Children with disabilities in low-income countries

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Disability is a major public health concern worldwide and the situation for children with disabilities is even more serious. The present article will focus on the issue of children with disabilities in low-income countries. Approximately one-third of the world's disabled population is children and many of these disabling conditions are preventable. In Africa, one the foremost causes of disability is infectious and communicable disease; the incidence of these diseases have been greatly reduced or eliminated in higher income countries. Other causes include war, trauma, accidents, and congenital and noninfectious diseases. The recent HIV/AIDS epidemic has further contributed to the prevalence of disability because many people living with HIV develop different types of impairments and functional limitations. Community-based rehabilitation is one approach that has been used in many low-income countries and which often focuses on children and their families. The work of one organization providing community-based rehabilitation in Tanzania is highlighted. The experiences of the coauthors in their work in Tanzania provide some field examples. For those readers who would like to become involved in international health, opportunities for engagement are described, including short- and long-term volunteer service or research experiences.

Key Words: *Children; Disabilities; Health care; Low-income countries*

Les enfants ayant des incapacités vivant dans des pays à faibles revenus

Les incapacités constituent une préoccupation importante en santé publique dans le monde, et la situation des enfants ayant des incapacités est encore plus grave. Le présent article porte sur les enfants ayant des incapacités vivant dans des pays à faibles revenus. Dans le monde, environ le tiers des populations ayant des incapacités sont constituées d'enfants, et bon nombre des pathologies sont évitables. En Afrique, l'une des principales causes d'invalidité provient des maladies infectieuses et transmissibles, dont l'incidence est très réduite ou inexistante dans les pays à revenus plus élevés. Parmi les autres causes, soulignons la guerre, les traumatismes, les accidents et les maladies congénitales et non infectieuses. La récente épidémie de VIH-sida a favorisé la prévalence d'incapacités, car de nombreuses personnes atteintes du VIH présentent divers types de déficiences et de limites fonctionnelles. La réadaptation dans la collectivité est utilisée dans de nombreux pays à faibles revenus et est souvent axée sur les enfants et leur famille. Les travaux d'un organisme qui offre une réadaptation dans la collectivité en Tanzanie sont mis en lumière. Les expériences des coauteurs dans leurs travaux en Tanzanie fournissent quelques expériences sur le terrain. Pour les lecteurs intéressés à s'engager en santé internationale, des possibilités d'engagement sont décrites, y compris des services volontaires à court et à long terme ou des expériences de recherche.

This article focuses on the issue of children with disabilities in low-income countries (LICs). Current literature regarding the extent of the problem and the most common disabilities are explored, and a current approach to intervention is described. The experiences of the coauthors in Tanzania provide some field examples. Opportunities for engagement are proposed for readers who would like to become involved in international health.

GLOBAL BURDEN OF CHILD DISABILITY

Disability is a major health concern worldwide. Ten per cent of the world's population, or approximately 600 million people, are living with a sensory, physical or intellectual disability. When the family members of people with disabilities are taken into account, disability affects up to 25% of the world's population (1,2). This burden is not evenly distributed.

When the statistics related to disability in LICs are examined, the picture becomes even more alarming. Close to two-thirds of all people with disabilities live in LICs. According to Inclusion International, the 10% global prevalence of disability actually translates to one in five of the world's poorest people (3). While this current disparity is striking, the rate of global disability is increasing rapidly, primarily due to population growth in less-developed regions. By the year 2025, the number of people with disabilities in LICs is expected to double (4).

The situation with children is dramatic. Children comprise approximately one-third of the world's disabled population and approximately 65% of the disabilities affecting children are preventable (4). For every child who is killed in a conflict situation, three more are permanently disabled (1). According to Inclusion International, 98% of children with disabilities in LICs do not go to school (3).

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CAUSES OF DISABILITY IN AFRICA

The World Health Organization (WHO) reported in a 29-country study in Africa (5) that the foremost cause of disability was infectious disease. The leading conditions included malaria, polio and leprosy, along with other communicable diseases such as tuberculosis, trachoma, otitis media, meningitis and parasitic disease. The incidence of many of these communicable diseases has been greatly reduced in developed countries but they remain a significant cause of disability in LICs. The second major cause of disability was war, trauma or accidents (primarily road accidents). The third most common cause of disability was congenital and noninfectious diseases such as epilepsy (5). The poor quality of perinatal care results in disabilities such as cerebral palsy (6). Other causes of disability include malnutrition due to vitamin A, iron and iodine deficiency (7), and chronic medical conditions such as rheumatic diseases and diabetes. The HIV/AIDS epidemic has further contributed to the prevalence of disability because many people living with HIV develop different types of impairments and functional limitations. HIV-positive infants experience an increased prevalence of cognitive and motor delay (8). Furthermore, HIV/AIDS is killing a generation of caregivers, leaving many children without proper care, especially children with disabilities. In recent years, research has indicated that the causes of disabilities in children have shifted away from some of the communicable diseases, such as polio, to cerebral palsy and other conditions that cause multiple disabilities.

Bach's study (9) provided some insight into the causes and consequences of disability secondary to musculoskeletal trauma in east Africa. Although the study was not specific to paediatric cases, many relevant points are made. From 1995 to 1998, the hospital under study had only one surgeon to serve a catchment area of 2.5 million residents. Of the 658 surgeries conducted, 168 were categorized as musculoskeletal trauma. Second-hand hospital equipment was often donated from more prosperous countries and surgical instruments, sterilization materials and blood for transfusion was often not available. Training and hiring of specialist doctors was also not affordable. The condition of the equipment and the challenges regarding sterilization made the operative treatment of fractures more dangerous. The number of trauma victims who become significantly disabled following injury is far higher in Africa. The significance of such physical disabilities is particularly striking in a society based on subsistence farming (9).

SAMPLE CASE: UNITED REPUBLIC OF TANZANIA

Tanzania is one of many LICs that struggle with the issue of childhood disability. Tanzania is currently experiencing several crises that dramatically impact the health of its children. According to the United Nations' "Human development report" (2), Tanzania is ranked 160 of 175 countries worldwide in human development. In 1998, it was estimated that more than one-half of the country's population lived in poverty (10). The economy is heavily dependent on agriculture; it accounts for 57% of the country's gross domestic product and 85% of exports, and employs 80% of the total work force (11). Poverty and malnutrition are persistent concerns, with 47% of citizens being undernourished (2).

Only 68% of urban residents and 45% of rural residents have access to clean, safe water (11). Tanzania's immunization rates for measles, diphtheria, polio and tetanus have all decreased in recent years (11). Similarly, the country has had escalating rates of infant mortality, mortality for children younger than five years of age and child malnutrition. The WHO recently concluded that the sharp rise in mortality rate was due, in part, to Tanzania's HIV/AIDS epidemic (11). Meanwhile, government health care spending is estimated to be US$4 per capita in urban centres, and it is significantly less in rural areas (11). The lack of public funding has been matched by the proliferation of privatized health care centres.

Health data illustrate rising mortality rates due to a decline in the access to and quality of health services, as well as the spread of HIV (12). There is a severe lack of skilled health care professionals and services due, in part, to the limited national budget and the elevated rates of illness (such as HIV) in health care providers (13). In addition to the fact that there are few training programs for health care professionals in Tanzania, once individuals receive training, they often leave for other countries with better opportunities. This has the effect of further reducing the limited number of professionals in the country and, in effect, means that LICs often subsidize the training of professionals for other more prosperous countries. Given the current situation, it is easy to see why only approximately 2% to 10% of people with disabilities in Tanzania have access to any type of rehabilitation services (14). For example, there are only two speech language pathologists in the entire country (Parnes, personal communication, February 24, 2005).

Many children with disabilities live in rural or remote areas, which seriously impacts their ability to access available services. Any services that are available in a country like Tanzania are usually located in major population centres. Children with disabilities living outside these centres have difficulty getting any services. Because of costs, lack of public transportation and lack of knowledge about available services, families from remote and rural areas may never see health care professionals.

Even if the services are available, the cost of medical care will be prohibitive to most families. While on a visit to conduct a needs assessment for rehabilitation training in Tanzania, one of the authors participated in a clinic for children with hydrocephalus in a hospital in Moshi. One small child was seen by a paediatrician who diagnosed a shunt blockage. The surgery to correct this would cost approximately $150 Canadian dollars, which seems very reasonable until it is considered that the average salary for someone working in Tanzania would be about $10 to $12 dollars per month. Children with shunted hydrocephalus usually require multiple shunt revisions due to infection and/or growth. The use of equipment and medical

supplies is also a major issue in LICs. Even if the materials are donated, the cost of replacement or upkeep is often too high for the facilities or agencies.

Disability and rehabilitation services have not been a priority in Tanzania (15). The need to address other urgent health crises such as malnutrition, HIV and sanitation has resulted in a neglect of research and development of rehabilitation services in Tanzania. The lack of a comprehensive national database has also led to major gaps in information regarding the incidence of disability and rehabilitation services in Tanzania.

The international community has not ignored the health care issues in Tanzania. International assistance accounts for an estimated 50% of the health care budget in Tanzania (16). Most agencies have offered support for essential health services and priority areas such as HIV/AIDS and poverty reduction programs. The WHO has made contributions for health sector reforms, research in tropical diseases and women's health, disease control, blood safety and the development of health guidelines (16). The United Nations Development Programme is also highly involved with development assistance in Tanzania. The program's priority goals address salient issues such as extreme poverty, HIV/AIDS, hunger, drinking water safety, primary education, gender equity, reproductive health, mortality of children younger than five years of age and environmental sustainability (12). From a Canadian perspective, the Canadian International Development Agency has identified Tanzania as one of its nine priority countries for assistance on issues such as poverty reduction, education and HIV/AIDS programs (17). One unique collaboration between Canada's International Development Research Centre and Tanzania's Ministry of Health is The Tanzania Essential Health Interventions Project. The project provided local health-planning teams in two large Tanzania districts with tools, strategies and modest funding increases that have allowed them to target their new resources on the largest contributors to the burden of disease and to improve the efficiency of on-the-ground health care delivery. The result of this project has been a large decrease in the mortality rates of both districts, particularly among children (18).

A COMMUNITY-BASED REHABILITATION PROGRAM IN TANZANIA

As mentioned above, many organizations and individuals are committed to improving the lives of children with disabilities in LICs. Community-based rehabilitation (CBR) is one approach that has been used in many LICs, and which often focuses on children and their families. The CBR approach was developed from United Nations' initiatives in the early 1970s to address disabilities at the community level. In a 2004 joint position paper (19), the International Labour Organization, the United Nations Educational, Scientific and Cultural Organization and the WHO described CBR as:

> "a strategy within general community development for rehabilitation, equalization of opportunities and social inclusion of all children and adults with disabilities. CBR is implemented through the combined efforts of people with disabilities themselves, their families and communities, and the appropriate health, education, vocational and social services."

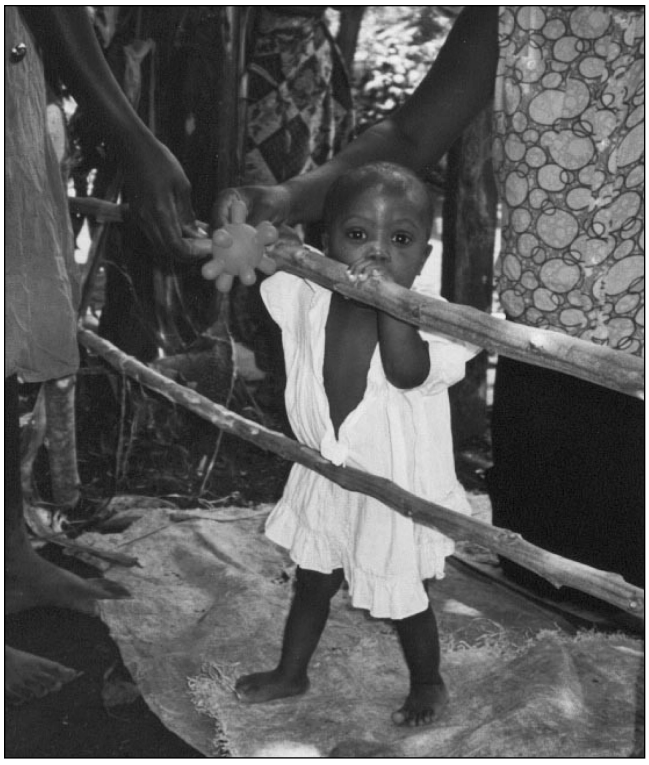

Figure 1) *Young girl in Tanzania practising standing by using a tree limb nailed between two trees for support*

Comprehensive Community Based Rehabilitation Tanzania (CCBRT) (15) is an example of a nongovernmental organization that provides a continuum of health care services to children with disabilities and their families in Tanzania. These services include CBR projects in the cities of Dar es Salaam and Moshi. The primary population served is children, particularly those with neurological, visual and/or auditory impairments. Community rehabilitation workers provide integrated home-based services under the supervision of rehabilitation professionals. These home-based services consist of early detection, referral, therapy and monitoring. Each program has two or three rehabilitation professionals and 10 to 20 community rehabilitation workers. The community rehabilitation workers live and work in the local communities of the children they service. Under the supervision of rehabilitation professionals, they carry out individual rehabilitation plans at no cost to the families. On a recent visit to the CCBRT, the authors of the present article saw firsthand the impact of this program on children and their families. Children were being taught skills that increase their independence, such as washing and transferring themselves from bed to chair (Figure 1). They were also learning skills that would allow them to contribute to their families and communities such as washing dishes and sweeping dirt floors. The development of basic skills allows some of these children with disabilities to attend school (15).

In addition, CCBRT operates the Disability Hospital in Dar es Salaam. This private, urban hospital was established in 2001 as a response to the need for eye surgery in Dar es Salaam. The hospital was later expanded to address other conditions such as orthopedic surgery and hydrocephalus. The hospital provides comprehensive care to patients at differential price rates depending on ability to pay. The funds generated are then reinvested into the hospital. In addition to the surgical department, the hospital also includes an outpatient eye department, an optical workshop, an orthotic/prosthesis workshop and a physiotherapy department.

The Holistic HIV/AIDS Related Program (HARP) is operated by CCBRT in collaboration with the government of Tanzania. Like CBR, HARP includes home-based care (primarily counselling and basic medical care) delivered by field workers under the supervision of registered nurses. HARP programs also include voluntary HIV/AIDS counselling and testing sites, and legal aid services such as will preparation, property issues and child custodianship. Alongside HARP is an HIV/AIDS awareness and prevention program called 'HIV/AIDS School Education Action Days'. Finally, CCBRT operates an 'Orphans Program' that provides a community-based, arm's-length supervision structure for orphans of HIV/AIDS victims, including home-based visits, integration in schools and counselling (15).

OPPORTUNITIES FOR ENGAGEMENT

Paediatricians and other health care professionals can get involved with children with disabilities in LICs in many ways. Many nongovernmental organizations, such as Médecins Sans Frontières (Doctors Without Borders), Canadian Executive Services Overseas and Health Volunteers Overseas, offer short- and long-term volunteer opportunities. Financial support for organizations like War Child and the United Nations Children's Fund support programs for children. Physicians interested in research initiatives can join the Canadian Coalition for Global Health Research. Several Canadian universities have international health initiatives associated with their faculties of medicine such as the Centre for International Health at the University of Toronto. Any health care professional interested in international health must ensure that the activities that are undertaken are culturally sensitive and appropriate to the country. The focus must be maintained on knowledge transfer and sustainability.

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