengthening of the legal and institutional framework, and (iii) amelioration of public and private service coverage and financing. In the attached matrix (see the appendix), they are also classified by cost (no or low cost, medium cost, high cost). Finally, some measures are highlighted to signal whether they are mainstreamed or self-standing/targeted measures.

### **Knowledge Building and Analysis**

Further analysis is needed in the following areas in order to better understand the needs of people with disabilities, the effectiveness of current programs, and to formulate an adequate policy response:

- Educational, training and employment opportunities for young people with disabilities;
- Health needs of people with disabilities, including rehabilitation;
- Cost analysis of excluding people with disabilities from society and the economy;
- Cost analysis of the implementation of the draft legislation;

- Enhancement of statistical and other data with Central Statistics Office and line ministries to assist with identification and targeting of people with disabilities to benefit from “free basic services such as health and education” and overall access to assistance programs by a larger majority of people with disabilities;
- Financial assessment of existing programs, expenditures and analysis of their impact on livelihoods of people with disabilities with specific attention to existing social protection schemes to determine which programs deserve to be scaled-up and supported with increased financing.

## **Improving the Legal and Institutional Framework**

### *Self-standing and targeted measures*

- Clarify roles and responsibilities of lead institutions in this area to ensure system-wide mainstreaming of disability at highest level;
- Implement outreach and training for the Parliamentary Human Rights Committee;
- Ratify CPRD and other pending legislation;
- Draft legislation on people with disabilities;
  - Improve, finalize, and enact draft legislation on people with disabilities as an overarching policy framework document;
  - Operationalize the monitoring and implementation of the draft Act;
  - Provide technical assistance to the Ministry of Social Welfare, Gender, and Children’s Affairs to lead the finalization of the draft Act including outreach in Parliament and Cabinet;
  - Strengthen DPO involvement in consultations, monitoring, and implementation.
- Sensitization and dialogue targeting key sector ministries, Ministry of Finance, and Office of the President

### *Mainstreamed measures*

- Support adoption of disability policy/action plans by all ministries including creation of employment opportunities for people with disabilities within public and private sector;
- Provide NaCSA support to boost its engagement in issues of people with disabilities within its mandate.

## **Improving Public and Private Program Coverage and Financing**

### *Self-standing and targeted measures*

- Ensure the draft legislation and policy are fully costed and considered within national budget;
- Support scale-up of successful NGO programs to improve coverage of people with disabilities and improve access to basic services;
- Accelerate and strengthen resource mobilization efforts to ensure that priorities are implemented, including, among others, the Truth and Reconciliation Commission recommendations for the War Victims Reparations Program.

*Mainstreamed measures*

## SECTOR MINISTRIES: PLANNING AND CAPACITY DEVELOPMENT

- Support all sector ministries to integrate disability issues, needs and priority expenditures into their annual sector budget;
- Emphasize support for prevention measures in sector programs such as nutrition (targeting mother and young children), transportation and road safety (to reduce road accidents), vaccinations and access to basic health services, early childhood development and early detection of disabilities through community-based screening and assessment tools;
- Advocate inclusiveness and community integration in all sector ministry programs especially on health, HIV/AIDS, education, transport, skills training, microcredit, and housing;
- Enhance dedicated technical capacity on disability issues (disability desks) in key ministries such as education, health, transport, and others so that they are able to effectively participate in the annual sector planning and budgeting process. Involve people with disabilities in the design, implementation, and evaluation of sector programs and policies.

## SECTOR MINISTRIES: FINANCING INTERVENTIONS BENEFITING PEOPLE WITH DISABILITIES

- Support MEST efforts to increase enrollment and school attendance of children with disabilities through the scaling-up of successful inclusive education programs and number of accessible schools;
- Support Ministry of Health to scale up successful rehabilitation programs, include preventive services in basic health care package and focus on longer-term decentralized and accessible health care services;
- Support Ministry of Social Welfare, Gender, and Children's Affairs to scale up successful skills training and employment schemes;
- Consider a disability grant that will work like a pension as part of the national social assistance scheme.

## DONOR PROGRAM FINANCING

- Advise all donors to include/mainstream disability issues in all donor financed/implemented projects.



## APPENDIX

# Policy Option and Cost Matrix

|   | No or low cost | Medium cost | High cost | By whom                        |
|---|----------------|-------------|-----------|--------------------------------|
| <b>Knowledge Building and Analysis</b>  |                |             |           |                                |
| Educational, training and employment opportunities for young people with disabilities   |                | X           |           | Ministries: Education; Welfare |
| Health needs of people with disabilities  |                | X           |           | Ministry of Health             |
| Human rights aspects of the “begging industry”  |                | X           |           | Ministry of Welfare            |
| Cost analysis of excluding people with disabilities from society and the economy  |                | X           |           | Ministry of Welfare            |
| Cost analysis of the implementation of the draft legislation  |                | X           |           | Ministry of Welfare            |
| Improve statistical and other data with Central Statistics Office and line ministries to assist with identification and targeting of people with disabilities to benefit from “free basic services such as health and education” and overall access to assistance programs by a larger majority of people with disabilities |                | X           |           | CSO                            |
| Finance survey of existing programs, expenditures and analysis of their impact on livelihoods of people with disabilities with specific attention on the existing social protection schemes   | X              |             |           | Ministry of Welfare            |

| <b>Improving Legal and Institutional Framework</b>  | <b>No or Low cost</b> | <b>Medium cost</b> | <b>High cost</b> | <b>By whom</b>                                |
|---|-----------------------|--------------------|------------------|---|
| Improve, finalize and enact the draft legislation on people with disabilities   | X                     |                    |                  | Ministry of Welfare                           |
| Ratify pending international conventions or legislation   | X                     |                    |                  | Ministries: Foreign Affairs; Justice; Welfare |
| Support adoption of disability policy/action plans by all ministries  | X                     | X                  |                  | Council of Ministers                          |
| Clarify roles and responsibilities of lead institutions in this area  | X                     |                    |                  | Office of the President, Council of Ministers |
| Operationalize the monitoring and implementation of the draft Act   |                       | X                  |                  | Council of Ministers                          |
| Strengthen DPO involvement in consultations, monitoring and implementation  | X                     |                    |                  | DPO   |
| Implement outreach and training for the Parliamentary Human Rights Committee  |                       | X                  |                  | Parliament                                    |
| Provide technical assistance to the Ministry of Social Welfare, Gender, and Children's Affairs to lead the finalization of the draft Act including outreach in Parliament and Cabinet |                       | X                  |                  | Donors  |
| Provide NaCSA support to be more engaged on issues of people with disabilities within its mandate   |                       | X                  |                  | Donors  |

| <b>Improving Public and Private Program Coverage and Financing</b>   | <b>No or Low cost</b> | <b>Medium cost</b> | <b>High cost</b> | <b>By whom</b>   |
|--|-----------------------|--------------------|------------------|--|
| Ensure the draft legislation and policy are fully costed and considered within national budget   | X                     |                    |                  | Ministry of Welfare; DPO   |
| Accelerate and strengthen resource mobilization efforts so that the Truth and Reconciliation Commission recommendations for the War Victims Reparations Program (among other priorities) are implemented |                       | X                  |                  | Ministry of Welfare; DPO   |
| Support scale-up of successful NGO programs (to be identified) to improve coverage of people with disabilities and improve access to basic services  |                       | X                  |                  | NGO; DPO; Donors   |
| Support all sector ministries to integrate disability issues, needs, and priority expenditures into their annual sector budgets  | X                     |                    |                  | Council of Ministers   |
| Advocate inclusiveness and community integration in all sector ministry programs targeting people with disabilities especially health, HIV/AIDS, education, skills training, and housing                 | X                     |                    |                  | Ministry of Welfare; DPO   |
| Enhance dedicated technical capacity on disability issues in key ministries such as education, health, transport, and others   |                       | X                  |                  | Ministries: Education, Science and Technology; Health and Sanitation; Transportation |
| Support MEST to increase enrollment and school attendance of children with disabilities via scaling up successful inclusive education programs   |                       |                    | X                | Ministry of Education, Science and Technology; Donors                                |
| Support Ministry of Health to scale-up successful rehabilitation programs  |                       |                    | X                | Ministry of Health and Sanitation; Donors  |
| Support Ministry of Social Welfare, Gender, and Children's Affairs to scale up successful skills training and employment schemes   |                       |                    | X                | Ministry of Welfare; Donors  |
| Advise all donors to include disability issues on all donor financed/implemented projects  | X                     |                    |                  | Ministry of Welfare; Council of Ministers; Donors                                    |





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