Reaching the “cocobai”: Reconstruction and persons with disabilities in Haiti

by Cassandra Phillips
Executive summary

In Haiti, Handicap International estimated that 800,000 people were living with disabilities before the Jan. 12, 2010 earthquake; they were among the poorest in the country. With the quake, the number of people with disabilities has increased dramatically, putting an even greater strain on an already weak infrastructure. Many newly-disabled children have also lost their parents and their homes, and the disabled previously congested in Port-au-Prince have shifted into outlying regions where services are scarce. The situation is compounded by prevalent myths about disability that erect strong barriers to assistance for persons with disabilities —who are called “cocobai” in slang Creole, implying they are worthless.

Rebuilding efforts offer a unique opportunity to incorporate a focus on disability issues. Haiti’s 10-year Action Plan for the Reconstruction and National Development of Haiti is mainly directed toward environmental sustainability and infrastructure development. Nonetheless, many of its sections are of relevance to persons with disabilities. Yet, only the section on health directly references persons with newly-acquired physical disabilities, and elsewhere disability is incorporated into the broader vulnerable groups category. Most importantly, the needs of persons with other disabilities such as epilepsy, autism, cognitive disability, mental health issues, visual or hearing impairment, who have been equally affected by the quake, remain invisible.

Recommendations:

1. Mainstreaming: Applying a disability lens to all rebuilding policies is key to avoid omitting this group. It would be sound to include the Secretariat of State for the Inclusion of People with Disabilities in all aspects of the rebuilding process.

2. Health: The integration of mental health services into primary care could be prioritized. The initiative to set up antenna clinics in rural areas to address the complex needs of persons with various disabilities and offer support to their families is promising in that regard.

3. Justice: Existing and new members of the police force would benefit from sensitivity training on different types of disabilities to ensure that the human rights of persons with disabilities are not violated.

4. Education: Haitian schools can provide more inclusive education for children with disabilities and implement preventive health strategies. Public education campaigns could also be mounted to challenge stigma surrounding disability.

5. Employment: Efforts to equalize opportunities for training and placement for the unemployed could also include measures for adults with disabilities, including adults with non-physical disabilities.

6. Public buildings: In reconstructing public buildings, it would be more cost-effective to integrate an architectural design sensitive to access issues for the disabled in the first stages of construction than to renovate buildings later.
Introduction

The way disability is defined and understood has changed in the last decade. Disability was once assumed as a way to characterize a particular set of largely stable limitations. In 2001, the World Health Organization (WHO) moved toward a new international classification system, the International Classification of Functioning, Disability and Health (ICF), which emphasizes functional status over diagnosis.

The WHO defines disability as a contextual variable, dynamic over time and in relation to circumstances, based on the individual and his or her environment. For example, a person with physical disabilities who uses a wheelchair is limited by society if he or she cannot gain access to a building for employment.

The ICF also acknowledges that the prevalence of disability corresponds to social and economic status. In Haiti, for example, more than 80 per cent of the population lives in dire poverty, which translates to homelessness, bad drinking water, poor diet and lack of health-care services. These, in turn, increase susceptibility to malnutrition, birth defects and long-term disabilities.

Before the Jan. 12, 2010 earthquake, according to Handicap International, the number of persons with disabilities in Haiti was estimated at 800,000, of which roughly 200,000 were children. In a country where, according to the World Bank, 54 per cent of persons live on less than one dollar per day, most people rely on their physical abilities to survive. In rural areas, because persons with disabilities may find themselves unable to plant crops, feed animals or fetch water, they are highly dependent on others for survival.

Conditions in urban settings are also difficult. Persons with disabilities are more likely to live in squalor. A September 2009 report produced by Haiti’s Ministry of Social Affairs and Work confirms that only 3.5 per cent of an estimated 120,000 children with disabilities in Port-au-Prince were accessing education. Only two schools in Port-au-Prince specifically addressed their needs; both collapsed in the quake. Breaking the cycle of poverty is more difficult for persons with disabilities when they are uneducated, malnourished and living in unhealthy surroundings.

From a health-care perspective, the WHO estimates that only two per cent of persons with disabilities in developing countries benefit from rehabilitation and appropriate health services. In Haiti, the state does not offer financial support to buy crutches, wheelchairs, orthotics or medication. Adults with serious mental health issues wander the streets while others are institutionalized in one of two major psychiatric facilities: Mars and Kline in Port-au-Prince where conditions are deplorable, and Défilé de Beudet in Croix-des-Bouquets which was seriously damaged during the quake. In Mars and Kline many patients are locked in isolation rooms or chained to beds. Post quake, higher incidences of post-traumatic stress disorder, psychosis and hysterical paralysis indicate an even greater demand for psychiatric care.

Myths about disability mount additional barriers to assistance for persons with disabilities. A host of cultural and religious beliefs leads to discrimination; in Haiti, disability is often viewed as supernatural in origin. For example, children experiencing epileptic seizures can be presumed possessed, and crop failure can be blamed on children with disabilities. Many parents of children with disabilities either abandon them or hide them from public view for fear of reprisal and because they lack the rudimentary skills, education, community support and financial means to cope.
An abandoned child with or without a disability has a very dire future in Haiti. According to Julie Bergeron, Head of Child Protection in Haiti with UNICEF, of the 600 existing childcare institutions, less than a quarter are legal, and the remainder are not monitored due to lack of resources. In some orphanages, there have been reports of children physically abused, raped and malnourished. For those families caring for their disabled children, there is a high dependence on foreign non-governmental organizations (NGOs) for support. And because many parents think that their child can be “cured” of the disability, many treatments fail. For instance, when given anticonvulsants for their child, parents have a hard time understanding there will not be an instant change; if their expectations are not met, they will discontinue the medication which could lead to more seizures, brain damage, even death of the child.

The demand for resources for persons with physical disabilities increased substantially following the quake. The Haitian government estimates the number of persons injured during the quake at more than 300,000. In the weeks immediately following the disaster, 2,000 to 4,000 amputations were performed. The number of physically disabled is likely to continue to rise due to poor sanitation and shortage of clean water which can result in wound infection and force amputation. Lack of mobility aids may result in limb shortening and permanent disability. Aware of the urgency, on Jan. 26, 2010 the United Nations (UN) and the WHO invited major NGOs specializing in disabled issues to co-ordinate all rehabilitation activities for injured persons in Haiti. This includes assisting persons with disabilities and the fitting of prosthetic limbs.

Today, these NGOs continue to work on rehabilitation with the Haitian Ministry for Public Health and Population and the Secretariat of State for the Inclusion of People with Disabilities, along with other stakeholders: more than 55,000 rehabilitation sessions have been performed; 4,000 mobility aids have been distributed; 300 people have been or are in the process of being fitted with prosthetic limbs and another 200 with orthotics. Psycho-social support for 13,000 people has also been offered.

This immediate attention given to the rehabilitation of persons with physical disabilities was imperative. However, children and adults with other types of disabilities that were equally affected by the quake have been largely forgotten. Funding for services may not become available for persons with congenital or other acquired disabilities such as cerebral palsy, schizophrenia, visual or hearing impairment, epilepsy, autism, cognitive disability or hydrocephalus.

The rebuilding of Haiti is multifaceted and complex, necessitating local, national and international collaboration. The Action Plan for the Reconstruction and National Development of Haiti is essential to this process. This paper analyzes this plan from a disability perspective to identify gaps and make recommendations as to what can be done to address these deficiencies at low costs. Finally, it identifies existing groups, local and international, already attempting to fill some of the gaps. They are working to improve care for all persons with disabilities, to increase educational opportunities, and to offer training and support to families. But improving the health and quality of life of children and adults with disabilities is only a first step in their social integration. It is also important that these groups continue to educate parents and to raise community awareness on the human rights and potential of persons with disabilities to challenge stigma and fear surrounding disability.
Disability gaps in the Action Plan

The Action Plan for the Reconstruction and National Development of Haiti (AP), completed March 2010, is a 10-year plan based in large part on the Post Disaster Needs Assessment, which evaluates losses and damages following the quake. The major thrust of the AP is on environmental sustainability and the building of infrastructure. Within these parameters and of relevance to persons with disabilities are sections of the AP that deal with health, safety, education, employment and reconstruction. Nonetheless, the needs of persons with disabilities other than physical disabilities are largely disregarded in this document.

Identifying the disabled as a separate category in rebuilding is essential to conception, formulation and implementation of policies and programs to avoid their omission. This can be done by applying a disability lens to new policies, much as one would apply a gender lens to ensure the inclusion of women and girls in new policies. Time and cost could be reduced by drawing on the knowledge and skills of persons with disabilities affiliated with the Secretariat of State for the Inclusion of People with Disabilities, creating job opportunities for the disabled at the same time.

Health

Persons with newly-acquired physical disabilities are referenced directly in the rebuilding and recovery of the health sector. The AP section entitled “Health care, food security and nutrition, water and sanitation” emphasizes the need for a concerted effort in primary health services and mobile clinics. Rebuilt and additional hospitals and health centres will deal with direct referrals, and expanded mobile clinics will provide rehabilitation services to children and adults with amputations. But this AP section does not mention if mobile clinics will offer support for persons with other types of disabilities and their families. To ensure equal access to information on communicable diseases, maternal and infant health care, personal hygiene, and mental health for persons who are visually impaired or have cognitive disabilities, it would be important to make information available in alternate format (large print), simple format (plain language) or in visual diagrams. Further, the continued support from the Injury, Rehabilitation and Disability Working Group within the UN Health Cluster will prove useful in developing antenna clinics in rural areas to address the complex needs of persons with a variety of disabilities, aside from those with physical disabilities.

Latin American countries on average spend less than two per cent of their national health budgets on mental health, according to Dr. Jorge Rodríguez, Senior Advisor on Mental Health at the Pan American Health Organization (PAHO). Most of this spending —as much as 90 per cent in some countries— goes to mental institutions rather than to primary health services or community care. The integration of mental health services into primary care is a central focus of PAHO’s new Strategy and Plan of Action on Mental Health, approved by ministers of health throughout the Americas in September 2009.

In Haiti, such decentralization of health services not only makes sense in light of the link between health and disability, but also saves money on rebuilding and continued spending on outmoded psychiatric institutions. The Strategy and Plan of Action on Mental Health focuses on implementing laws for mental health reform, improving treatment and care for childhood mental development, shifting mental health services out of institutions into primary health care settings, and increasing capacity of trained mental health workers. Following this roadmap would serve Haiti’s disabled population well.
Justice
In the AP, persons with all types of disabilities are inferred under the category of “vulnerable” groups. For example, the “Justice and security” section makes recommendations that call for the reconstruction of correctional facilities, capacity building among the police force, and preventive strategies to protect vulnerable and displaced people. However, the World Bank reports that the needs of children and women tend to be prioritized over those of a person with a disability when all have been labelled as vulnerable, especially following a crisis. A man with paranoid schizophrenia for example is rarely viewed as vulnerable since police may witness resistant behaviour due to delusions. In addition, the AP mentions that in order to protect women from rape and physical assault in correctional facilities, they will be placed in separate cells from men. There is no indication that a man with paranoia or any other disability will be secluded from other male inmates, even though the potential for that person to be abused is as great.

This AP section also disregards the complex needs in terms of accommodations for persons with a variety of disabilities. The needs of a person with a physical disability are entirely different from those of a person who is blind. For example, a person who uses a wheelchair would need to be able to transfer across onto a latrine using grab bars, whereas a person who is blind will need direction on where to go for meals.

Finally, this AP section does not consider that existing and new members of the police force would benefit from sensitivity training on different types of disabilities to better manage prisoners with disabilities, and to ensure that the dignity and human rights of persons with disabilities are safeguarded.

Education
The AP section on education guarantees equal access to education for all. The Consolidated Recommendations of the Haitian Diaspora Forum to the AP that emerged from a gathering held in March 2010 is explicit in promoting the inclusion of persons with disabilities in the school system. The intent is not to favour the disabled but to level the playing field by providing equal opportunity for all in learning, which is so closely tied with social inclusion.

Thus, new approaches to developing and teaching the curriculum in Creole need to incorporate the learning needs of the disabled, utilizing large print text books, Braille, visuals and, when possible, technological aids. Access to education is directly related to social inclusion and employment to ensure that persons with disabilities can gain freedom from extreme poverty.

With regard to the link between health policy and education, it is important to highlight that health strategies within the school system are key to early detection and prevention of disabilities. Before the quake, the ministries of Public Health and Education, with external financial and technical assistance, had initiated school health policies that included early detection of hearing and vision problems, nutritional surveillance (to prevent type 3 diabetes, rickets and bone deformity), detection of iron deficiency and early detection of poor posture; they also offered sex education. There is, unfortunately, no reference to this in the AP.
Employment
Information in the section on job creation is relevant not only to economic development in regions that are inundated with displaced persons, but also to human dignity. Families and caregivers of amputees are directly referenced in this section. In job creation programs, priority will be given to persons caring for persons with physical disabilities to help them take up their responsibility. Unfortunately, there is no mention of priority to those caring for persons with other types of disabilities equally traumatized by the quake. Further, there is no reference to employment training for persons with disabilities so that they too can contribute to the economic sustainability of the region.

Public buildings
Finally, the construction or rebuilding of health facilities, prisons, schools and public buildings presents planners with the opportunity to incorporate from the onset principles of universal design, a concept that makes products and environments as usable as possible by as many people as possible regardless of age, ability, or situation.6 While the application of universal design principles has made ground in developed nations, little is known about the concept in developing countries.

It is more cost-effective to make structural changes such as door width, height of sinks or swing of door to a new building than it is to renovate an older one. Ultimately, changing the environment benefits both the person with a disability and the community. For example, software applications, such as screen readers will help the worker with a visual impairment to read and produce reports, making him or her more productive to the organization. Large print signage in high contrast colours in public buildings benefits persons with and without disabilities when it comes to directions.

Conclusion
Haiti signed and ratified the UN Convention on the Rights of Persons with Disabilities (CRPD) in July 2009. The Convention is a human rights instrument that affirms that persons with all types of disabilities must enjoy all human rights and fundamental freedoms. Relevant to the AP and this discussion are CRPD articles linked to access, equality and non-discrimination, health, respect for families, education, and work and employment. Haiti is accountable to the Convention’s state parties to include persons with disabilities in all aspects of society.7 To this end, disabled peoples organizations serve as valuable resources in overall planning for Haiti’s future. Consultation with these organizations in the conception, formulation and implementation of policies, structures and programs is important in the rebuilding of Haiti to ensure the needs of persons with disabilities are fully addressed. Disability should be recognized as a category separate from vulnerable groups such as women and children to avoid omission.

Haiti’s AP covers some but not all of the points outlined in the Consolidated Recommendations of the Haitian Diaspora Forum. In moving forward, these two documents should always be read jointly to ensure equalization of opportunity for all. Yet, both documents omit the challenges facing persons with mental health issues in institutions.
Improving the health, education, access and living conditions of children and adults with disabilities is the first step. It is also crucial to bring about change in their families and the environment by raising awareness of the issue. Families need to learn how to interact with and care for their children living with disabilities, and the community needs to recognize the human rights and full potential of persons with disabilities.

**Recommendations**

The *Action Plan for the Reconstruction and National Development of Haiti* completed March 2010 proposes a 10-year blueprint to guide Haiti’s reconstruction post quake. But this plan suffers from many gaps with regard to the inclusion of persons with disabilities, as identified in this paper. Haiti is accountable to the UN’s CRPD state parties to include persons with disabilities in all aspects of society. To this end, the Haitian government would do well to involve the Secretariat of State for the Inclusion of People with Disabilities in planning for Haiti’s future.

The gaps identified could be addressed by following these recommendations:

1. **Mainstreaming:** Identifying the disabled as a separate category in rebuilding is essential to conception, formulation and implementation of policies and programs to avoid their omission. This can be done by applying a disability lens to new policies. In the context of reconstruction in Haiti, time and cost could be reduced by drawing on the knowledge and skills of persons with disabilities affiliated with the Secretariat of State for the Inclusion of People with Disabilities, simultaneously creating job opportunities for the disabled.

2. **Health:** There is a need to expand access to health services for all persons with disabilities, beyond those with physical disabilities. The integration of mental health services into primary care could become a central focus. Decentralizing mental health services would allow for closure of psychiatric institutions in time, offer better assistance to persons with disabilities and reduce costs. The development of antenna clinics in rural areas to address the complex needs of persons with a variety of disabilities is a promising initiative in that regard. Health-related materials for these clinics could be produced at reduced cost in alternate format to inform persons with disability. Families with children with disabilities would benefit from support for respite care and from guidance on how to care for their child with a disability.

3. **Justice:** Existing and new members of the police force would benefit from sensitivity training on different types of disabilities to better manage prisoners with disabilities, and to ensure that the dignity and human rights of persons with disabilities are safeguarded.

4. **Education:** Haitian schools would need to provide inclusive education for children with disabilities. Making educational materials available in large print, Braille and other formats for children and adults with disabilities is one step in the right direction. Further, preventive health efforts could be deployed in schools to reduce onset of disabilities. Public education campaigns could also be mounted in communities to challenge stigma surrounding disability.
5. Employment: Efforts to equalize opportunities for training and placement for the unemployed could also include measures for adults with disabilities, including non-physical disabilities.

6. Public buildings: For the reconstruction of public buildings, principles of universal design—a concept that makes products and environments as usable as possible by as many people as possible regardless of age, ability or situation—could be considered. It is more cost-effective to integrate an architectural design sensitive to access issues for the disabled in the first stages of construction than to renovate an older building.

About the author

Cassandra Phillips is the Editor of Disability International, a publication of DPI, and the Editor of DPI’s Electronic Newsletter. DPI is the largest cross-disability grassroots organization in the world with a network of 134 national assemblies, mostly in developing nations.

Appendix

Groups, both local and international that are addressing some of the gaps identified in the analysis of the AP

Handicap International, Canada

Locations: Cap-Haïtien, Grand-Goâve, Gonaïves, Jacmel, Petit-Goâve, Port-au-Prince


Activities: Two levels: Hospitals and Community Outreach

Hospitals:
• Intervention in seven hospitals in Port-au-Prince
• Injury care
• Post-operative care and rehabilitation
• Training of Haitian nurses and rehabilitation workers in case management
• Psycho-social support: individual and groups
• Temporary fitting of prosthetic limbs and orthotics

Community Outreach:
• Tented “Disability Focal Points” (currently eight in Port-au-Prince and two in Petit-Goâve)
  • Health services to persons with and without disabilities
  • Rehabilitation and follow-up
  • Psycho-social support: groups
  • Recreational activities for children
• Co-ordination with Healing Hands for Haiti (including Team Canada Healing Hands) in Champs de Mars, Port-au-Prince in the production and fitting of prosthetic limbs
• Training of Haitian community and rehabilitation workers
• Distribution of Shelter Boxes that take into consideration the needs of persons with a variety of disabilities
• Construction of wood houses in Petit-Goâve with ramp access
• “Cash for work” activities to employ local Haitians

Christian Champigny, Programs, HI Canada states that HI plans to adopt a Community-Based Rehabilitation (CBR) approach to the operation of more permanent Antenna Points across Haiti to better address the health needs of the community long-term.

Maison de bénéédiction

Location: Cap-Haïtien
Affiliations: Haiti Hospital Appeal, Healing Hands
Activities:
• Respite care to a total of 70 children with a variety of disabilities, mostly congenital, and with high needs
• Number of children is approximately 24 per week, 24 hours per day, Monday to Friday
• Provision of education to over 70 parents in Creole
  • Life skills
  • Diet
  • Health and hygiene
  • Socialization and play
  • Physiotherapy
  • Sensitivity training to challenge stereotypes and myths about disability
• Recreational activities
• Sensory room for children with autism
• Employment and training of local Haitians

Reninca Hill, Director of Maison de bénéédiction, states that the organization’s goal is to empower families to look after their children with disabilities and integrate these children into mainstream life, offering them the life skills and ability to become active members of society. Her future plans are to begin a weekend teen program for youth with a variety of disabilities. The work at Maison de bénéédiction is relevant to current and longer term rebuilding efforts in Haiti.

Wings of Hope

Location: Jacmel
Affiliations: Hearts with Haiti, Broken Wings Missions
Activities:
• Residential care for 36 children with disabilities who were abandoned
• Day school for children with disabilities from the local community
• Recreational activities
• Employment of Haitians

Wings of Hope is closely affiliated with two homes for street children, one of which is located in Jacmel. Peter Eyvindson, who founded Broken Wings Missions in Canada, states that some of the graduates of St. Joseph’s home in Jacmel help with the children at Wings of Hope. The combination of the two marginalized groups, the disabled
and the abandoned, is disrupting cultural myths and stereotypes about disability in the local community.

**The Creole-based and Technology-Enhanced Learning of Reading, Writing, Math and Science in Haiti Project**

**Location:** La Gonave  
**Affiliations:** Matènwa Community Learning Centre (MCLC), Mother Tongues Book Project, One Laptop per Child Foundation  
**Activities:**  
- Teaching of 200 children in elementary school using Creole as language of instruction  
- Incorporation of children’s cultural and linguistic assets into the curriculum  
- Provision of audio and other books in Creole  
- Provision of child-friendly laptops with Creole-based educational software packages  
- Adaptation of audio, written and technology to meet the needs of students with disabilities, such as visual impairment and dyslexia

Michel DeGraff, Professor at the Massachusetts Institute of Technology, heads up this project which encourages student-centred, inquiry-based and technology-enhanced learning. Outcomes have the potential to inform curriculum and teacher development in Haiti. The intent is not to limit education to Creole and impose monolingualism on all Haitians, but to help Haitian schools make systematic use of Creole as the language of instruction for all academic subjects, especially for literacy.

**Endnotes**

6 The Global Partnership for Disability and Development (GPDD) is in the process of designing a toolkit for long-term recovery in Haiti that is inclusive of universal design principles. See http://www.gpdd-online.org/media/news/toolkit_on_inclusive_reconstruction_chapter_1_physical_environment.pdf.  
7 Background on the United Nations’ CRPD and a detailed breakdown of each article can be found at http://www.un.org/disabilities/default.asp?navid=13&pid=150.
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Haiti has been and will continue to be Canada’s priority in the Americas. The Canadian commitment to Haiti is both significant and long-term. FOCAL’s work through the Research Forum on Haiti focuses on three areas: the private sector’s role in development through job creation and economic growth as well as support for education; research and dialogue to facilitate an expanded role for Latin America in Haiti as well as to strengthen the Haitian diaspora as a development actor in its own right. FOCAL’s Research Forum on Haiti enhances ongoing Canadian assistance and co-operation efforts in Haiti by sharing information, building partnerships identifying new ideas and policy options for Haitian, Canadian, Latin American and multilateral actors engaged in Haiti.