



Research and Studies

Representation and evaluation of disability in Haiti (Port-au-Prince, 2012)

Technical Resources Division
International Centre for Evidence in Disability
2013

Authors

Lisa Danquah

London School of Hygiene and Tropical Medicine
International Centre for Evidence in Disability
Research Fellow

Aude Brus

Handicap International
Studies and Research Coordinator

Contributors

Pierre Gallien
Claire Houdon Perrin
Patrick Sénia

Layout

Stéphanie Deygas
Pôle Management des Connaissances

Translation

« Version originale »

Photo credits

© William Daniels / Handicap International

Publication produced with the support of:

- FIRA
- BSEIPH

The opinions represented in this publication are those of the authors.

This document may be used or reproduced, provided the source is mentioned and only for non-commercial use.

Table of contents

List of Tables	p. 3
List of Figures	p. 5
Foreword	p. 6
Presentation of organisations involved in the study	p. 7
Summary	p. 9
INTRODUCTION	p. 12
I. METHODS AND DATA PROCESSING	p. 15
1. The quantitative approach	
2. The qualitative approach	
II. DESCRIPTION OF RESULTS	p. 27
1. General description of the study sample	
2. Prevalence of disability in the general population	
3. Distribution of disabilities in the sample of people with disabilities	
4. Causes of disabilities	
5. Situation of people with disabilities in 2012 in the study area	
6. Dedicated services and assistance for people with disabilities	
7. Informal services	
8. Stigma and prejudice	
III. MAIN RESULTS AND DISCUSSION	p. 69
1. Methodology: from theory to practice	
2. The study population and extrapolation of prevalence	
3. The tool used to measure disability: the Washington Group short set of questions	
4. Prevalence and comparison with other studies	
5. The causes of disabilities	
6. The situation of people with disabilities in 2012, compared with other data	
7. Stigma and discrimination	
IV. RECOMMENDATIONS	p. 86
1. Recommendations for politicians (local and national)	
2. Recommendations for organisations that represent people with disabilities (with the support of NGOs, if necessary)	
3. Recommendations for service managers (including NGOs)	
APPENDICES	p. 92

LIST OF TABLES

Table 1: Characteristics of the sample (population)

Table 2: Presentation of the general population survey and the case-control study

Table 3: Prevalence of disability in the general population according to levels of analysis (at household and individual level) and according to different definitions from the Washington Group screening questions

Table 4: Characteristics of the respondents to the population survey and the results of the comparison between those identified as individuals with disabilities and those without (N=3132 for gender and N=3125, for age categories)

Table 5: Distribution of households according to the presence of a person with disabilities in the household and by district

Table 6: Prevalence of disability according to the type of impairment and the level of severity reported in the general population (N=3132)

Table 7: Distribution of the types of impairment according to the level of severity reported and gender amongst the people with disabilities identified (N=178)

Table 8: Distribution of the types of impairment according to the level of severity reported and the age category of the people with disabilities identified (N=178)

Table 9: The reported causes of disability according to gender, age category and the perceived level of severity (N=178)

Table 10: Average scores for activity limitation by domain for people with disabilities and controls (N=356)

Table 11: Average score for the impact of environmental factors on participation in activities over the past year (N=356)

Table 12: Characteristics of households visited during the general population survey (N=665) and comparison between households with people with disabilities and those without people with disabilities

Table 13: Socio-economic index of households visited during the general population survey (N=599)

Table 14: Socio-economic index of individuals aged 16 years and over (N=138 individuals)

Table 15: Education data for subjects aged under 16 years questioned during the case-control study (N=141)

Table 16: Data on education for subjects aged over 16 years questioned as part of the case-control study (N=196)

Table 17: Reading level among individuals over 16 years old questioned during the case-control study (N=173)

Table 18: Data on the employment status of people aged over 16 years interviewed in the case-control study (N=202)

Table 19: Data on the use of health services by the subjects included in the case-control study (N=355)

Table 20: Number and percentages of awareness of, need for and use of services by people with disabilities (N=178)

Table 21: Reasons most frequently given by people with disabilities to explain the lack of coverage of the need reported

LIST OF FIGURES

Figure 1: Description of the quantitative data collection process in the field

Figure 2: Variations in the prevalence of disability in the general population according to the definition of disability used (N=3122)

Figure 3: Prevalence of disability (%) according to the type of impairment and the level of severity reported, within the sample of people with disabilities who participated in the case-control study (N=178)

Figure 4: Reported causes of disabilities (N=178)

Figure 5: Percentage of children in formal education at the time of the survey amongst individuals aged under 16 years in the case-control group (N=141)

Figure 6: Reading level for people with disabilities aged over 16 years according to gender (N=83)

Figure 7: The difficulties most frequently encountered while using health services by the individuals in the case-control study

Figure 8: Relationship between the reported need and the services used by people with disabilities, by type of service

FOREWORD

The World Report on Disability, produced by the World Health Organization and the World Bank, highlights “a lack of rigorous and comparable data on disability and evidence on programmes that work can impede understanding and action. Understanding the numbers of people with disabilities and their circumstances can improve efforts to remove disabling barriers and provide services to allow people with disabilities to participate.”

This observation has been made in countries throughout the world and is especially true in crisis situations or when natural disasters hit. These situations often lead to deep-seated changes in a country’s organisation, affecting both its social structure and its infrastructure.

Whilst it is important in the initial phases to focus resources and efforts on humanitarian interventions to save lives, our experience as practitioners working in emergency and development settings has taught us that the decisions made during this emergency phase can have a long-term impact on the reconstruction and recovery period.

Within these key areas, which put the issues of social cohesion and service provision at the forefront, the production of factual, objective data is particularly important in order to inform decision-makers and practitioners on the direction their programmes should take.

Handicap International, in close collaboration with the Secretary of State for the Integration of Persons with Disabilities (SEIPH), and in conjunction with the London School of Hygiene and Tropical Medicine’s International Centre for Evidence in Disability, wanted to obtain an accurate and objective picture of the situation in which people with disabilities find themselves in Port-au-Prince, as well as the difficulties they have accessing services.

The publication of this report is the result of this approach, which combines the methodological rigor and the analytical power of a research centre, with the knowledge of the situation in the field and understanding of operational constraints of an organisation working on the ground.

We hope that the different structures and organisation working on development issues in Haiti will find that the information in this document helps them to better focus their actions to support people with disabilities.

Pierre Gallien

Head of the Knowledge Management Unit
Technical Resources Division

Patrick Sénia

Haiti Field Programme Director

PRESENTATION OF ORGANISATIONS INVOLVED IN THE STUDY

FIRAH (International Foundation of Applied Disability Research)

Founded in 2009 and state-approved, FIRAH is the first foundation entirely dedicated to applied disability research.

The foundation has two key means of actions which it uses in synergy to work towards meeting its objectives:

- Calls for projects to select and fund applied research projects involving field stakeholders, including Disabled People's Organisations and researchers.
- The Resource Center, which develops a network of research and operational stakeholders in the field in order to promote the applied research carried out in France and worldwide, and ensure its transfer. This collaborative project is based on a network of partnerships, set up to create innovative and practical tools to improve the practices of field operators and the lives of people with disabilities.

The FIRAH works on the effective implementation of the principles enshrined in the Convention on the Rights of Persons with Disabilities.

All the information about FIRAH, its calls for projects and Resource Center can be found at: www.firah.org

Handicap International

Handicap International is a not-for-profit non-governmental organisation which has worked with people with disabilities for over 25 years.

Its expertise in the field of disability is acknowledged internationally and the organisation has already published analyses of disability in other countries (Afghanistan, Mozambique, Indonesia and West Africa).

Handicap International has been working in Haiti since 2008, and was therefore already in place when the 2010 earthquake hit. It immediately took up an active role in managing the victims, in particular the large number of amputees. Its in-depth knowledge of the local network of disabled people's organisations, health structures and local authorities mean the logistics were already in place to deploy the study, host the additional staff required and find competent local interviewers for this project.

London School of Hygiene & Tropical Medicine (LSHTM)

The LSHTM is the United Kingdom's national school of public health. It is a world-leading centre for research and postgraduate education in public and global health. It is the largest establishment of its kind in Europe and its expertise covers a range of disciplines from epidemiology and statistics to economics and health policy. It is one of the United Kingdom's top research institutes.

International Centre for Evidence in Disability (ICED)

The ICED is a Research Centre, founded in 2010 and based at the London School of Hygiene & Tropical Medicine.

Its researchers have extensive experience in carrying out disability and incapacity studies in low-income countries.

It has notably undertaken research to assess the impact of disability on various aspects of daily life, in particular poverty, quality of life, activities and participation using both quantitative and qualitative approaches.

The ICED's expertise also includes the analysis of health systems in low-income countries in fragile situations, as is the case in Haiti.

The ICED provides academic support and contacts with governmental and non-governmental organisations, in order to work with local contributors and translate the results into practical applications.

The ICED members already work in close collaboration with Handicap International and CBM.

SUMMARY

Context

Haiti is one of the poorest countries in the western hemisphere. Haitians' overall living conditions and their health in particular have deteriorated still further since the earthquake which hit the country on 12 January 2010. Access to and even the existence of health, administrative, education or other services has also been hard hit. Across the board, the country's needs have increased exponentially. The Haitian government, which has ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD), has expressed its determination and commitment to improving structures and services, in collaboration with a variety of international organisations.

Primary objective

Handicap International and the International Center for Evidence in Disability (ICED) at the London School of Hygiene and Tropical Medicine (LSHTM) joined forces to carry out a cross-sectional study to analyse the situation in which people with disabilities found themselves in Port-au-Prince in 2012, and thereby identify the operational mechanisms by which the needs of people with disabilities can be best met.

Specific objectives

- (1) Provide statistically reliable data on disability and people with disabilities in Port-au-Prince (prevalence, reported causes, profile of people with disabilities identified);
- (2) Provide a snapshot of the situation for people with disabilities and compare it to a control group without disabilities in order to reveal restrictions on participation and barriers that specifically affect the study population (family environment, living standards, education, employment and health);
- (3) Investigate from a qualitative perspective people with disabilities' difficulties in terms of inclusion, access and social participation.

Location

The study was carried out in 2012 in 5 districts from the Port-au-Prince metropolitan area: Carrefour, Delmas, Pétionville, Tabarre and Port-au-Prince.

Data collection

A mixed approach combining quantitative and qualitative approaches was used. The quantitative data was collected in three phases: a population-based prevalence survey (3,122 individuals aged 5 years and over recorded), a specific disability study of people with

disabilities (178 people, identified using the Washington Group short set of questions) and finally, a nested case-control study (356 individuals). The qualitative data was collected using semi-structured interviews with 30 people with disabilities.

Main results

- **Prevalence of disability in persons aged 5 years and over:** 17.8% (CI 95%: 16.5 - 19.2) of individuals said they had some difficulty in at least one functional domain; 4.1% (CI 95%: 3.4 - 4.7) said they had some difficulty in at least two functional domains, or a lot of difficulty or cannot do in at least one functional domain; and 2.2% (CI 95%: 1.7 - 2.8) said that they had, a lot of difficulty in at least one functional domain. The prevalence of disability is higher for women than for men (4.8% vs. 3.1% respectively), and increases with age (23.8% in elderly people, 2.7% in adults, and 2.4% in children under 18 year olds). The most common impairments found in the study sample were minor difficulties seeing and concentrating, with a prevalence of 5.8% and 5.5% respectively, followed by difficulty walking, (5.0%), and finally, difficulty hearing, with self-care and communicating (1.4%, 0.8% and 0.8% respectively).
- **Prevalence of disability at household scale:** 15.9% of the households visited had at least one member with disabilities.
- **Causes of disability:** The two most commonly cited causes of disability were birth or congenital anomalies (23.5%) and non-communicable diseases (19.0%). Our study found the earthquake to be the third most common cause, representing 14.0% of causes.
- **Participation of people with disabilities:** A significantly higher number of people with disabilities reported experiencing activity limitation in their daily life, compared to the controls. This was the case across all the functional domains investigated.
- **The average economic dependency ratio for the households studied** showed that the economic burden on the working members of the household was greater in households with one member with disabilities. The socio-economic index shows that households with at least one member with disabilities often rank amongst the poorest households in the study sample.
- **The education of children aged 5 to 16 years:** At equivalent ages, 94.4% of controls were in formal education whilst only 48.6% of children with disabilities were enrolled in a school at the time of the survey. Furthermore, children with disabilities have more learning difficulties (at equivalent ages, there were more children with disabilities at school in the first cycle than in subsequent cycles and they were more likely to have

repeated a school year). The main reasons given for this were the child's disability and the household's lack of funds to pay their school fees.

- **The education of people aged over 16 years:** 22.4% of adults reported that they had never been formally educated, mainly due to their families refusing, a lack of funds or a lack of educational infrastructure in their district. The reading level differed significantly between the people with disabilities and the control group: 22.9% people with disabilities said they could not read at all (compared to 8.9% of the people in the control group). Women seemed to be more vulnerable in this area than men.
- **Employment:** 61.6% of people with disabilities said they were unemployed compared to 35.9% of their counterparts. This lack of employment was linked to their health, and had lasted for seven days for 88.7% of people with disabilities who reported being unemployed, and for a year for 74.5%. Only 7.1% of people with disabilities reported being salaried employees, compared to 19.4% of the controls.
- **Health:** The number of people with disabilities who had visited health services over the past year was the same as the number of people in the control group (57.7% and 54.7% respectively), but they did report using these services more often: 59.4% of them had used such services three times or more, compared with 34.4% of the controls. People with disabilities had encountered difficulties significantly more frequently, notably due to the cost of care (lack of funds to buy medical products, lack of funds for post-visit follow-up care, and being refused services because of a lack of funds) and transport (difficulties covering the cost of transport and unavailability of transport). The qualitative interviews also revealed difficulties related to the attitudes of health professionals.
- The study of people with disabilities showed that whilst they are aware of the **existence of dedicated services**, the actual level of use of these services is relatively low. Nearly 70% of people met reported needing a technical aid which they had not yet received.
- The interviews revealed the importance of two types of support, in addition to the services provided by the State, NGOs or other associations: **family and faith**.
- The people with disabilities interviewed said that the attitudes of the people around them at home, at school and at work **limited their involvement in activities** that were important to them. They also said that they felt they were more frequently victim to prejudice than the controls.

INTRODUCTION

The definition and understanding of disability have changed considerably over the last decades. Indeed, local and international disability stakeholders have moved away from a medical model, which considered that the day-to-day problems were solely related to the person's disability, towards a more holistic approach which integrates the impact of the person's physical, social and cultural environment¹. This model presents disability as the result of a limitation on people's activity participation in all areas of community life (education, health, employment, political, economic and cultural life) due to environmental and social barriers (Barnes, 2011). The reality of a disabling situation therefore covers a range of realities according to the type of impairment(s) (visible or invisible, temporary or long-term etc.), the severity of the functional limitation (painful or not etc.), the level of inclusion in the community, the extent of the perceived social disadvantage, the environmental factors (Ravaud et al., 2002). People with the same disability can express different needs to accommodate their impairment which they may also experience in different ways (Shakespeare and Watson, 2002).

The Convention on the Rights of Persons with Disabilities (CRPD)'s definition of a person with disabilities corresponds to this comprehensive model². The convention thereby defends their right to full access and equal rights in all areas of daily life (family, education, employment, health, living standards, protection, cultural life and leisure etc.). The CRPD focuses on the barriers which hinder or deprive people with disabilities of their basic freedoms and lead to exclusion or even discrimination (Schulze, 2010).

Haiti ratified the CRPD on 23 July 2009. This breakthrough was part of a comprehensive plan by the Haitian State to promote the rights of people with disabilities. In 1998, at an international level, together with the other Caribbean and Latin American States, Haiti signed the San Juan de Puerto Rico declaration, which recognises the need for people with disabilities to participate in the democratic process. The Inter-American Convention on the Elimination of all forms of Discrimination against People with Disabilities was also adopted by the Organization of American States (OAS) in 1999 and ratified in 2008.

At the national level, the Secretary of State for the Integration of Persons with Disabilities (SEIPH) was created in 2007, under article 32-8 of the Haitian constitution of 1987, which sets out the State's obligation to guarantee that the disabled and gifted shall have the

¹ World Health Organization: <http://www.who.int/classifications/icf/en/>

² Convention on the Rights of Persons with Disabilities (2006), Article 1, "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others", <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>

means to ensure their autonomy, education and independence. The SEIPH's remit is to create a national policy to help people with disabilities and to put in place concrete actions to further the fulfillment and integration of people with disabilities in Haiti (Ministry of Social Affairs - MAST and SEIPH, 2009). In 2012, the enactment of the LIPH (Law on the Integration of People with Disabilities)³ created a legal framework for this process at national level. This law aims to promote the principles and values contributing to the full and complete inclusion of people with disabilities in all spheres of Haitian society (prevention, training for medical staff, housing, access to public buildings, transport, education, employment, justice, information, leisure and culture).

In 2009, the SEIPH communicated on the difficulties that people with disabilities encountered at national level, in an economic context that was already very difficult (MAST and SEIPH, 2009): limited access to health care, problems with the accessibility of services, public buildings and transport, an education system that does not take impairments into account, a reluctance to include people with disabilities in employment systems, lack of legal support, etc. The 12 January 2010 earthquake, which affected Port-au-Prince, Leogane, Petit and Grand Goave and Jacmel, worsened the already precarious situation, notably in terms of access to, and even the existence of, health, administrative, educational or other services⁴. The Action Plan for the National Recovery and Development of Haiti launched in March 2010 has reported on the losses and damage resulting from the earthquake and set out a blueprint for an inclusive approach to the country's reconstruction.

However, there is little or no methodologically reliable data on the situation of people with disabilities in Haiti. Few scientific studies have actually been carried out. Article 31 of the CRPD, however, encourages States Parties to gather appropriate information, including statistical data and research results, in order to formulate and apply policies to help people with disabilities.

Handicap International and the International Centre for Evidence in Disability (ICED), of the London School of Hygiene and Tropical Medicine (LSHTM) joined forces to propose a cross-sectional study to analyse the situation in which people with disabilities find themselves in Port-au-Prince in 2012, and thereby identify the operational mechanisms by which the needs of people with disabilities can be best met. The main objective is, therefore, operational as the end purpose of this assessment is to determine the strategic focus of the activities implemented for people with disabilities in the study area.

³ Journal Officiel de la République d'Haïti, 2012. Loi portant sur l'Intégration des Personnes handicapées, Le Moniteur, 21 Mai 2012, n°79 : 1-24.

⁴ UNOCHA (United-Nations Office for the Coordination of Humanitarian Affairs), <http://www.unocha.org/issues-in-depth/haiti-one-year-later>

The specific objectives of this study are:

- **Objective 1:** Provide statistically reliable data on disability and people with disabilities in Port-au-Prince:
 - What is the prevalence of people with functional limitations?
 - What are the main reported causes and what proportion of disability can be directly attributed to the 2010 earthquake in Port-au-Prince?
 - What is the profile of the people with disabilities identified (gender, age)?
- **Objective 2:** Provide a snapshot of the situation for people with disabilities and compare it to a control group without disabilities in order to reveal restrictions on participation and barriers that specifically affect the study population:
 - Are there any differences between the two groups in terms of family environment, living standards, education, employment and health?
 - What were the main barriers to accessing services identified by people with disabilities themselves (education sector, employment, health)?
 - What are the needs of people with disabilities in terms of dedicated services and specialised aid? What are the barriers to using these services?
- **Objective 3:** Investigate from a qualitative perspective people with disabilities' difficulties in terms of inclusion, access and social participation.

A mixed approach combining quantitative and qualitative analyses was used. The quantitative approach sets out a study of the prevalence of disability in the general population and a nested case-control study to compare the situations and access to services of people with disabilities with a control group without disabilities. The qualitative analysis aims to provide first-hand accounts of the lives of people with disabilities.

This report is divided into four parts.

- A detailed presentation of the methodology used, which presents the different phases of the quantitative and qualitative studies, as well as the analysis methods for the data collected;
- A presentation of the study results;
- A discussion section which presents the main results in the context of official national and international data;
- Recommendations, presented in terms of the type of actor targeted and then by sector of activity.

I. METHODS AND DATA PROCESSING

1. The quantitative approach p. 16

1.1	Study setting	p. 16
1.2	Study design	p. 16
1.3	The study population and inclusion criteria	p. 16
1.4	Sampling	p. 17
1.5	Data collection	p. 19
1.6	Data validation	p. 22
1.7	Ethics	p. 22
1.8	Data processing	p. 22

2. The qualitative approach p. 23

2.1	Study design	p. 23
2.2	Target population and inclusion criteria	p. 23
2.3	Data collection	p. 25
2.4	Data processing	p. 26

A mixed approach combining quantitative and qualitative analysis was used. The quantitative study was conducted in partnership with the ICED (LSHTM) and Handicap International and it is the most robust part of the project and its mainstay. The qualitative approach was conducted in order to include first-hand testimony and to guide the use of the quantitative data by suggesting new lines of investigation.

1. The quantitative approach

1.1 Study setting

The study setting was the metropolitan area of Port-au-Prince. The selection of this setting was informed by local Handicap International programmatic expertise in addition to the overall aims of the study. Five districts within this area were selected: Port-au-Prince, Carrefour, Delmas, Tabarre and Pétionville. Cite Soleil was excluded from the outset for security reasons. Other areas, notably the displaced persons camps, were also excluded for security reasons and due to the volatility of these areas.

1.2 Study design

A population-based prevalence survey of disability was undertaken in sixty randomly selected clusters across five districts of the metropolitan area of Port-au-Prince. This first phase of the study was undertaken to identify people with disabilities and estimate the prevalence. A disability study formed the second phase of the study and was conducted with people from the survey identified to have a disability to assess the cause of disability, age of onset, awareness and use of rehabilitation services and barriers to the usage and the use and source of assistive devices. The third phase consisted of a nested case-control study to compare people with disabilities according to the case definition in this study to people without disabilities (controls) in the domains of education, employment and health. One age-sex and cluster matched control without a disability (i.e. not meeting the case definition) was selected for every case identified. Controls and cases were matched by age ± 1 year for those aged under 16, and ± 3 year for those aged 16 years and above).

1.3 The study population and inclusion criteria

In the population-based prevalence survey, all members of the household were enumerated regardless of age. However, only individuals aged 5 years and above were included in the analyses. In order to be considered a member of a household, an individual had to have lived in the home for at least three months in the previous year and taken part in the meal in the shared living room. Members of the same household are not, therefore, necessarily directly or indirectly related.

All household participants aged ≥ 5 years were screened for disability. For the purpose of this study, we defined persons with disabilities as “people who have long-term physical, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”. We identified cases with disability using the Washington Group (WG) screening questions. Using this tool we asked the household head or person primarily responsible for the household if people living within the household experienced difficulties with any of 6 activities (seeing, hearing, walking or climbing stairs, remembering or concentrating, washing all over or dressing, communicating) as a result of a health problem that lasted at least 6 months or was permanent. These were rated by the responder (“no difficulty”, “some difficulty”, “a lot of difficulty”, “unable”).

Disability was defined as answering “some” difficulty with at least two activities or “a lot of difficulty/unable” to do any one activity above.

1.4 Sampling

- **Sampling frame**

Two-stage cluster sampling was used. This sampling method was chosen because it means all individuals have an equal probability of being selected.

The 2003 national census in Haiti was used as the sampling frame in order to select clusters with probability proportionate to their demographic size (IHSI, 2003) which was updated to best represent changes in the demographics of the Haitian population since 2003. The IHSI (*Institut Haïtien de Statistique et d'Informatique*) participated in this phase and provided all the documents required.

- **Sample size**

- **The estimated prevalence of disability used to calculate the sample size**

The calculations were based on a prevalence of disability in people aged over 5 years of 5%. This was a conservative estimate of disability based on findings from previous surveys (the 2001 Survey into Living Conditions in Haiti which reported a prevalence of 10.5% (IHSI, 2003); the 1998 study by the Ministry of Public Health and Population that identified a prevalence of 7% (MSPP, 1998); and the 2003 General Population Census which reported a prevalence of 1.5% (IHSI, 2003).

- **Sample size calculation**

A sample size of 3,000 individuals (60 clusters of 50 people per district) was required to estimate the prevalence with 20% precision, a confidence interval of 95%, a design effect of 1.4 and 15% non-response). According to the estimated prevalence selected, this sample

size would make it possible to identify approximately 150 people with disabilities, including around 110 adults and 40 children. A sample of 3,000 people would therefore allow us to reliably estimate the prevalence of disability. Active case finding of children was undertaken in each cluster as the sample size was insufficient for children. Case finding was therefore undertaken using local key informants to identify one extra child (case) and control in each cluster, to produce a similar sample size for the children as the adults.

The 60 clusters were randomly selected using probability proportionate to size sampling using purpose-built software developed by the International Centre for Eye Health at the LSHTM (ICEH, 2007). Within the clusters, the households were selected using the compact segment sampling method (Milligan et al., 2004). Using maps, each cluster was divided into segments, each containing approximately 50 people. One segment was randomly selected and all the households in this segment were visited, going door to door until the target size was reached. The first house visited was the first on the left.

However, the number of children with disabilities identified was insufficient for the planned case-control study following on from the population-based prevalence survey. It was therefore decided to include one additional child with disabilities in each cluster (along with their control) in order to obtain equivalent numbers of children and adults in the samples.

Case finding

The data collection interviewers were trained to undertake active case finding after fully completing and locating and interviewing the required 50 individuals in the selected segment in each cluster. Case finding was undertaken by the team leader of each team and the data collectors visiting a different randomly selected segment of the cluster than the one that they had located the 50 individuals in (one of the segments not chosen).

Once in this segment, the supervisor's and interviewers role was to identify local key informants in each segment and ask them to whether there was a child with a disability living in the area. The household with the child with a disability was then located and identified and the study was explained and informed consent was taken if the household head agreed to the study. The household questionnaire, disability study and case control questionnaire were then administered to the head of household and the child identified to have a disability in the presence of an adult.

Additional children (58 children/households) were therefore included in the study in order to balance the child and adult samples for the case-control study. These were the children identified through active case finding. It is important to stress that these additional households were excluded from the analyses which were carried out in order to estimate the prevalence of disability.

1.5 Data collection

- **The data collection period**

The data was collected between February and April 2012.

- **The organisation of data collection**

- **Training interviewers and adapting tools**

Two ICED researchers were involved in the data collection process. One was based in Port-au-Prince and was responsible for training the interviewers and providing technical support throughout the data collection phase. The second person provided support for the training of the interviewers.

Handicap International provided the logistical and technical support required to collect the study data. The Disability Coordinator and Project Manager for the study also provided support.

The various tools used in the field were developed by LSHTM researchers and the Handicap International team, first drafted in English and then translated into French and Creole. These questionnaires were tested by interviewers in a Physical Rehabilitation Centre managed by Handicap International and in one cluster. During this pre-test phase, the feedback and observations obtained allowed us to make certain adjustments. The three questionnaires used can be found in Appendix 4.

- **Procedure in the field**

The data collection process took place in three stages and used three different questionnaires (Appendix 4): one for the household survey, one for the disability survey and one for the case-control study.

The different stages of the data collection process are set out in figure 1.

Phase 1: Population-based prevalence survey - Identifying people with disabilities

In each household, a key informant was questioned to identify the head of the household, its members and its assets. The Washington Group screening questions on disability (CDC and NCHS, 2010) were then put to the head of the household, on behalf of all members of the household aged 5 years and over, in order to identify people with disabilities. The six questions were asked in order to identify any impairments: Do you have difficulty seeing, even if wearing glasses? / Do you have difficulty hearing, even if using a hearing aid? / Do you have difficulty walking or climbing stairs? / Do you have difficulty remembering or concentrating? / Do you have difficulty (with self-care such as) washing all over or dressing? / Using your usual (customary) language, so you have difficulty communicating, for example understanding or being understood? The four response categories made it possible to assess the level (No, no difficulty / Yes, some difficulty / Yes, a lot of difficulty / Cannot do at all).

A person was considered to have a disability if they answer “yes, some difficulty” to at least two questions, or “yes, a lot of difficulty” or “cannot do at all” to at least one question.

Phase 2: Specific data concerning people with disabilities - Collecting data on disability

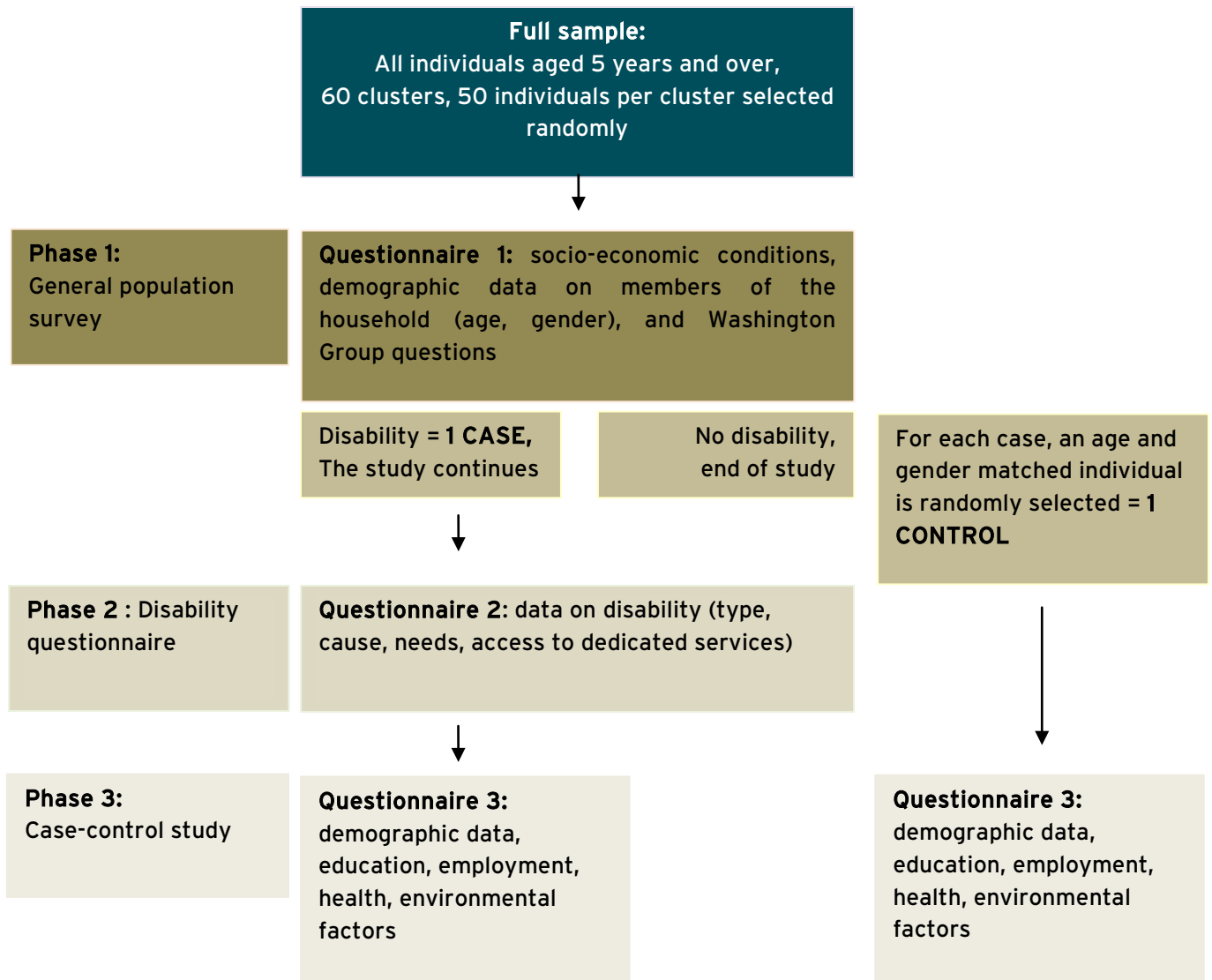
In the second phase, the people with disabilities identified answered a questionnaire specifically concerning their impairment. First of all their disability was confirmed by asking each person with a disability to directly answer the Washington Group questions themselves. They were then questioned about the cause of their disability, their needs and their access to various dedicated services (medical rehabilitation or support services, for example), as well as the use of technical and functional aids for vision, hearing and mobility.

Phase 3: Nested Case-Control Study - Comparing the needs and barriers to equal social participation between people with disabilities and the controls

In the third phase, people without disabilities matched for gender and age with the people with disabilities identified, were included in the study. The people with disabilities and controls answered an in-depth questionnaire which addressed a range of subjects:

- Socio-demographics: Age, gender and marital status.
- Inclusion in education: School attendance, duration of school attendance and literacy for people aged over 16 years; school attendance, current class attended, type of school attended, barriers to attendance, number of days of absence in the previous month and number of school years repeated for those aged under 16 years.
- Health: Frequency of visits to health centres and difficulties encountered (for all respondents) and for women aged 15 - 49 years old, information on mother and child health (number of children, antenatal care, children's vaccination status).
- Employment (respondents aged 16 years and over): Professional status, type of employment, duration of unemployment, difficulties encountered.
- Activity limitation and restrictions on participation due to environmental factors.

Figure 1: Description of the quantitative data collection process in the field



- Field teams

Sixteen interviewers were involved in the data collection process. They underwent one week of training which included a general presentation of the study and its various components, a presentation of the methodologies used and a practical trial in the field. Four teams were set up, each composed of one supervisor and three interviewers. Each team visited one cluster per day.

1.6 Data validation

As the interviewers collected data in the field, two data entry operators, trained in the use of Access and Epi-Info software, encoded the data. Three databases from the three different questionnaires were designed: One for the household survey, one for the disability survey and one for the case-control study. Each of the three questionnaires was entered on a daily basis into Access twice over by the two operators and compared using Epi-Info to correct any processing errors. A daily log of all households visited was also kept and the number of forms processed monitored in Excel.

The data entry started from the beginning of the survey process and lasted for six weeks.

1.7 Ethics

This protocol was submitted to and approved by the MSPP (Ministry of Public Health and Population) bioethics committee, the Haitian Ministry of Health and the ethics committee of the London School of Hygiene and Tropical Medicine.

Formal written consent or thumbprint was obtained from respondents after the content of the interview was carefully explained for each phase of the study. Children and teenagers were questioned with an adult present. A close friend or relative was asked to answer the questions for the youngest children questioned or those unable to communicate.

For people age <16 or those with intellectual impairment consent was sought from a family member, who was present during all interviews. All people with a disability requiring services were referred as appropriate.

The drafting of the protocol and data collection process conform to article 31 of the Convention on the Rights of Persons with Disabilities, and care was taken to ensure confidentiality and respect the privacy of the people with disabilities involved.

1.8 Data processing

The databases were validated, cleaned and analysed using the software programme Stata 12.0.

The univariate statistical analyses were carried out in order to describe the characteristics of the study sample and the prevalence of disability: This allowed us to calculate the populations (presented in the results table under the letter "N"), the percentages for ordinal quantitative variables and the averages for continuous quantitative variables (with a confidence interval of 95%).

Bivariate analyses were also applied and revealed statistically significant relationships between different variables (for the ordinal quantitative data: Parametric χ^2 tests for populations higher than five and non-parametric Fisher's exact test for populations lower than five; for continuous quantitative data: Student's t-test) (Kirkwood, 1988).

2. The qualitative approach

2.1 Study design

Semi-structured interviews were carried out with people with disabilities in order to provide a diverse range of testimony on their experiences of living with a disability.

2.2 Target population and inclusion criteria

Any person with a disability, aged over five years, living in the areas where the quantitative study had already been conducted (Pétionville, Delmas, Carrefour, Tabarre and Port-au-Prince), were eligible.

The sample was not intended to be representative of the population with disabilities in Port-au-Prince, but to represent different situations in terms of gender, age and impairments (Table 1). A total of thirty people were interviewed (13 women and 17 men).

Table 1: Characteristics of the sample (population)

Variables	Women	Men
Gender		
Women	13	
Men	17	
Age categories*		
Children/teenagers	5	6
Adults	4	4
Elderly	4	7
Type of impairment **		
Difficulty seeing	3	6
Difficulty hearing	3	1
Difficulty walking	2	6
Difficulty remembering or concentrating	2	0
Difficulty washing or dressing	2	1
Difficulty communicating	1	3
Nature of the interview		
Person with disability alone	5	7
Person with disability and third party	3	5
Third party	5	5
Interview location		
Port-au-Prince	6	9
Pétionville	1	4
Carrefour	1	2
Delmas	3	1
Tabarre	2	1

*Children: People with disabilities under the age of 18 years. Adults: People with disabilities aged between 19 and 59 years. Elderly: People with disabilities aged 60 years and over.

**The combination of different impairments renders this classification problematic. This is therefore simply an estimation of the main difficulties reported by the people interviewed.

2.3 Data collection

- **The data collection period**

This study was carried out between 20 March and 2 April 2012 in the same areas as the quantitative study.

- **Interview guide**

Two interviewers, specifically trained for this purpose using technical support provided by Handicap International, conducted the interviews.

The interview guide used was based on the work carried out by the Organisation for Economic Cooperation and Development (OECD)⁵ to define quality of life, and the research into Wellbeing in Developing Countries conducted by the University of Bath (England)⁶. Nine themes were investigated:

- The resources required to have a good standard of living;
- Participation in activities, family life and the community;
- The construction of social relationships (friends, professional contacts etc.);
- The quality of close relationships (family);
- Levels of self-esteem;
- Description physical and mental state;
- Spiritual contentment;
- Quality of the environment.

- **Interview process**

Prior to each interview, the person interviewed was given detailed information on the purpose of the survey and signed an informed consent form.

The interviews lasted 25 minutes on average but this varied widely according to how available and willing the people interviewed were (ranging from 12 minutes to one hour). The conditions in which the interviews took place also varied widely (in the person's house or in the street).

The interview sample can be divided into two categories:

- **People with disabilities.** The interviews also took place in very different circumstances: Individually (12 interviews) or with other family members or friends (8 interviews);

⁵ Organisation for Economic Co-operation and Development,
<http://www.oecd.org/statistics/howlife.htm>

⁶ University of Bath, <http://www.welldev.org.uk/research/methods-toobox/com-prof-toolbox.htm>

- **People close to people with disabilities.** One-third of interviews, the people with disabilities were not actually directly interviewed because the subjects were either absent, too young, or unable to directly communicate with the interviewer. Six mothers, three close family members and one young girl acted as proxy-respondents for a relative with a disability.

2.4 Data processing

The interviews were conducted in Creole, recorded and then transcribed verbatim.

The thematic analysis of the resulting corpus was then analysed using NVivo software in order to determine the lines of force from the interviews and determine the strategy for the in-depth analysis (Olivier de Sardan, 2009). The main steps for decontextualisation (i.e. the segmenting the corpus based on subjects or codes) and then recontextualisation were followed in order to interpret and give meaning to the extracts selected.

The results presented were based on two registers:

- what is expressed, represented by the raw discursive data (notably for the sections relating to the shortfalls, needs and support for people with disabilities);
- what is expressible (notably for the section on collective representations of disability and the role of magic and religious beliefs in the lives of people with disabilities).

II. DESCRIPTION OF RESULTS

1.	General description of the study sample	p. 28
2.	Prevalence of disability in the general population	p. 29
2.1	Prevalence of disability	p. 29
2.2	Profiles of the people with disabilities identified amongst general population: gender, age and geographical location of the household	p. 32
2.3	Prevalence in the general population according to the type of impairment and level of severity	p. 34
3.	Distribution of disabilities in the sample of people with disabilities	p. 35
3.1	Type of impairment and level of severity reported by the people with disabilities interviewed	p. 35
3.2	Distribution of the types of impairment according to the level of severity reported and gender	p. 37
3.3	Distribution of the types of impairment according to the level of severity reported and age	p. 38
4.	Causes of disabilities	p. 40
4.1	Frequency of reported causes of disability in the full sample of people with disabilities	p. 40
4.2	The earthquake and disability: distribution by gender, age and level of severity	p. 40
5.	Situation of people with disabilities in 2012 in the study area	p. 41
5.1	Personal factors: measuring activity limitation	p. 42
5.2	Environmental factors as a barrier to participation	p. 44
5.3	Family environment in the household	p. 46
5.4	Living standards at household level	p. 47
5.5	Education	p. 50
5.6	Employment	p. 55
5.7	Health	p. 57
6.	Dedicated services and assistance for people with disabilities	p. 60
6.1	Dedicated services	p. 60
6.2	Awareness of, need for and use of technical aids	p. 65
7.	Informal services	p. 66
7.1	Family	p. 66
7.2	Faith	p. 66
8.	Stigma and prejudice	p. 67

1. General description of the study sample

As set out in the methodology, this study was comprised of three phases. Table 2 provides a summary of the study population for each phase.

In the population-based prevalence survey, 665 households were identified across the 60 clusters from the 5 different districts of the Port-au-Prince metropolitan area, selected for this study. A total of 3,390 people were enumerated. From this initial sample, 258 children (7.6%) were excluded as they were under the age of 5 years old. This resulted in 3,132 individuals (92.4%) who were eligible to participate in the study and who were then assessed using the Washington Group Short set of six questions to ascertain disability status.

The disability survey formed the second phase of this study.

A nested case-control study formed the last phase of this study, for which 356 people were interviewed including 178 cases and 178 controls. Twelve individuals with disabilities were not included in this phase due to a lack of time or because the participants refused to continue.

Table 2: Presentation of the population-based prevalence survey and the case-control study

Descriptives variables	Frequency
Population-based prevalence study	
Total number of households surveyed	665
Total number of clusters visited	60
Number of districts visited (Port-au-Prince)	5*
Number of individuals recorded in the general population survey	3,390
Number of eligible individuals aged over 5 years	3,132
Case-control study	
Number of people with disabilities aged over 5 years interviewed	178
Number of matched controls interviewed	178

*The five districts concerned are: Carrefour, Delmas, Pétionville, Tabarre and Port-au-Prince.

2. Prevalence of disability in the general population

The prevalence and other statistical data presented in this section are taken from the population-based prevalence survey, but also the specific disability study conducted with people with disabilities. Efforts were made, in line with article 31 of the CRPD⁷, to assess the data where possible, according to the type of impairment, the reported level of severity, and also by gender and age. Regarding this final point, the total sample was segmented into three age categories: Children aged 5 to 18 years, in order to respond to the definition of young people⁸, adults aged 19 to 59 years and elderly people aged 60 years and above.

2.1 Prevalence of disability

Table 3 presents several different rates of prevalence of disability based on two different levels of analysis (households and individuals) and according to the inclusion criteria for identifying the group of people with disabilities. This data is taken from the population-based prevalence survey that identified 3,122 individuals aged five years and above.

Out of the 665 households surveyed during the population-based survey, 106, i.e. 15.9% (CI 95%: 13.2 - 18.7) were identified to have a household member with a disability aged 5 years and above. A more detailed analysis demonstrated that households most commonly had one member with a disability (in 13.4% of the households surveyed). Indeed, households with more than one person with a disability are the minority (2.6% of the full sample).

The Washington Group approach means several different rates of prevalence can be calculated according to the level of severity (Figure 2). Of course, the prevalence of disability varies if the inclusion criteria, including the definition of a disabling situation, are adjusted. Therefore with a broad definition of a disabling situation, including all those who report “some difficulty” in one or more area, the prevalence is as high as 17.8% (CI 95% 16.5 - 19.2 (definition 1 in table 3). Conversely, if the definition is limited to “cannot do at all” for at least one of the activities, it decreases to 0.5% (CI 95% 0.3 - 0.8 (definition 4 in table 3).

⁷ Convention on the rights of persons with disabilities (2006), Article 31 : “The information collected in accordance with this article shall be disaggregated, as appropriate”,
<http://www.un.org/disabilities/convention/conventionfull.shtml>

⁸ Convention on the Rights of the Child (1989), Article 1 : “For the purposes of the present Convention, a child means every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier”,
<http://www.ohchr.org/EN/ProfessionalInterest/Pages/CRC.aspx>

For the purposes of this study, a median definition was selected. Therefore, the 127 men and women aged over 5 years who reported “some difficulty” in at least two activities in the questionnaire or “a lot of difficulty / cannot do at all” for at least one activity were identified as people with disabilities. According to this definition the prevalence of disability in the study sample is 4.1% (CI 95% 3.4 - 4.7). It is therefore possible to obtain different estimations of the prevalence of disability using different approaches which will provide target actors with different information according to their objectives.

Finally, the prevalence of disability in this study is estimated at 4.1% in the population aged five years and above. However, this figure masks certain gender and age disparities: The prevalence of disability is higher for women than for men (4.8% vs. 3.1% respectively). It stands at 2.4% in children aged 5 - 18 years old, 2.7% for adults aged 19 - 59 years old and 23.8% in elderly persons aged 60 years and above.

Table 3: Prevalence of disability according to different levels of analysis (at household and individual level) and according to different definitions from the Washington Group screening questions

Level of analysis and definitions of disability	Frequency
Household level analysis	
Number of households without a person with disabilities	559
Numbers of households with one or more persons with a disabilities	106
Prevalence of disability at household level	15.9% (IC 95% : 13.2 - 18.7)
Individual level analysis	
Number of eligible individuals aged 5 years and over (having answered the set of 6 Washington Group questions)	3,122
Definition 1: "Yes, some difficulty", or more reported in one or more functional domains <ul style="list-style-type: none"> Number of individuals identified with disabilities Prevalence of disability at individual level 	556 17.8% (IC 95% : 16.5 - 19.2)
Definition 2**: "Yes, some difficulty" in at least two basic actions from the questionnaire or "Yes, a lot of difficulty" or "Cannot do at all" in at least one basic action. <ul style="list-style-type: none"> Number of individuals identified with disabilities Prevalence of disability at individual level 	127 4.1% (IC 95% : 3.4 - 4.7)
Definition 3***: "Yes, a lot of difficulty" or more reported in one or more functional domains. <ul style="list-style-type: none"> Number of individuals identified with disabilities Prevalence of disability at individual level 	70 2.2% (IC 95% : 1.7 - 2.8)
Definition 4****: "Cannot do at all" reported in at least one functional domain. <ul style="list-style-type: none"> Number of individuals identified with disabilities Prevalence of disability at individual level 	16 0.5% (IC 95% : 0.3 - 0.8)

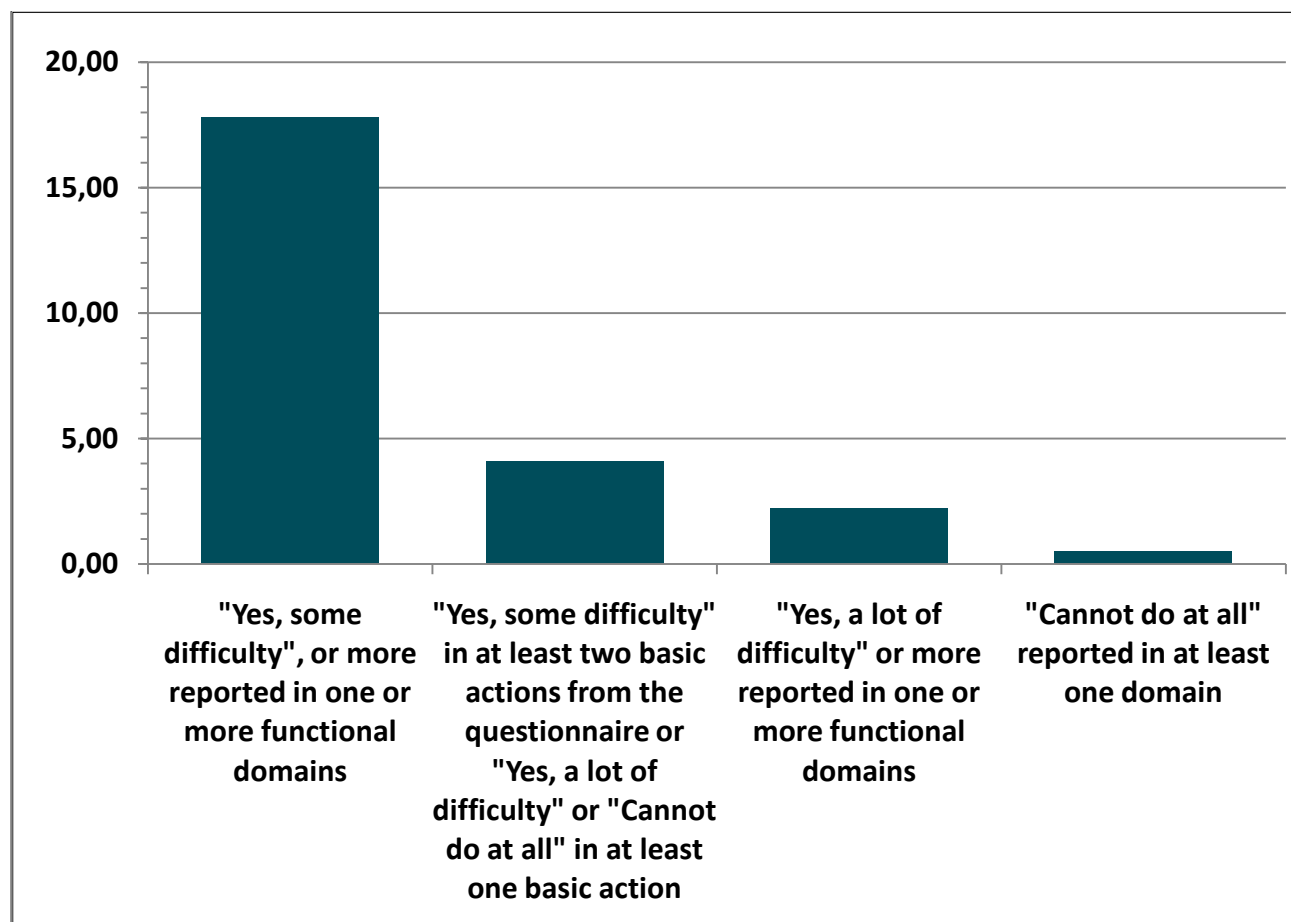
* This definition is large and includes all levels of difficulty, from the least to the most severe.

** This definition is the one used in this study to define a disability.

*** This definition excludes the lower and intermediate levels of severity.

****This definition emphasises the most severe cases.

Figure 2: Variations in the prevalence of disability in the study sample population according to the definition of disability used (N=3122)



2.2 Profiles of the people with disabilities identified amongst the study population: gender, age and geographical location of the household

Table 4 provides a summary of the characteristics of respondents identified through the population-based survey and the results of the comparison between the individuals identified as having disabilities, according to the definition used in this study, and people without disabilities.

Out of the 127 people with a disability, 43 are men and 84 women (33.9% and 66.1% respectively). This over-representation of women is found in both reference samples. However, in the sample of people without disabilities, this difference is statistically significant (χ^2 test $p < 0.05$), with men and women represent 44.9% and 55.1% respectively.

The distribution of the sample of people with disabilities according to age is significantly different from the sample without people with disabilities (chi² test, p<0.001). Children under 18 years old are under-represented, and the over 60s are over-represented in the population of people with disabilities. Children aged 18 years and under represent 17.6% of the people with disabilities identified (compared to 29.7% of the sample of people without disabilities), and the elderly 39.2% (compared to 5.2% in the control group).

Table 4: Characteristics of the respondents to the population-based survey and the results of the comparison between those identified as individuals with disabilities and those without (N=3132 for gender and N=3125, for age categories)

Identifying factors	Full Sample (N= 3132)		Group without disabilities (N=3005)		Group with disabilities (N= 127)		p*
	Popu- lation	Percentage	Popu- lation	Percentage	Popu- lation	Percentage	
Gender							
Men	1,391	44.4%	1,348	44.9%	43	33.9%	p=0,02
Women	1,741	55.6%	1,657	55.1%	84	66.1%	
Age category							
5 to 18 years	914	29.3%	892	29.7%	22	17.6%	p<0.001
19 to 59 years	2,005	64.2%	1,951	65.0%	54	43.2%	
60 years and over	206	6.5%	157	5.2%	49	39.2%	

* Chi² test, level of statistical significance p< 0.05

Table 5 sets out the percentage of households with at least one member with a disability in each district visited. The highest number of households with a household member with a disability were found in Pétionville (22.9%), followed by Tabarre (17.3%), Carrefour (15.2%), Port-au-Prince (13.0%), and Delmas (4.0%).

Table 5: Distribution of households according to the presence of a person with disabilities in the household and by district

Geographical location	Full Sample (N=665)		Household without PWD ⁹ (N=599)		Household with PWD (N= 106)	
	Population	Percentage	Population	Percentage	Population	Percentage
Carrefour	191	100,0%	162	84.8%	30	15.2%
Delmas	25	100,0%	24	96.0%	1	4.0%
Pétionville	157	100,0%	121	77.1%	36	22.9%
Port-au-Prince	262	100,0%	228	87.0%	34	13.0%
Tabarre	29	100,0%	24	82.8%	5	17.3%

* Chi² test, level of statistical significance $p < 0.05$.

2.3 Prevalence of disability in the study sample population according to the type of impairment and level of severity

Table 6 presents the prevalence of disability according to the type of impairment and level of severity reported. The classification is based on the Washington Group short set of six questions which cover six core functional domains of basic actions: seeing, hearing, walking, concentrating, self-care and communicating. Prevalence in each of these six domains was calculated, on three levels of severity or difficulty.

The highest levels of prevalence are found at the lowest levels of severity. Difficulties seeing and concentrating are the most commonly reported in the study sample, with prevalence of 5.8% and 5.5%, respectively. There is also a high prevalence of difficulties walking (5.0%). Finally, difficulties hearing, with self-care and communicating were the least frequently cited, with rates of prevalence of 1.4%, 0.8% and 0.8% respectively. These percentages decrease with the level of severity. The prevalence of total incapacity is situated around 0.0 and 0.3%, with difficulties walking being the most commonly cited at 0.3%. Finally, it is rare that individuals report only one disability. There was a clear trend of individuals reporting several different disabilities with varying levels of severity.

⁹ For practical reasons, the acronym PWD is used for “people with disabilities” in tables and figures.

Table 6: Prevalence of disability according to the type of impairment and the level of severity reported in the general population (N=3132)

Type of impairment*	Level of severity		
	At least some difficulty N (%)	At least a lot of difficulty N (%)	Cannot do at all N (%)
Vision	182 (5.8%)	8 (0.3%)	3 (0.1%)
Hearing	45 (1.4%)	5 (0.2%)	2 (0.1%)
Mobility	155 (5.0%)	22 (0.7%)	9 (0.3%)
Cognition	171 (5.5%)	27 (0.9%)	1 (0.0%)
Self-care	24 (0.8%)	17 (0.5%)	5 (0.2%)
Communication	24 (0.8%)	9 (0.3%)	5 (0.2%)

* Based on the Washington Group screening questions on six types of impairment (seeing, hearing, walking, remembering or concentrating, with self-care, and communicating).

**The population here is larger than the 127 people with disabilities previously cited. The statistics presented in this table are based on the full sample. People who reported "Yes, some difficulty" have not been systematically identified as having a disability because according to the Washington Group definition used, an individual has a disability if he reports "Yes, some difficulty" in at least two functional domains.

3. Distribution of disabilities in the sample of people with disabilities

The statistics presented in this section have been taken from the data collected during the second phase of the survey, from the disability questionnaire administered to people with disabilities or a proxy on their behalf who reported "some difficulty" with at least two of the basic domains addressed in the Washington Group survey or "a lot of difficulty" or "cannot do at all" in at least one domain. The disability questionnaire was administered to 178 individuals who were identified to have a disability¹⁰.

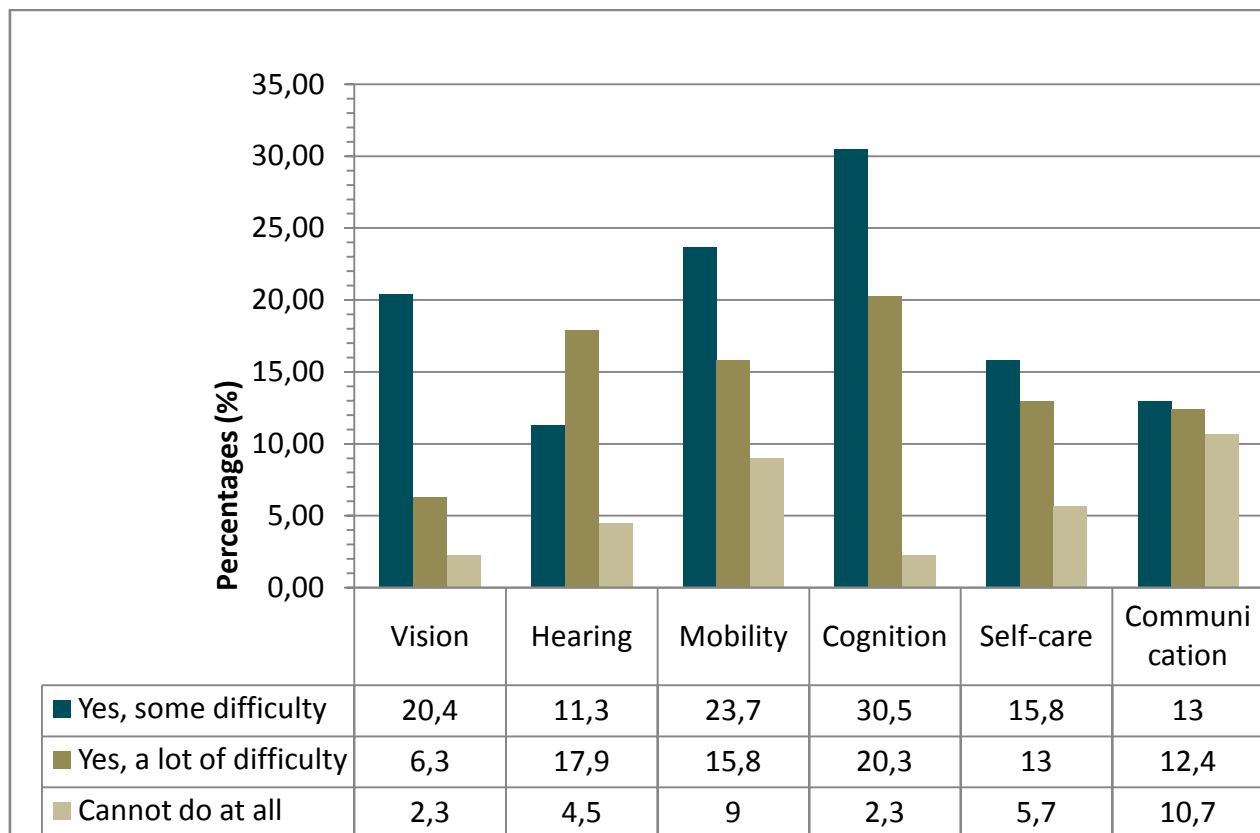
3.1 Type of impairment and level of severity reported by the people with disabilities interviewed

Figure 3 shows the distribution of the people with disabilities identified and interviewed, according to their type of impairment and level of severity. As for the study population (table 6), the highest percentages are found for the lowest levels of severity. Difficulties

¹⁰ From the population-based prevalence survey, 127 people were identified as having a disability. This figure was used to assess the prevalence of disability amongst the study population, according to the criteria established for this study. However, 178 people with disabilities actually participated in the case-control study. The 51 additional individuals were children with disabilities (see methodology: http://www.hiproweb.org/uploads/tx_hidrtdocs/MethodologicalReportHaitiSurvey.pdf) included to balance the composition of the study sample between children and adults.

seeing, walking and concentrating are the most commonly reported in the study sample, with prevalence of 30.5% and 23.7% and 20.4% respectively. These percentages then decrease with the level of severity, except for difficulty hearing, for which the highest prevalence is found at the intermediate level of severity. The number of total incapacities is situated between 2.3% and 10.7%. Difficulties communicating and walking are the most commonly cited at 10.7% and 9% respectively.

Figure 3: Prevalence of disability (%) according to the type of impairment and the level of severity reported, within the sample of people with disabilities who participated in the case-control study (N=178)



3.2 Distribution of the types of impairment according to the level of severity reported and gender

The distribution of the different impairment is presented by level of severity and by gender in table 7.

Women more often reported difficulties seeing, walking, concentrating and hearing than men, across all levels of severity. However, the differences were only statistically significant for seeing and walking. In total 35.9% of women reported difficulties seeing, compared to 20.9% of men, but those who reported that they could not see at all were all men (Fisher's test, $p < 0.01$). Furthermore, 57.7% of women reported difficulties walking, regardless of severity, compared to 34.7% of men.

Finally, more men reported difficulties with self-care and communication, but this is merely an observed trend and no statistically significant results were found on analysis.

Table 7: Distribution of the types of impairment according to the level of severity reported and gender amongst the people with disabilities identified (N=178)

Type of impairment*	Level of severity				p*
	No difficulty N (%)	Yes, Some difficulty N (%)	Yes, A lot of difficulty N (%)	Cannot do at all N (%)	
• Vision					
Men	57 (79.2%)	9 (12.5%)	2 (2.8%)	4 (5.6%)	p=0.002
Women	67 (64.4%)	27 (26.0%)	10 (9.6%)	0 (0.0%)	
• Hearing					
Men	58 (80.6%)	3 (4.2%)	7 (9.7%)	4 (5.6%)	p= 0.67
Women	82 (78.8%)	9 (8.7%)	7 (6.7%)	6 (5.8%)	
• Mobility					
Men	47 (65.3%)	9 (12.5%)	11 (15.3%)	5 (6.9%)	p=0.007
Women	44 (42.3%)	33 (31.7%)	16 (15.4%)	11 (10.6%)	
• Cognition					
Men	40 (55.6%)	18 (25.0%)	13 (18.1%)	1 (1.4%)	p= 0.15
Women	42 (40.4%)	40 (38.5%)	18 (17.3%)	4 (3.8%)	
• Self-Care					
Men	47 (65.3%)	10 (13.9%)	12 (16.7%)	3 (4.2%)	p= 0.57
Women	70 (66.7%)	16 (15.2%)	11 (10.5%)	8 (7.6%)	
• Communication					
Men	40 (60.3%)	10 (12.8%)	12 (15.4%)	9 (11.5%)	p= 0.21
Women	72 (69.2%)	13 (12.5%)	8 (7.7%)	11 (10.9%)	

* Fisher's test, level of statistical significance $p < 0.05$.

3.3 Distribution of the types of impairment according to the level of severity reported and age

The distribution of the different disabilities is presented by level of severity and by age in table 8.

There were statistically significant differences across age categories for four types of impairment: seeing, hearing, walking and communicating. Only 6.6% of children aged 18 years and under reported difficulties seeing, whilst 50.0% of people aged 60 years and above experienced some form of sight impairment (Fisher's test, $p < 0.001$). The same trend was found for walking: Children reported less difficulty in this area than the elderly (27.3% vs. 78.3% respectively; Fisher's test, $p < 0.001$), but it is interesting to note that the reported level of severity was lower for the elderly than for children. However, children reported significantly more difficulties hearing and communicating (29.9% and 58.4% of children compared to 19.6% of adults and the elderly in both cases; Fisher's test, $p < 0.01$ in both cases), notably at the highest level of severity.

Table 8: Distribution of the types of impairment according to the level of severity reported and the age category of the people with disabilities identified (N=178)

Type of impairment*	Level of severity				p*
	No difficulty N (%)	At least some difficulty N (%)	At least a lot of difficulty N (%)	Cannot do at all N (%)	
• Vision					
5 to 18 years	71 (93.4%)	1 (1.3%)	3 (3.9%)	1 (1.3%)	p<0.001
19 to 59 years	29 (56.9%)	19 (25.0%)	3 (3.9%)	0 (0.0%)	
60 years and over	23 (50.0%)	15 (19.7%)	5 (6.6%)	3 (3.9%)	
• Hearing					
5 to 18 years	54 (70.1%)	6 (7.9%)	10 (13.2%)	7 (9.2%)	p=0.006
19 to 59 years	41 (80.4%)	8 (10.5%)	1 (1.3%)	1 (1.3%)	
60 years and over	37 (80.4%)	6 (7.9%)	3 (3.9%)	0 (0.0%)	
• Mobility					
5 to 18 years	56 (72.7%)	5 (6.6%)	8 (10.5%)	8 (10.5%)	p<0.001
19 to 59 years	23 (45.1%)	16 (21.1%)	9 (11.8%)	3 (3.9%)	
60 years and over	10 (21.7%)	21 (27.6%)	10 (13.2%)	5 (6.6%)	
• Cognition					
5 to 18 years	36 (46.8%)	19 (25.0%)	19 (25.0%)	3 (3.9%)	p=0.30
19 to 59 years	22 (43.1%)	16 (21.1%)	12 (15.8%)	1 (1.3%)	
60 years and over	23 (50.0%)	18 (23.7%)	5 (6.6%)	0 (0.0%)	
• Self-Care					
5 to 18 years	45 (58.4%)	16 (21.1%)	10 (13.2%)	6 (7.9%)	p=0.21
19 to 59 years	38 (74.5%)	3 (3.9%)	8 (10.5%)	2 (2.6%)	
60 years and over	31 (67.4%)	9 (11.8%)	4 (5.3%)	2 (2.6%)	
• Communication					
5 to 18 years	32 (41.6%)	14 (18.4%)	16 (21.1%)	15 (19.7%)	p<0.001
19 to 59 years	41 (80.4%)	3 (3.9%)	3 (3.9%)	4 (5.3%)	
60 years and over	37 (80.4%)	6 (7.9%)	3 (3.9%)	0 (0.0%)	

* Fisher's test, level of statistical significance p< 0.05

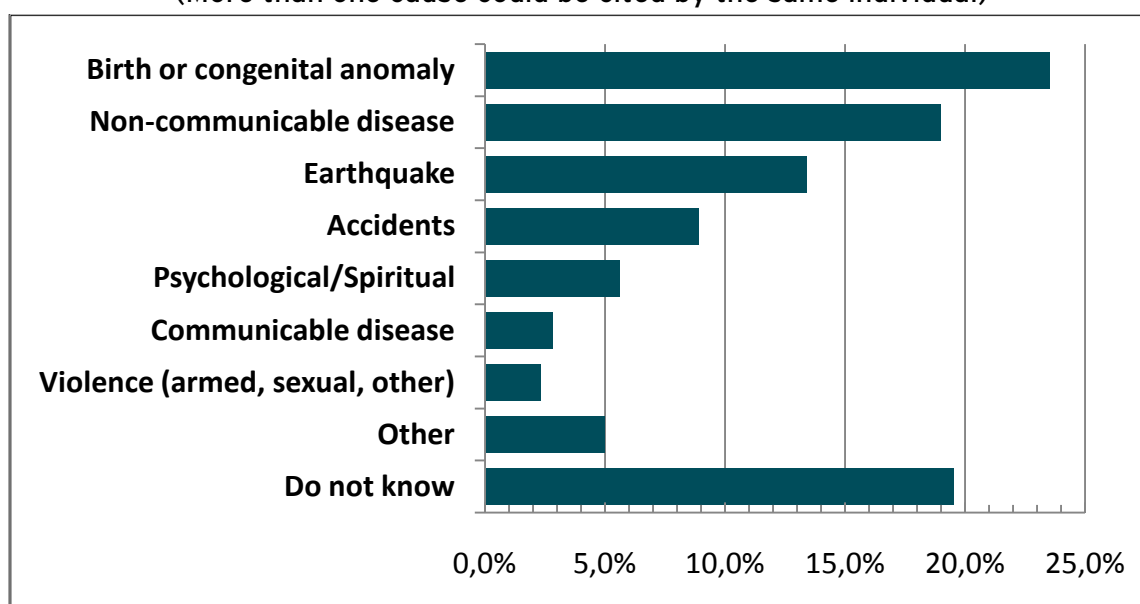
4. Causes of disabilities

Statistics presented in this section are taken from the second phase of the quantitative study, as said from the questionnaire designed specifically for people with disabilities. This section presents data for all persons identified to have disabilities including those identified through case finding.

4.1 Frequency of reported causes of disability in the full sample of people with disabilities

Figure 4 shows the percentages for each different cause reported by the 178 people with disabilities surveyed. The four most commonly cited causes were: birth or congenital anomalies (23.5%), non-communicable diseases (19.0%), the earthquake (13.4%), and finally, accidents. Almost 20% of people with disabilities were unable to identify the cause of their disability.

Figure 4: Reported causes of disability (N=178)
(More than one cause could be cited by the same individual)



4.2 The earthquake and disability: distribution by gender, age and level of severity

Table 8 presents the populations and proportion of disabilities caused directly by the 2010 earthquake, and those resulting from other causes, according to gender, age category and the reported level of severity.

Whilst no relationship was found with age, there was a significant difference between men and women. Women represent 79.2% of the individuals reporting disabilities resulting directly from the earthquake (Fisher's test, $p < 0.05$). Furthermore, the level of severity also appears to be related to the cause of disability: 50.0% of the people with disabilities reporting a severe level of difficulty also reported that their disability had been caused by the earthquake (compared to 26.0% for other causes; χ^2 tests, $p < 0.05$).

Table 9: The reported causes of disability according to gender, age category and the perceived level of severity (N=178)

Variables	Cause: 2010 earthquake		Other causes		p
	Population	Percentage	Population	Percentage	
Gender					
Men	5	20.8%	67	43.8%	p=0.04*
Women	19	79.2%	86	56.2%	
Age category					
5 to 18 years	9	37.5%	68	45.3%	p=0.75*
19 to 59 years	8	33.3%	43	28.7%	
60 years and over	7	29.2%	39	26.0%	
Level of severity					
Some difficulty in two or more functional domains	12	50.0%	111	74.0%	p=0.02**
A lot of difficulty or cannot do at all	12	50.0%	39	26.0%	

* Fisher's Test, level of statistical significance $p < 0.05$.

** χ^2 test, level of statistical significance $p < 0.05$.

5. Situation of people with disabilities in 2012 in the study area

This section of the report presents an overview of the situation in which the people with disabilities interviewed find themselves. Some of the data presented, specifically the data describing the households, is taken from the population-based prevalence study. The case-control study also enabled comparison of the situation of people with disabilities with a control group matched by gender and age (+/- 1 year for under sixteen year olds and +/- 3 years for adults). In total, 356 people were interviewed, 178 people with disabilities and 178 controls. The gender distribution was also identical in both samples: 73 men and 105 women.

Several concepts are addressed in this section. Some relate to the holistic modelling of disabling situations known as the disability creation process¹¹, notably the concepts of activity limitation, personal and environmental factors. Others correspond to articles of the CRDPH¹², which are also found in Haiti's law on the inclusion of people with disabilities¹³. The subjects addressed include living standards, educational services, employment, or health services.

5.1 Personal factors: measuring activity limitation

This section of the study was directly inspired by the questionnaire developed by the SINTEF, used in Namibia, Zimbabwe, Malawi, Zambia and in Mozambique (Eide et al., 2003; Loeb and Eide, 2003, 2004; Eide and Loeb, 2006; Eide and Kamaleri, 2009).

Questions on activity limitation were asked to all participants (with or without disabilities), in order to assess the level of activity limitation, i.e. people's ability to accomplish certain activities without support or assistance. Forty activities were recorded and grouped into nine domains:

- Sensorial experiences (seeing, hearing),
- Basic learning (learning to read, write, count, resolve problems etc.),
- Communication (understanding other people, producing written/verbal/signed messages etc.),
- Mobility (changing position, walking, driving etc.),
- Self-care (washing, drinking etc.),
- Home life (cooking, washing up, taking care of personal belongings etc.),
- Inter-personal relationships (making friends, interacting with strangers etc.),
- Education and employment (going to school, holding down a job, earning money etc.),
- Community and social life and citizenship (joining clubs and societies, religious activities etc.).

For each of the 40 activities a score was given from 0 - 4 depending on the person's response (no difficulty, some difficulty, a lot of difficulty, cannot do at all). Each individual's responses for each item were added up in order to obtain an individual activity score. In this way an activity limitation score was obtained for each of the nine areas of activity. The higher the score for a given area of activity, the higher the level of difficulty encountered.

¹¹ International Network on the Disability Creation Process, the Human Development Model, Disability Creation Process, <http://www.indcp.gc.ca/hdm-dcp/hdm-dcp-key-concepts>

¹² Convention on the rights of persons with disabilities (2006), <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>

¹³ Journal Officiel de la République d'Haïti, 2012. *Loi portant sur l'Intégration des Personnes handicapées*, Le Moniteur, 21 Mai 2012, n°79 : 1-24.

- **Scores for people with disabilities and for the controls**

The breakdown of the activity limitation scores per area of activity amongst people with disabilities and the controls is presented in table 10.

The differences between the scores for the people with disabilities and the controls were statistically significant, with people with disabilities systematically more limited in all the areas of activity (Student t-test, $p < 0.001$). For people with disabilities, the areas of activity with the highest actual scores are mobility and home life. However, according to the relative scores, the areas in which people with disabilities are most limited are education and employment and home life.

Table 10: Average scores for activity limitation by domain for people with disabilities and controls (N=356)

Areas of activities	Population	Maximum Score	PWD group score		Control group score		p **
			Actual score	Relative score*	Score Actual	Relative score*	
Sensory experiences	356	8	2.9	0.36	2.2	0.27	<0.001
Basic learning	332	20	9.8	0.49	5.8	0.29	<0.001
Communication	354	12	4.9	0.41	3.2	0.27	<0.001
Mobility	350	32	12.1	0.38	8.3	0.26	<0.001
Self-care	348	20	7.5	0.37	5.2	0.29	<0.001
Home life	309	20	11.1	0.55	6.6	0.33	<0.001
Inter-personal relationships	226	20	7.7	0.38	6.2	0.31	<0.001
Education and employment	195	12	7.8	0.65	5.9	0.49	<0.001
Community, social life and citizenship	179	16	6.9	0.43	4.5	0.28	<0.001

*As maximum scores were different for each domain, each score has been converted to the same scale in order to compare domains.

** Student t-test, level of statistical significance $p < 0.05$.

- **Scores for people with disabilities and controls according to gender and age**

Further analyses revealed that the scores for people with disabilities were significantly higher than those in the control sample, regardless of gender, age category or the area of activity analysed (Student t-tests, $p < 0.05$).

Women reported more difficulties than men in the areas of sensory experiences, mobility, self-care and inter-personal relationships. As for men, they experience more difficulties with learning, communication, home life and employment or education.

Finally, the activity limitation scores in the areas of sensory activities, mobility, employment and education and social life, increase with age. Conversely, difficulties in the areas of communication, interpersonal relationships and self-care, decrease with age.

5.2 Environmental factors as a barrier to participation

Questions on environmental factors were asked to all participants, with or without disabilities, in order to assess the impact of the various environmental factors affecting their participation in activities they enjoy, over the last year. For each of the twelve areas considered, a score of between 1 and 5 was assigned according to the individual's response (difficulty encountered daily, weekly, monthly, less than once a month, never). The lower the score for a given area of activity, the more frequently the difficulty is encountered.

Table 11 sets out the average scores for the impact the environment has on the participation of people with disabilities and the controls. The scores for people with disabilities are significantly lower than those for the control group. This shows that people with disabilities report that they face difficulties and that their activity is restricted more frequently than their counterparts without disabilities (Student t-tests, $p < 0.05$). The area of trade laws and regulations is the only exception and actually has the highest score. Transport and the accessibility of health services are the areas with the lowest scores for people with disabilities. Finally, people's attitudes and information supports were the areas in which the greatest discrepancies were recorded between people with disabilities and the controls.

Table 11: Average score for the impact of environmental factors on participation in activities over the past year (N=356)

Environmental Factors	Population	Average score per group		p*
		People with Disabilities	Control Group	
Transport	340	3.8	4.1	0.04
Natural Environment (climate, terrain, etc.)	347	4.0	4.3	0.01
Physical Environment (noise, over population, etc.)	346	4.1	4.4	0.03
Adapted information aids	310	4.1	4.7	<0.001
Accessibility of health services	321	3.9	4.5	<0.001
Requires assistance in the home	347	4.2	4.6	<0.001
Requires assistance at school	160	4.1	4.6	0.02
Attitude of those at home	342	4.5	4.8	0.01
Attitude of people (at school or at work)	187	4.1	4.9	<0.001
Victim of prejudice and discrimination	329	4.2	4.8	<0.001
Trade laws and regulations	105	4.8	5.0	0.09
Laws and government programmes	156	4.4	4.7	0.04

* Student t-test, level of statistical significance $p < 0.05$.

In addition, within the sample of people with disabilities, the women systematically had lower scores than men for all activities, except those relating to legal issues. It would therefore appear that women are more vulnerable, as they experience more difficulties than men in a lot of their activities. Children aged 18 and under had higher scores than adults and elderly people, except for attitudes at school, and prejudice and discrimination.

The results from this section will be reiterated and illustrated in subsequent sections (for example, the need for assistance, the accessibility of health service and attitudes towards people with disabilities).

5.3 Family environment in the household

This analysis was conducted at the household level and therefore uses the data taken from the population-based prevalence study.

Table 12 details the characteristics of the households visited with at least one member with disabilities and in those with no members with disabilities.

The number of members of the household was significantly higher for households with one member with disabilities (5.8 members vs. 5.0 members; Student t-test, $p < 0.001$). An analysis of the composition of the households confirms this finding: more children aged 16 years and under and more elderly people are reported living in households with at least one member with disabilities (chi² test, $p < 0.001$). This composition has a direct impact on the households' average economic dependency ratio¹⁴. This index gives the ratio between the number of people who are too young or too old to work (i.e., aged under 15 years or over 65 years old) and the number of individuals in active employment (i.e., people aged from 15 to 64 years old). The closer the calculated index is to one, the more balanced the ratio between the active/inactive members of the household, and the greater the economic burden. Households with disabled members have a significantly higher economic dependency ratio than other households (0.67 (CI 95%: 0.53-0.82) vs. 0.48 (CI 95%: 0.42-0.53).

Finally, households with at least one member with disabilities are more likely to have a female head of household, although this is an observed trend.

¹⁴ Index commonly used in demographic studies to determine the percentage of the population of an age to be engaged in active employment.

Table 12: Characteristics of households visited during the population-based survey (N=665) and comparison between households with people with disabilities and those without people with disabilities

Characteristics	Full Sample (N=665)		Households without PWD (N=599)		Households with PWD (N= 106)		p*
	Popu- lation	Percentage	Popu- lation	Percentage	Popu- lation	Percentage	
- Average number of people in household		5,1		5,0		5,8	<0.001
- Composition of household:							
Number of children under 16 years							
None	231	34.7%	193	34.5%	38	35.8%	0.005
From 1 to 3	383	57.6%	331	59.2%	52	49.1%	
Over 4	51	7.7%	35	6.3%	16	15.1%	
Number of +60 years							
None	495	74.4%	447	80.0%	48	45.3%	<0.001
1	137	20.6%	96	17.2%	41	38.7%	
2 or more	33	5.0%	16	2.9%	17	16.0%	
- Households' average Economic dependency ratio (CI, 95%)	659	0.51 (0.46 -0.55)	555	0.48 (0.43 - 0.52)	104	0.67 (0.53 - 0.82)	0.002
- Female head of household:							
Yes	343	51.6%	283	50.6%	60	56.6%	p =0.26
No	322	48.4%	276	49.4%	46	43.4%	

*Chi2 Test, level of significance p< 0.05.

5.4 Living standards at household level

Article 28 of the CRPD recognises people with disabilities' right to "an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living condition." The data collected from households for the purposes of the population-based survey provides an overview of the living conditions and context in which people with disabilities live.

Table 13 presents the socio-economic index for the households visited. This index was calculated as part of the general population study. Several questions address the environment in which the household lives: The materials used to build the walls, roof and floors, the number of bedrooms, the type of toilet facilities, access to drinking water, the source of electricity, and an inventory of their possessions (white goods etc.). These indicators were then used in a Principal Component Analysis (PCA). The PCA score was divided into four quintiles ranging from level 1 (poorest households) to level 4 (richest households).

- **Socio-economic index of households**

Since the differences are not significant, the analyses highlight the homogeneous distribution of households according to socio-economic factors.

Table 13: Socio-economic index of households visited during the general population survey (N=599)

Socio-economic index of households	Full Sample (N=599)		Households without PWD (N=502)		Households with PWD (N= 97)		p*
	Population	Percentage	Population	Percentage	Population	Percentage	
1 (the poorest)	142	23.7%	120	23.9%	22	22.7%	0.95
2	147	24.5%	121	24.1%	26	26.8%	
3	156	26.0%	132	26.3%	24	24.7%	
4 (the richest)	154	25.7%	129	25.7%	25	25.8%	
Total	599	100.0%	502	100.0%	97	100.0%	

* Chi² test, level of statistical significance $p < 0.05$.

However, although the living conditions were difficult for all the people interviewed, further analyses demonstrated that children under the age of 16 years are significantly more likely to be members of households with a low socio-economic index (41.2% vs. 21.4%) (Table 14).

The interviews also revealed that the situation is even more precarious for single mothers who cannot work for reasons relating to their child's disability. The close family (parents or siblings) therefore constitute a safety net, although they are not always themselves in a position to help, as one young mother explained¹⁵ : "I do not have husband, the situation is not good for me, it's my family who help me and things are not so good for my family."

¹⁵ Individual 5: Mother of a child suffering from paralysis and mental retardation, Delmas.

**Table 14: Socio-economic index of individuals aged 16 years and over
(N=138 individuals)**

Socio-economic index of individuals	PWD group (N=68)		Control group (N=70)		p*
	Popula- tion	Percentage	Popula- tion	Percentage	
1 (the poorest)	28	41.2%	15	21.4%	p=0.007
2	19	27.9%	13	18.6%	
3	9	13.2%	18	25.7%	
4 (the richest)	12	17.6%	24	34.3%	

* Chi² test, level of statistical significance p< 0.05.

- **Isolated indicators on living conditions**

The living conditions for most of the general population in Port-au-Prince significantly deteriorated after the earthquake and can be qualified as poor.

The various indicators concerning housing did not reveal any significant differences: the households visited were living in constructions with solid walls (85.2% of cases), concrete floors (76.3%) and a concrete or sheet metal roof (60.0% and 38.9% respectively). The number of bedrooms and light sources were also similar for both groups. The means for accessing drinking water were also comparable, the main sources being water sellers (42.9%) and public facilities (31.9%). Finally, traditional toilets were more common in households with members with disabilities than in other households (50.0% vs. 45.3%), but this trend was not statistically significant.

The interviews did however reveal generally poor standards of hygiene (access to drinking water, wastewater systems, accumulation of waste and stagnant water in residential areas). The mother of one young child with disabilities¹⁶ compared her district to a ghetto: "nobody feels comfortable because we live in a slum, or a ghetto, people dump faeces, sometimes there's an accumulation of waste in the sewers which comes out right on our doorstep."

The interviews also raised another issue, that of safety and violence in the districts. Some people interviewed brought up the presence of vagabonds, frequent incidents of theft, rape and murder, and the organisation of demonstrations, all of which cause stress for inhabitants. The mother of a child with epilepsy¹⁷ stated: " it is not safe, [...] young girls are sexually assaulted, if they go to the toilet we have to go with them to avoid sexual assaults

¹⁶ Individual 8: Mother of a child with difficulties communicating and walking, Port-au-Prince.

¹⁷ Individual 6: Mother of a child with epilepsy and suffering from mental retardation, Delmas.

[...] and you can't give a child money to go out and buy something, people will beat them up to get that money".

5.5 Education

According to article 24 of the CRPD, States Parties shall ensure that "persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live". The data on education obtained in the case-control study provides an overview of mainstream education in 2012. The results are presented below firstly for subjects under the age of 16 years, and secondly for adults aged over 16 years.

- **Education for under 16-year olds**

A total of 141 children under the age of 16 years were interviewed in the case-control study.

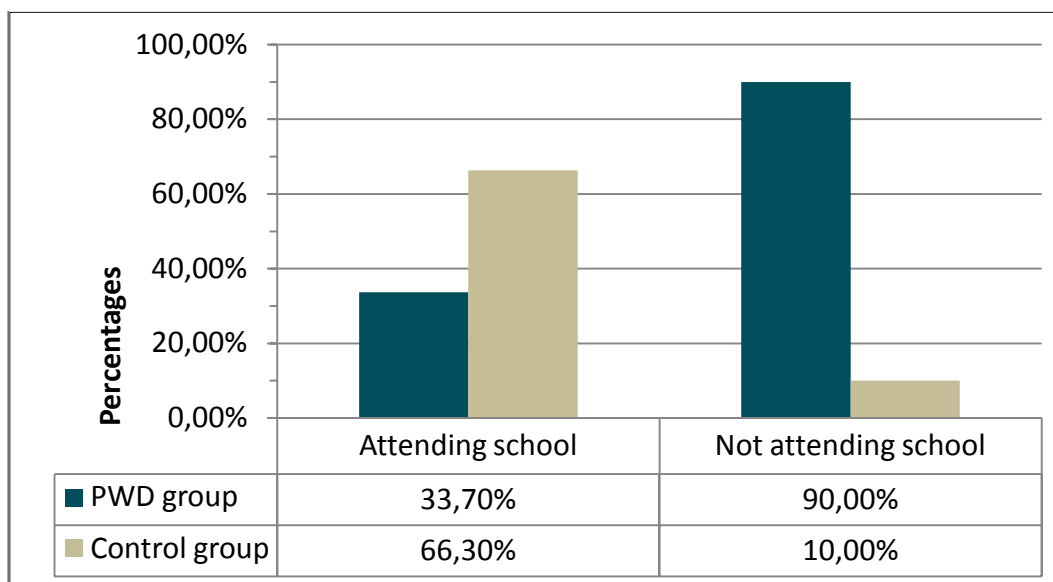
- ✓ **School attendance**

Figure 5 presents the percentages of the children under the age of 16 interviewed, who were in formal education at the time of the survey. Table 15 provides the breakdown of the data on education for these individuals.

In the full sample, 40 individuals (i.e. 28.4% of the full sample) reported that they were not in formal education at the time of the survey. This percentage was significantly higher for people with disabilities, as over half of children with disabilities were not in formal education (51.4%) compared to just 5.6% of children without any functional impairments (Fisher's test, $p < 0.001$).

Analyses were carried out to investigate if there was a relationship between school attendance, gender and age but no significant relationship was found.

Figure 5: Percentage of children in formal education at the time of the survey amongst individuals aged under 16 years in the case-control group (N=141) (chi² test, p<0.001)



✓ **Children in formal education at the time of the survey**

Table 15 shows that whilst 94.4% of children without disabilities attend school, this is the case for just 48.6% of children with disabilities.

Furthermore, the distribution of children in formal education at the time of the survey, according to the level of education is significantly different for children with disabilities and the controls (Fisher's tests, p<0.01). At the same age, children with disabilities are more often enrolled in formal education in the first cycle than their counterparts (79.4% vs. 59.7% respectively). However, this trend is completely reversed in the second cycle (5.9% vs. 16.4% respectively) and the gap widens still further in the third cycle (8.8% vs. 22.4%). Children with disabilities are under-represented at the two higher levels.

Other figures highlight the difficulties experienced by children with disabilities even if the trends observed are not statistically significant. Children with disabilities repeat a school year more often than their classmates (55.9% vs. 36.4%), and miss days of school more often (44.1% vs. 38.8%).

Finally, children with one or more disability, more often reported attending private schools or faith schools than other children (61.2% vs. 50.0% and 19.4% vs. 14.7% respectively).

Table 15: Education data for subjects aged under 16 years questioned during the case-control study (N=141)

Education variables	PWD group		Control group		p*
	Popu- lation	Percentage	Popu- lation	Percentage	
School attendance at the time of the survey					p<0.001*
Yes	34	48.6%	67	94.4%	
No	36	51.4%	4	5.6%	
For children attending school at the time of the survey					
School level at the time of the survey					p=0.009*
None	2	5.9%	1	1.5%	
First cycle	27	79.4%	40	59.7%	
Second cycle	2	5.9%	11	16.4%	
Third cycle	3	8.8%	15	22.4%	
Secondary education	0	0.0%	0	0.0%	p=0.24*
Type of establishment					
Public	5	14.7%	13	19.4%	
Private secular school	17	50.0%	41	61.2%	p=0.06**
Private faith school	12	35.3%	13	19.4%	
Repeating a school year					
Yes	19	55.9%	24	36.4%	p=0.71*
No	15	44.1%	42	63.6%	
Days absence					p=0.71*
None	19	55.9%	41	61.2%	
1 to 3 days	6	17.6%	14	20.9%	
4 to 7 days	5	14.7%	8	11.9%	
Over 8 days	4	11.8%	4	6.0%	
For children not attending school at the time of the survey					
Attendance of an educational establishment in the past					p=0.57*
Yes					
No	14	42.4%	2	66.7%	
	19	57.6%	1	33.3%	

* Fisher's Test, level of statistical significance $p < 0.05$.

** Chi² test, level of statistical significance $p < 0.05$.

✓ Children not in formal education at the time of the survey

Table 15 shows that 28.4% of the children interviewed were not enrolled in formal education at the time of the survey. However, this figure masks some major disparities. Indeed, whilst 5.6% of children without disabilities were not in formal education at the time of the survey, this figure reached 57.6% for children with disabilities.

The two main reasons given concern their disability (37.5% of cases from the full sample) and lack of funds (32.4% of cases from the full sample).

• Education for over 16-year olds

A total of 196 individuals over the age of 16 years were interviewed in the case-control study.

✓ School attendance

Table 16 presents the breakdown of data on education for individuals aged over 16 years old interviewed for the case-control study.

Forty-four individuals in the sample (22.4% of the full sample) reported that they had never attended formal education. This percentage is higher for people with disabilities (24.7% vs. 20.2%) but the difference is not significant.

Furthermore, it would appear that amongst the people who attended school, the people with disabilities most commonly left during the first cycle (20.0% vs. 15.9%) and more rarely reached secondary level (31.3% vs. 39.0%). However, these differences were not found to be significant in the study sample.

Analyses were also carried out to investigate whether there was a relationship between school attendance, gender and age. Whilst no differences were found for gender, school attendance did appear to be related to age category, as elderly people aged 60 years and over were the most likely to report never having attended formal education (chi² test, $p < 0.01$).

Finally, the reason most commonly cited by people who did not attend formal education, was their family's refusal (47.5% of cases in the full sample). Equal second, the lack of funds and the lack of a local school were both cited in 15% of cases.

Table 16: Data on education for subjects aged over 16 years questioned as part of the case-control study (N=196)

Education variables	PWD group		Control group		p*
	Popu- lation	Percentage	Popu- lation	Percentage	
Past school attendance					
Yes	73	75.3%	79	79.8%	p=0.45
No	24	24.7%	20	20.2%	
Highest reported level of schooling					
None	8	10.0%	5	6.1%	p=0.76
First cycle	16	20.0%	13	15.9%	
Second cycle	15	18.8%	16	19.5%	
Third cycle	16	20.0%	16	19.5%	
Secondary education	25	31.3%	32	39.0%	

*Chi² Test, level of significance p< 0.05.

✓ Reading level

Table 17 sets out literacy levels (reading levels) for the people aged over 16 years interviewed during the case-control study.

There is a statistically significant difference in literacy levels between the group of people with disabilities and the control group (chi² test, p<0.01). In the group of people identified with disabilities 22.9% reported not knowing how to read (compared to 87.9% in the control group) and 47% stated that they can read properly (compared to 68.9% of the control group).

Table 17: Reading level among individuals over 16 years old questioned during the case-control study (N=173)

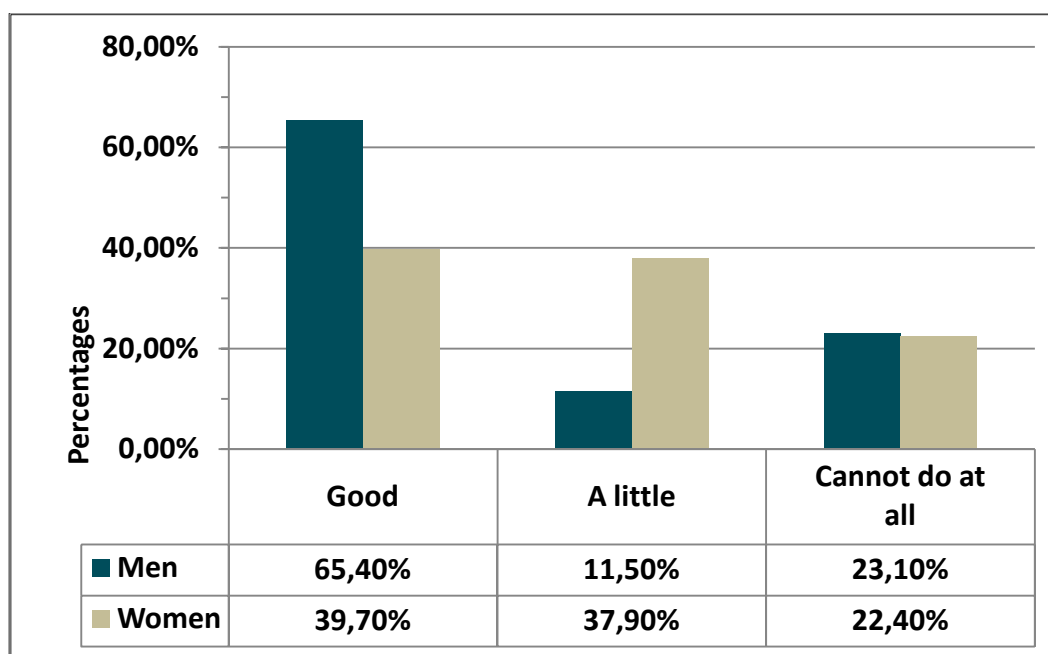
Literacy (reading)	PWD group		Control group		p*
	Population	Percentage	Population	Percentage	
Good	39	47.0%	62	68.9%	p=0.007
A little	25	30.1%	20	22.2%	
Cannot do at all	19	22.9%	8	8.9%	

*Chi² Test, level of significance p< 0.05.

Further analyses were carried out to investigate whether there was a relationship between reading level, gender and age. Gender appeared to be significantly related to reading level across the full sample (chi² test, $p < 0.01$), with more men reporting a good reading level than women. Figure 6 shows that this difference is also significant for people with disabilities (Fisher's test $p < 0.05$).

There is also a relationship between age category and level of literacy across the full sample (chi² test, $p < 0.001$), with elderly people aged 60 years and above reporting more difficulties than other categories in the sample. This trend is also found in the group of people with disabilities, but is not statistically significant.

Figure 6: Reading level for people with disabilities aged over 16 years according to gender (N=83) (significant Fisher's Test, $p < 0.05$)



5.6 Employment

According to article 27 of the CRPS on work and employment States Parties recognize “the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market “. The employment data from the case-control study allows us an overview of the situation in 2012.

A total of 202 children under the age of 16 years were interviewed for this part of the case-control study. The breakdown of this data is provided in table 18.

The distribution according to professional status differs significantly between people with disabilities and controls (chi² test, $p < 0.001$). Only 7.1% of people with disabilities reported their status as a salaried employee, compared to 19.4% of the controls. Furthermore, whilst 48.7% of people reported being unemployed, unemployment is more prevalent amongst people with disabilities (61.6% of people with disabilities compared to 35.9% of their counterparts). The greatest difference is in unemployment due to health reasons as 85.7% of the people who gave this reason for their unemployment were people with disabilities.

In addition, people with disabilities more often reported having no paid work over the last seven days (88.7% vs. 60.2%) (chi² test, $p < 0.001$), and even over the last year (74.5% vs. 51.5%). Amongst the people who had no paid work over the last 7 days, the reason most commonly cited was illness (35.1%). Disability or insufficient skills were only rarely cited.

Table 18: Data on the employment status of people aged over 16 years interviewed in the case-control study (N=202)

Employment variables	PWD group		Control group		p*
	Popula- tion	Percentage	Popula- tion	Percentage	
Socio-professional categories					
Salaried employment	7	7.1%	20	19.4%	p<0.001*
Freelance work	16	16.2%	24	23.3%	
No paid work (students, retired, housewives)	15	15.2%	22	21.4%	
Unemployment (for health reasons)	24	24.2%	4	3.9%	
Unemployment (for reasons other than health)	37	37.4%	33	32.0%	
Has worked in the last 7 days					
Yes	11	11.3%	41	39.8%	p<0.001**
No	86	88.7%	62	60.2%	
Has worked in the last 12 months					
Yes	24	25.5%	49	48.5%	p<0.001**
No	70	74.5%	52	51.5%	

* Fisher's Test, level of statistical significance $p < 0.05$.

** Chi² test, level of statistical significance $p < 0.05$.

5.7 Health

According to article 25 of the CRPD on health, States Parties recognize “that persons with disabilities have the right to the enjoyment of the highest attainable standard of health” and provide health care “with the same range, quality and standard of free or affordable as provided to other persons”. The data on health services and sexual and reproductive health taken from the case-control study provides an overview of the situation in 2012.

A total of 355 individuals answered questions related to health.

• Use of health services

Table 19 presents the data on use of health services by those included in the case-control study. The same percentage of people with disabilities used health services in the last year as in the control group (57.7% and 54.7% respectively). Further analyses were conducted to investigate whether there was a relationship between use of health services, gender and age, but no relationship was found.

However, people with disabilities did report using health services significantly more often (chi² test, $p < 0.01$). Indeed, 59.4% of them had used them three times or more, compared with 34.4% of the controls.

Table 19: Data on the use of health services by the subjects included in the case-control study (N=355)

Health services variables	PWD group		Control group		p*
	Popula- tion	Percentage	Popula- tion	Percentage	
Use of health services over the past year					
Yes	101	57.7%	93	54.7%	p=0.6
No	74	42.3%	77	45.2%	
Number of times used over the past year					
1 or 2 times	41	40.6%	61	65.6%	p=0.002
3 or 4 times	32	31.7%	19	20.4%	
5 times and more	28	27.7%	13	14.0%	
Difficulties encountered in the health services					
Yes	60	45.5%	19	33.3%	p<0.001
No	72	54.5%	38	66.7%	

*Chi² Test, level of significance $p < 0.05$.

- **Difficulties experienced when using health services**

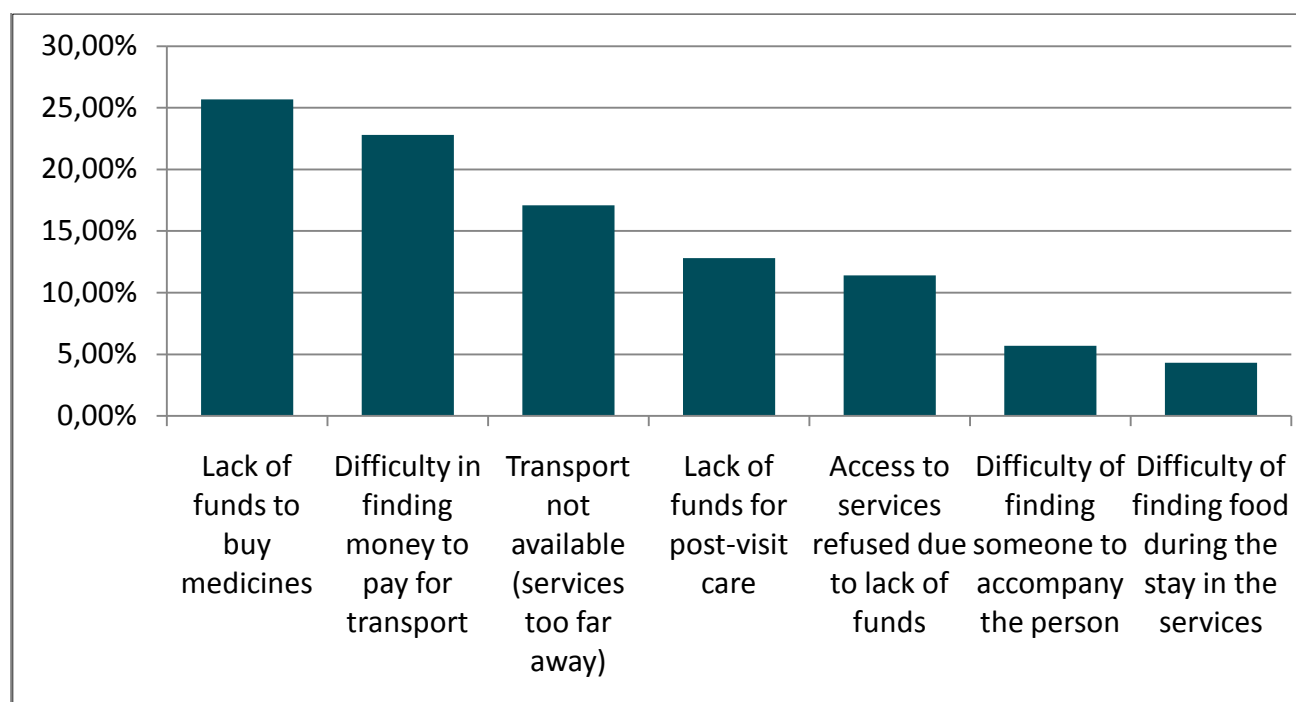
Figure 7 sets out the difficulties most commonly cited during the study. Two main points were raised:

- 1- The financial cost of health care: Lack of funds to purchase medical products (or charms and talismans etc.), lack of funds to pay for post-visit follow-up care, and being refused services due to lack of funds represented 49.9% of responses;
- 2- Transport: Difficulties finding the money to pay for transport and the unavailability of transport represented 39.9% of responses.

The surveys also provided more detailed information on these issues, although the therapeutic pathways were very different for each person with disabilities. Difficulties covering the cost of medical care were often cited (doctor's appointments, medical products, treatment, operations etc.). One elderly person in a disabling situation following a heart attack¹⁸ summarised the situation: "seeing a doctor might be the best solution but if you don't have the money you cannot see them, and if you don't have any money you cannot buy any medicine." Furthermore, all those interviewed had at one time or another been in contact with a representative of the medical profession (for a diagnosis, operation, prescription etc.). However, this contact was sporadic and often difficult ("difficulty getting along with the care provider").

¹⁸ Individual 2: An elderly person with difficulty walking, Pétionville.

Figure 7: The difficulties most frequently encountered while using health services by the individuals in the case-control study



- **Focus on mother and child health**

A series of questions on reproductive health, antenatal care, and the vaccination status for children born during the last five years were asked to women aged 15 to 49 years old. The data obtained is informative but only represents observed trends as the populations concerned are very small.

- ✓ **Sexual and reproductive health**

A total of 69 women answered the questions in this section of the study. Out of the respondents:

- 27 (i.e. 39.1%) have no children and 42 (60.9%) have had children. No significant difference was found between women with disabilities (38.1% of those interviewed) and their controls without disabilities.
- The average number of children was three.
- Eight women reported pregnancies which ended before term. Six of these were women with disabilities.

✓ Antenatal care and birth

A total of 29 women answered the questions in this section of the study. Out of the respondents:

- 26 (92.9%) reported having received antenatal care. No significant difference was found between women with disabilities and their counterparts.
- Most of the women interviewed were followed by a health professional or doctor (88.0% of cases). Only four women reported having appointments with a midwife or traditional birth attendant.
- Nine women had given birth at home, seven in a public-sector hospital, six in a private-sector hospital and finally two in a public health centre and two in a clinic.

✓ Vaccination status of children born in the last five years

A total of 27 mothers answered this question. Out of the respondents: 25 (92.6%) reported that their child had already been vaccinated. The two women who had not had their children vaccinated both had a disability.

6. Dedicated services and assistance for people with disabilities

According to article 19 of the CRPD on living independently and being included in the community States Parties “recognize the equal right of all persons with disabilities to live in the community, with choices equal to others”. During the disability study conducted amongst 178 people with disabilities, data was collected on the need for and use of specialised services.

6.1 Dedicated services

• Awareness of, need for and use of dedicated services

Three issues relating to specialist services were addressed:

- 1- Are people with disabilities aware of existing services?
- 2- Do people with disabilities need these services?
- 3- Have people with disabilities already used these services?

Table 20 sets out the populations and percentages by type of service according to the awareness of, need for and use of the service by people with disabilities.

Generally speaking, there is a downwards trend in positive responses from awareness, to service need and to service use. Over half of the population reported that they were aware of five of the services on offer, all related to the health sector (health services, traditional

healers, health information, specialised health services and functional rehabilitation services). However, only two services had 50% of positive responses concerning need for the service (health services and health information) and none of them were actually used by more than half of the people with disabilities interviewed.

Health services and traditional healers were considered by people with disabilities to be the most accessible, cited by 69.1% and 68.5% of respondents respectively. However, whilst 65.2% of people with disabilities reported needing health services, this percentage decreased to 40.5% for traditional therapies and decreased further to 29.8% for traditional therapies. Health services however remain the most commonly used services (47.2%). The services least commonly cited are professional training and legal advice. Very few people with disabilities are aware that these services exist (24.2% and 16.3% respectively), feel there is a need for these services (15.7% and 11.8% respectively) or have used these services (2.8% and 3.9% respectively).

Further analyses were conducted to investigate whether there was a relationship between awareness of, need for and use of services, and gender or age.

There was a significant relationship between the use of traditional therapies and gender. Women were more likely to use this type of service than men (61.4% vs. 38.6%; χ^2 test, $p < 0.05$).

Age was significantly related to:

- The use of certain services: Health services are significantly more frequently used by young people aged under 18 years and elderly people aged 60 years and above (χ^2 test, $p < 0.05$);
- Reported need: The need for support services for parents and family decreases with age, with the highest level being 86.7% for the youngest participants (χ^2 test, $p < 0.05$);
- And finally, awareness of available services: Awareness of specialist educational services decreases significantly with age, decreases from 58.4% for children to 34.8% for the elderly (χ^2 test, $p < 0.05$).

Table 20: Number and percentages of awareness of, need for and use of services by people with disabilities (N=178)

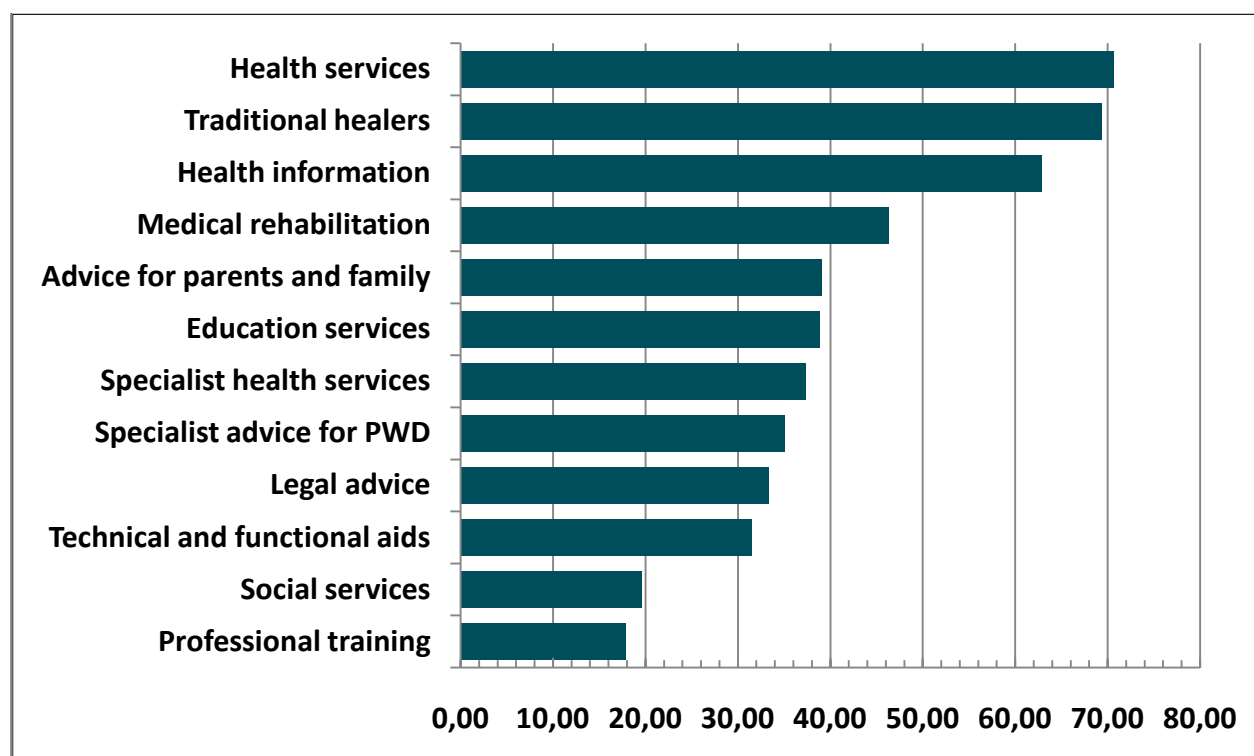
List of services	Awareness		Need		Use	
	Popu- lation	Percen- tage	Population	Percentage	Popula- tion	Percenta- ge
Health services (primary care in clinic, hospital, home visits etc.)	123	69.1%	116	65.2%	84	47.2%
Traditional healers	122	68.5%	72	40.5%	53	29.8%
Information about health (media, clinics, schools, etc.)	104	58.4%	97	54.5%	62	34.8%
Specialised health services	101	56.7%	83	46.9%	33	18.5%
Medical Rehabilitation (physiotherapy, occupational therapy, etc.)	93	52.2%	82	46.1%	39	21.2%
Education services (special schools, early stimulation, etc.)	84	47.9%	72	40.5%	29	16.3%
Specialist advice for PWD (psychologists, social workers, etc.)	84	47.2%	74	41.6%	26	14.6%
Technical and functional aids (sign language interpreters, Braille, etc.)	71	40.1%	54	30.5%	17	9.6%
Social services (financial assistance, etc.)	50	28.1%	46	25.8%	9	5.1%
Advice for parents and family	48	27.0%	46	25.8%	18	10.2%
Professional training (training to develop skills, etc.)	43	24.2%	28	15.7%	5	2.8%
Legal advice	29	16.3%	21	11.8%	7	3.9%

- **Coverage of needs for services**

Figure 8 presents the results of a gap analysis based on the gap between the reported needs for services and the services actually used by people with disabilities, broken down by type of service.

The services with the best coverage and the lowest gap between need and use are those relating to health services: health services, traditional healers and health information have the highest levels of cover with rates of 70.7%, 69.4% and 62.9% respectively. However, the cover rate drops below 50% for the other services, in particular rehabilitation (46.3%). For example, nearly 70% of people met expressed a need for a technical aid but had not yet received one. The percentage of non-coverage reaches 80% for social and legal services.

Figure 8: Relationship between the reported need and the services used by people with disabilities, by type of service



- **Difficulties met when using specialist services**

The reasons most commonly cited by people with disabilities for the non-coverage of their needs, for all the services considered, were:

- The high cost of services: 49.0% of those who expressed the need to see a medical specialist think this service is too expensive. The financial implications were also

cited in 38.1% of cases for medical rehabilitation, 36.6% for educational services and 36.1% for technical aids.

- The lack of information on where to find these services: 65.0% of people who felt the need for professional training but whose need was not covered, reported that they did not know where to find this type of service. This finding was the same for social services (54.3% of cases).

All the barriers to use cited for each service are set out in table 21.

Table 21: Reasons most frequently given by people with disabilities to explain the lack of coverage of the need reported

Reported barriers	Too expensive N (%)	Where? N (%)	Availability N (%)	Distance N (%)	Communication N (%)	Discrimination N (%)	Does not know N (%)
Medical rehabilitation	16 (38.1%)	16 (38.1%)	2 (4.8%)	2 (4.8%)	-	1 (2.4%)	5 (11.9%)
Technical aids	13 (36.1%)	16 (44.4%)	4 (11.1%)	1 (2.8%)	-	-	2 (5.6%)
Educational services	15 (36.6%)	17 (41.5%)	3 (7.3%)	1 (2.4%)	1 (2.4%)	-	4 (9.8%)
Professional training	4 (20.0%)	13 (65.0%)	1 (5.0%)	-	1 (5.0%)	-	1 (5.0%)
Advice for PWD	16 (33.3%)	21 (43.8%)	4 (8.3%)	-	-	1 (2.1%)	6 (12.5%)
Advice for parents	6 (22.2%)	12 (44.4%)	4 (14.8%)	-	2 (7.4%)	-	3 (11.1%)
Social services	8 (22.9%)	19 (54.3%)	4 (11.4%)	-	-	-	4 (11.4%)
Health services	9 (30.0%)	8 (26.7%)	5 (16.7%)	3 (10.0%)	-	-	5 (16.7%)
Information on health	4 (12.1%)	13 (39.4%)	9 (27.3%)	1 (3.0%)	2 (6.1%)	-	4 (12.1%)
Traditional healers	3 (14.3%)	5 (23.8%)	5 (23.8%)	2 (9.5%)	1 (4.8%)	-	5 (23.8%)
Legal advice	4 (28.6%)	3 (21.4%)	3 (21.4%)	-	-	1 (7.1%)	3 (21.4%)
Specialised health services	25 (49.0%)	11 (21.6%)	7 (13.7%)	2 (3.9%)	-	-	6 (11.8%)

6.2 Awareness of, need for and use of technical aids

According to article 26 of the CRPD on habilitation and rehabilitation, States Parties “shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation”. During the disability study comprised of 178 people with disabilities, data on awareness of, the need for and use of technical aids was collected.

The questions covered three types of disability: Seeing, hearing and walking. Generally speaking, the percentages of respondents who reported never having needed a technical aid in order to see, hear or walk better, were high. The data obtained is informative but only represents observed trends as the populations concerned were very small.

- **Sight**

For the people with disabilities interviewed, the technical aids most commonly used to improve their vision were glasses (16.1%). Glasses were most commonly provided by the private sector (44.1%), followed by state-run services (26.5%). Furthermore, 22.5% of respondents reported needing glasses but not using them at the time of the survey.

People are generally unaware of the existence of other aids (magnifying lenses, contact lenses etc.).

- **Hearing**

Very few of the people with disabilities used technical aids to improve hearing (less than 5% of cases). However, 19.7% of people with disabilities reported needing, but at the time of the survey did not have, a hearing aid and 10.4% a sign language interpreter.

- **Mobility**

For the people with disabilities interviewed, the technical aids most commonly used to improve their mobility were wheelchairs (6.9%) and walking sticks (5.7%). The former were mainly provided by state-run services and non-governmental organisations, the latter by the person with disabilities’ friends or family. In total 9.7% of respondents reported needing a wheelchair or walking stick.

Respondents are generally unaware of the existence of other aids (walking frames, etc.).

7. Informal services

The interviews revealed the importance of two types of support, in addition to those proposed by the State, NGOs or other associations.

7.1 Family

The respondents answers to the interview questions revealed the immediate family to be the main source of support. Members of the family (parents, partners, children) provide the different types of help needed by the person with disabilities to ensure their independence: they provide care by helping with personal tasks (washing, dressing) and domestic tasks (cooking, housework, fetching water, shopping); financial support by providing food and shelter; and even provide specialist care when they stimulate or distract the person with disabilities to keep them alert.

However, this dedication is not without constraints or consequences; one concept that was repeatedly brought up by the friends and family interviewed was that of duty. A woman is tied to her husband by the bonds of marriage, for better and for worse ("that means that we are married, we said yes, and we agreed to be together. It means you should be ready to accept everything in the bad times, like you do in the good times and I cannot expect help from a member of the family, because I am the one he's married," the wife of a man with multiple disabilities)¹⁹; and bound to her child by blood ("because she is my flesh and blood I do not feel disheartened with her," the mother of a child with multiple disabilities)²⁰. However, as detailed above, the time devoted to the person with disabilities makes it difficult for the carers to work and stops them from contributing to the household's income.

7.2 Faith

Repeated references were made throughout the interviews to faith and to God/the Good Lord/The everlasting Lord. The interview guide contained a section on spirituality but all the respondents spontaneously referred to religious concepts. God features as a key provider of support for an individual in their daily life: he comforts, strengthens and even heals. A man, suffering from a visual impairment²¹ said "the person who takes the most care of me is the Good Lord, followed by my wife and my sons." This hope can constitute a barrier and foster a passive attitude, but above all, it constitutes a means for escaping a reality that is sometimes too harsh and their flagrant lack of resources.

¹⁹ Individual 2: An elderly person with difficulty walking, Pétionville.

²⁰ Individual 5: Mother of a child suffering from paralysis and mental retardation, Delmas.

²¹ Individual 14: Adult man with visual impairment, Port-au-Prince.

However, it would be simplistic to limit this protective higher force to a single religious dimension and not mention the possible influences of voodoo, although all of the people interviewed reported being Christians (with a majority of Catholics, reflecting national statistics²²). Haiti is an important platform for ritualistic practices (Clormeus, 2012) that have officially fallen into disuse today (the few direct allusions to voodoo are clearly negative: one woman²³ declared "I do not know how I got through with voodoo. With voodoo, I was a vagabond."). However, they certainly remain very real in people's imaginations (two individuals ascribed their ills to a bad spell or to the jealousy of those around them. In this light, the many forms of worship/ thanks/requests for grace and the fervour of prayer are imbued with renewed power. We will not enter into an overly-simplified description of the influences of voodoo, which is characterised by a complex cosmology, a combination of Christian elements and ancient African and Arawak beliefs (Metraux, 1958; Hurbon, 2005). Nevertheless, it is relevant here to acknowledge the existence of supernatural spirits (lwas and others) who have a great influence on the body and the origins of a handicap (a punishment, a fright, etc.). Disability is never simply the result of an accident or a genetic anomaly... Numerous authors have highlighted the fact that this close "relationship" with the spirits was intended to obtain their mercy and was therefore generated by fear, rather than by respect. This fear may explain the ardour poured into prayer and the emphasis placed on a higher force (Poizat, 2008; Vonarx, 2012).

8. Stigma and prejudice

The people with disabilities interviewed reported that the attitudes of others at home, at school and at work limited their involvement in activities that were important to them. They also reported suffering prejudice more frequently than the controls.

It was not possible to go into further detail regarding this stigma and discrimination in the quantitative study. However, these issues were raised during the interviews. The respondents' answers enabled us to analyse the register of the expressible. This made it possible to analyse individuals' reactions to disability, in terms of behaviour, attitudes or prejudice against people with disabilities.

People with disabilities can be defined as a stigmatised group, in the sense that something (here a physical difference or character difference) disqualifies them and prevents them from being fully accepted by society (Goffman, 1975). Three types of reaction in the community were revealed, reactions which people with disabilities report as repeat attacks in the form of:

²² Data from the '*Institut Haïtien de Statistique et d'Informatique*', http://www.ihsi.ht/rqph_resultat_ensemble_population.htm

²³ Individual 16: elderly woman with difficulties walking, Pétionville.

- **Verbal attacks:** people state their difference in relation to the disability and the person with the disability. People "say strange things", they "mock", they "make ironic comments", about people with disabilities. Other terms are also used: "gosso modo", "gros nanm" etc. As Goffman pointed out (1975), "on seeing an imperfection, we are inclined to imagine a whole series": people with disability are also mendicants (beggars) or massissi (homosexuals). An elderly man suffering from a sight impairment²⁴ immediately said: "Of course, you know that in Haiti, when you are disabled, you are humiliated [...] they think you are no better than a dog."
- **Avoiding contact:** people keep their distance to avoid contamination. Such representations are generated through a complex socio-historic process of construction (Stiker, 1982) which will not be considered in depth here, but this particular reaction can be explained by the popular belief that a "spirit" (or lwa) who has been offended (for various reasons, such as an incorrectly completed ritual) resides in the body of the person with disabilities and can move from one body to another through simple contact (Poizat, 2008). A mother of a child with disabilities ²⁵ said: "I went to the hospital with the child, they gave me a wheelchair, when I had to take a tap tap with the child on the journey, no one wanted to give me a hand ... everyone was afraid to touch him."
- **Ignoring:** the person with disabilities becomes transparent, they no longer exist in their own right, become worthless in the eyes of other people. As one blind man said: "If you are disabled, you become invisible... people pretend they can't see you"²⁶.

These attitudes, associated with the restrictions that result from their disabilities, impact people with disabilities' well-being and ability to go about their daily life. It is, however, difficult to assess the impact attitudes have on people with disabilities self-image from the data available. This negative behaviour contributes to the persistence of discrimination in all the areas of activity studied in this project: education, employment, health, or even within the family circle.

²⁴ Individual 30: elderly man with difficulty seeing, Carrefour.

²⁵ Individual 8: mother of a child with difficulties with communication and walking, Port-au-Prince.

²⁶ Individual 24: blind adult man, Port-au-Prince.

III. MAIN RESULTS AND DISCUSSION

1.	Methodology: from theory to practice	p. 70
1.1	The sampling frame: out-of-date data	p. 70
1.2	Sampling plan: logistics and safety constraints	p. 70
2.	The study population and extrapolation of prevalence	p. 71
3.	The tool used to measure disability: the Washington Group short set of questions	p. 72
4.	Strengths	p. 73
5.	Prevalence and comparison with other studies	p. 74
5.1	Review of the results from other studies	p. 74
5.2	Haitian studies	p. 75
5.3	Caribbean studies	p. 76
5.4	Other national and international studies	p. 76
6.	The causes of disabilities	p. 77
7.	The situation of people with disabilities in 2012, compared with other data	p. 78
7.1	Participation of people with disabilities	p. 78
7.2	Living conditions at household level	p. 78
7.3	The economic impact of people with disabilities on households	p. 79
7.4	Education	p. 80
7.5	Employment	p. 81
7.6	Health	p. 82
7.7	Needs and specific support	p. 82
7.8	Informal services	p. 84
8.	Stigma and discrimination	p. 85

1. Methodology: from theory to practice

1.1 The sampling frame: out-of-date data

The 2003 national census in Haiti, was used as the sampling frame in order to select clusters with probability proportionate to the population size. This data was obtained from the IHSI (*Institut Haïtien de Statistique et d'Informatique*).

However, as this data is more than ten years old, adjustments were made to take into account the demographic changes which have occurred since. The adjustments are only estimates and the demographic weighting of certain geographical areas may have been over- or under-estimated.

It is also important to note that since 2003, some districts have changed. During the data collection phase, some intervention segments had to be modified. For example, Pétionville was a mainly residential area in 2003 but by 2012 had become a business district. It was therefore necessary to carry out a second round of segment selection.

1.2 Sampling plan: logistics and safety constraints

The initial sampling plan had to be modified at the data collection stage, mainly for logistics and safety reasons.

- **Study location**

The original plan was to conduct the study in Leogane, which was the epicentre of the 2010 earthquake, where 70% of houses were damaged or destroyed (Office for the Coordination of Humanitarian Affairs, 2011). However, working in this area would have implied overcoming serious logistical difficulties and it was therefore decided to conduct the study in Port-au-Prince.

- **Clusters selection**

The sampling frame was the 2003 National Housing and Population Census of Haiti. Sixty clusters were randomly selected using probability proportionate to size. Some administrative areas “section communales” areas were considered to be unsafe (e.g. high crime rates) for the survey teams and were therefore excluded from the sampling frame prior to the selection of clusters. These areas included one in the commune of Carrefour (9ème Bizoton), three in the commune of Delmas (1ère Varreux, 2ème Varreux and 5ème Saint Martin) and one in the commune of Port-au-Prince (8ème Martissant). The Cite Soleil district located within two of the three section communales in Delmas was also excluded due to security considerations. Areas excluded were likely to have been poorer and included those people displaced by the earthquake. Had they been included in the survey, the prevalence of disability may have been higher (CRD and FHAIPH, 2009).

After consultation with Handicap International's teams the decision was made to exclude the areas with the highest crime rates or where the interviewers might be put at risk. For example, the Cite Soleil district was not selected despite the fact that a lot of people with disabilities, particularly physical disabilities, live in this area in a plain region (CRD and FHAIPH, 2009).

Furthermore, once the study started, access to some areas and security conditions within them seriously hindered data collection in certain clusters, some of which had to be abandoned or replaced. For example, in two clusters interviewers had to leave the area urgently due to threats to their safety.

The zones excluded on the basis of security criteria were also mainly the poorest areas, home to the most vulnerable populations. It was therefore important to strike a balance between the teams' safety and the accuracy of the scientific approach.

- **The exclusion of displaced populations living in camps**

Almost 1.5 million people were left homeless in the wake of the 2010 earthquake and were accommodated in organised or makeshift displaced persons camps. One year later, 810,000 people were still living in 1,150 camps (Office for the Coordination of Humanitarian Affairs, 2011).

At the time of the study an estimated 15% of the population were living in these camps. The initial sampling plan intended to recruit 15% of the sample from these camps. However, for security reasons it was not possible to operate in these areas, despite the fact that they are home to the most vulnerable populations, worst affected by the earthquake.

- **The exclusion of institutions for children**

The sampling was based on the demographic data from the census. The clusters were selected according to population size, and the segments were selected at random. The sampling plan used did not include any provision for recruitment in institutions for children (such as orphanages) or specialised institutions (psychiatric or other).

2. The study population and extrapolation of prevalence

Ultimately the study sample was not representative of the general population in Port-au-Prince as it was extremely difficult to include the most vulnerable populations due to logistical and security reasons. Had these areas been included in the survey, the prevalence of disability may have been higher. It was also decided to exclude children aged 0 - 4 years from the study for methodological reasons, because the tool used to measure disability (the Washington Group Short set) is not adapted to this age group. Working groups have been set up to work on these issues and progress is being made but at the time of the survey no consensus had been reached on a tool fit for purpose. The study population was therefore

made up of people aged 5 years and over, who had survived the 2010 earthquake, distributed across the Port-au-Prince, Pétionville, Carrefour, Delmas and Tabarre districts, accessible to the teams of interviewers. Finally, this study was conducted in an urban setting. However, the 2003 census estimated the prevalence of disability at 1.5% of which 65% of the people with disabilities identified were located in rural areas.

The statistics presented herein cannot therefore be extrapolated to the whole of Port-au-Prince nor the whole of the country but provide initial data on disability in Haiti following the earthquake.

3. The tool used to measure disability: the Washington Group short set of questions

It is often difficult to collect statistical data on disability due to its multi-dimensional nature (physical impairment, functional disability, restricted participation). The Washington approach takes into account this complexity and is based on the international classification of functioning. It emphasises the concepts of activity limitation and restricted participation (by means of six types of disabilities).

The set of six questions is often used in national censuses to measure disability in the general population. The main advantage of this tool is that it standardises the approach and makes it possible to make international comparisons (Loeb, 2012).

Furthermore, the scaled responses allow respondents to express the perceived severity of their disability. This made it possible to establish several different prevalence scenarios. For the purposes of this study we opted for an intermediate definition of disability as used in studies in Zimbabwe (Eide et al., 2003) and Zambia (Eide and Loeb, 2006). The prevalence of disability, estimated at 4.1% (CI: 3.4% - 4.7%) includes people reporting some difficulty in at least two functional domains or a lot of difficulty or cannot do at all in at least one functional domain. If the inclusion criteria limits the definition of disability to people reporting a lot of difficulty in at least one functional domain, prevalence drops to 2.2%; and again to 0.5% if only people reporting total incapacity are retained. However, if all people reporting some difficulty in at least one functional domain are included, prevalence reaches 17.8%. The prevalence therefore depends on the definition used. Another prevalence scenario is also proposed in this study, but at household level as 15.9% of the households visited included one member with a disability.

However, using this set of questions means very careful consideration has to be taken with:

- Training the interviewers to ensure they grasp the subtleties of the questionnaire and can explain to respondents how it works and thus guarantee the validity of the answers given;

- Translating the questions into the local language, which should be work on carefully to be sure the concepts are correctly conveyed.

Furthermore, as with all tools, it also has its limitations:

- As previously mentioned, it is not adapted to use with children under the age of 5 years;
- It covers several functional domains (physical, sensory etc.) but neglects psychological functions for example;
- The estimations of prevalence are based on the participants reported answers, their reported disabilities are not confirmed or infirmed with a clinical evaluation.

Finally, other weaknesses were revealed over the course of our population-based survey:

- The boundaries between levels of severity were sometimes unclear for the people interviewed notably the difference between no/some difficulty and some/a lot of difficulty. This means the prevalence of intermediate disabilities might be under-estimated.
- A disabling situation is the result of an interaction between personal factors, an environment, and lifestyles and is therefore unique to each individual. However, the Washington Group questions were answered by the head of the household on behalf of each member of the household. This approach was used because it was impossible to directly interview all members of the household visited. However, the people with disabilities identified were then interviewed for the case-control study which meant their disability could be confirmed.

4. Strengths

This research provided a unique opportunity to understand and assess the magnitude of disability and service needs among those surveyed residing in permanent household structures in the sixty randomly selected areas of Port-au-Prince that withstood the 2010 Haitian earthquake.

To date, there have been limited to no studies or baseline data identified in Haiti focusing on assessing both the magnitude of disability using the Washington Group Short Set of questions and the service needs among peoples with disabilities. Neither have there been any studies assessing the situation of people with disabilities compared to those without a disability.

This study enabled an estimation of the prevalence of disability among the surveyed households and information on the types and causes of disability, and the proportion that could be attributed to the earthquake in the surveyed areas of Port-au-Prince. Although the interpretation of these findings to the whole country and Port-au-Prince more generally is

limited due to previously discussed limitations, the strengths of this study are discussed in turn.

The study population in this study is representative of the population structure of Haiti with respect to age and sex. The development of the survey instruments was based on internationally used data collection instruments e.g. SINTEF and the use of the Washington Group Short Set of questions on Disability used widely in national censuses to assess disability prevalence. The use of the Washington Group Short Set of questions to assess disability enabled the estimation of disability based on different thresholds.

Survey instruments were translated and pilot tested in-country and extensive training of data collectors was undertaken for one week on both the survey methodology and data collection instruments. Data collection forms were checked rigourously and double entered into Access databases and compared using Epi-Info and corrected for any errors. The study used population based cases and controls to improve the generalisability of results. For the nested case control study, persons with a disability (cases) were age and sex matched to persons without a disability (controls) with 1:1 matching, one case matched to one control. This matching was undertaken to account for confounding with respect to age and sex. This matching allowed for tight control of confounding effects.

5. Prevalence and comparison with other studies

5.1 Review of the results from other studies

The prevalence of disability was estimated by this study at individual level at 4.1% (CI 95%: 3.7-4.8). This prevalence is higher for women than for men (4.8% vs. 3.1% respectively), and increases with age (23.8% in the elderly, 2.7% in adults, and 2.4% in children aged under 18 years old). The prevalence of disability decreases with the level of severity. The most common impairments found in the study sample were minor difficulties seeing and concentrating, with a prevalence of 5.8% and 5.5% respectively, followed by difficulty walking, (5.0%), and finally, difficulty hearing, with self-care and communicating (1.4%, 0.8% and 0.8% respectively). The prevalence of total incapacity is situated around 0.0 and 0.3%, difficulties walking being the most commonly cited at 0.3%.

At household level, 15.9% (CI 95%: 13.2-18.7) of households visited had a member with disabilities. The highest number of households with a member with disabilities were found in Pétionville (22.9%), followed by Tabarre (17.3%), Carrefour (15.2%), Port-au-Prince (13.0%), and Delmas (4.0%).

The low prevalence of disability identified in this study is a reflection of the low level of life expectancy in the country which is on average is 62 years and the high level of mortality. The population of the country is young in structure and the distribution of disability identified in our sample follows the general trend of increasing levels of disability with increasing age.

Older people are more likely to have co-morbidities and particular health conditions are more prevalent in older age groups. Particular health conditions are more prevalent in women, for example, blindness due to higher incidence rates coupled with women being less likely to access health services.

5.2 Haitian studies

Several studies were carried out prior to the earthquake which already indicated a wide variation in prevalence, ranging from 1.5% to 10.4%. In 1998, the first estimation of the prevalence of disability was 7% (MSPP, 1998). In 2001, a study of living conditions was carried out at national level amongst 7,000 households (IHSI, 2003). Out of the 32,877 individuals, 10.4% reported a long-term illness, accident or disability. Women were more affected than men (11.9% vs. 8.5%), and this prevalence increased with age. In 2003, the Haiti national census included one question on disability. The estimated prevalence at this time was 1.5% (126,000 individuals). Sight impairments were the most commonly reported (glaucoma, cataracts, corneal infection or retinopathy resulting from diabetes) (IHSI, 2003). Finally, in 2003, Handicap International and the RANIPH (*Réseau Associatif National pour l'Intégration des Personnes Handicapées*) identified 800,000 people with disabilities in Haïti, i.e. 10% of the disabled population, with a distribution of impairments as follows: 43% learning difficulties, 25% with motor impairments, 9% with sight impairments, 9% with hearing impairments, 6% untreated epileptics, 1% with leprosy and 1% with strange behaviour (MAST and SEIPH, 2009).

Data post-2010 is much harder to come by. Phillips (2011) reported an increase in the number of people with disabilities. The large number of amputations should be taken into consideration when examining this trend (Redmond et al., 2011; Knowlton et al., 2011). As well as physical injuries, cases of post-traumatic stress disorder and psychosis were also reported as being on the increase (Phillips, 2011). However, no studies were able to assess whether there was any excess mortality of people with disabilities before and after the earthquake which would have counterbalanced the onset of new disabilities.

The prevalence presented in this study falls within the boundaries of estimated prevalence from previous studies. Furthermore, this comparison confirms that women and the elderly are among the most vulnerable groups.

5.3 Caribbean studies

In 2008 the United Nations Economic Commission for Latin America and the Caribbean published a study which drew together all the data from national censuses carried out in the 2000s in 15 countries in the region (ECLAC, 2008). Disability is described as not only an impairment but an incapacity which limits daily activity. In total, 340,636 people reported a disability, giving a regional prevalence of 5.6%, with the lowest prevalence found in Barbados (4.0%) and Trinidad and Tobago (4.1%) and the highest prevalence in Jamaica and the Netherlands Antilles (6.3% and 8.5%). In all the countries considered, women and people aged over 60 years were more likely to report a disability. The comparison with the data from 2012 shows that the prevalence reported in this study is one of the lower estimates and confirms the trends observed for gender and age.

5.4 Other national and international studies

On a global scale, the percentage of households with a member with disabilities is around 20 - 25% (Mont, 2007) and the prevalence of disability was estimated by the WHO in 2010 at 15% of the world's population (WHO and World Bank, 2011). In high-income countries, prevalence was also generally higher than 10%, often reaching up to 20% (Mont, 2007).

In this context, the estimated prevalence found in this study may seem low. However, these studies cannot be considered as equivalent. Indeed, as the Washington Group illustrated, the definition of disability varies from one study to another and little progress has been made in attempts to define precise, consensual inclusion criteria. The selection of a social or medical model and the range of impairments included are just some examples of areas where discrepancies are found. In addition; Moreover, the data collection methods used and the recurrent lack of sampling frame make it difficult to compare studies. Metts (2000) does not hold back from qualifying many of these estimations at national, regional and international level as "speculation" given the lack of an initial disability database, and considers that prevalence is more likely to be around 4% in developing countries and 7% in high-income countries.

Differences in prevalence of a similar magnitude have been found in other studies and there are several explanations for this. Access to health care services, notably for antenatal care, could play a role in widening this gap (INSERM, 2004). In developed countries, significant levels of resources are devoted to saving children with severe disabilities, helping them survive and providing them with care. In developing countries, these types of services are extremely difficult to access. The infant mortality rate in the first year of life is 87.1 per 1,000 births in Haiti, but is just 8.0 per 1,000 births in the United States²⁷. Furthermore, the prevalence of disability increases with age, but life expectancy is lower in developing

²⁷ United Nations Development Programme, <http://hdrstats.undp.org/en/countries/profiles/HTI.html>

countries. In Haiti, average life expectancy in 2011 was estimated at 62.1 years compared to 78.5 years in the United States, for example²⁸.

Furthermore, in the specific context of Port-au-Prince, studies have shown that the 2010 earthquake and also the ensuing cholera epidemic have had a particularly hard impact on the most vulnerable (elderly and/or disabled people) (Handicap International, 2011).

Whilst the number of deaths is still an estimate, at least 220,000 died on the day of the earthquake and almost 6,000 people died due to the cholera outbreak. Managing the burials was a feat in itself but recording the exact extent of loss of human life with information on gender, age or disability was simply impossible. A posteriori, this survey could have included a set of questions designed to collect information on this issue (Did any members of the household die in the earthquake? Did they have disabilities?).

6. The causes of disabilities

The two most frequently reported reasons for disability in this study were birth or congenital anomalies (23.5%) and non-communicable disease (19.0%). This distribution follows the trends observed in other studies, genetic diseases mainly being reported by young people and non-communicable diseases (chronic diseases such as diabetes) being more common amongst older people (Schmid et al., 2003). Non-communicable diseases represent the second cause of death at a national level after maternal and perinatal complications (53% and 22% respectively)²⁹ but are one of the main causes of disability in the general population.

The earthquake came in third position in our study cited as causing 13.4% of cases. More women reported disabilities caused by the earthquake than men (79.2% vs. 56.2%) with a higher reported level of severity. Many theories have been put forward to explain this gender differentiation. The most common reason given was the time the earthquake hit, at the end of the afternoon.

²⁸ United Nations Development Programme, <http://hdr.undp.org/en/data/profiles/>

²⁹ World Health Organization, http://www.who.int/nmh/countries/hti_en.pdf

7. The situation of people with disabilities in 2012, compared with other data

7.1 Participation of people with disabilities

The case-control study conducted as part of this study revealed that people with disabilities reported daily activity limitations significantly more often than the controls. This was true in all the areas of activity considered (school and employment and home life had the highest scores in terms of limitations) and systematically and significantly more frequently met with difficulties in their direct environment. Transport and health services were the two most frequently cited areas, and the attitudes of people, information support were the sectors where the largest gaps were identified.

The results are presented in relation to various articles of the CRPD. This discussion will follow the same pattern.

7.2 Living conditions at household level

The economic context and living conditions for Haitians were already difficult prior to the earthquake. In 2006, a multidimensional poverty index, based on household deprivation in the areas of education, health and living conditions, indicated that 56.4% of the Haitian population lived in multidimensional poverty and 54.9% of the population subsisted on less than 1.25 dollars a day (UNPD, 2011). A study assessing the living conditions of people with disabilities in Haiti, carried out in 2009 by the FHAIPH, (CRD and FHAIPH 2009), showed that before the earthquake, people with disabilities' living conditions were difficult, from obtaining clothing through to accessing sanitary systems. The 2010 earthquake accentuated the structural problems in the country, such as poverty, a low development index, limited access to education, health and basic needs³⁰.

The living conditions of most of the general population in Port-au-Prince significantly deteriorated and can be qualified as poor. The living conditions of people with disabilities and their families and friends remain even more difficult. This study showed, for example, differences in hygiene and sanitation indicators. The people with disabilities interviewed more often reported that their natural and physical environments frequently limited their daily activities.

The interviews also raised another issue: that of safety and violence in the districts. Women and children are the most vulnerable groups (Pierre et al., 2010). Women are more often victims of violence (physical or sexual) and may subsequently develop the symptoms of

³⁰ UNOCHA (United-Nations Office for the Coordination of Humanitarian Affairs, <http://www.unocha.org/issues-in-depth/haiti-one-year-later>

post-traumatic stress disorder, depression, anxiety and sleep disorders. The children who live with this chronic insecurity, aggravated by violence experienced at school or at home, may experience developmental lag, social difficulties, affective disorders, behavioural problems and learning difficulties.

7.3 The economic impact of people with disabilities on households

A comparison of the composition of households including a person with disabilities and those without, shows that the former are more frequently have a female head of household, have more members than the others, and, in particular, include more children under the age of 16 years and elderly people. The over-representation of these two age categories has direct repercussions on the households' average economic dependency ratio which shows that the economic burden on the active members of the household is higher in households with a member with disabilities. The survey on living conditions carried out in Haiti in 2001 (IHSI, 2003) showed that the incidence of poverty increased with the economic dependency ratio.

These results are obtained through the calculation of the socio-economic index which shows the households in which at least one member has disabilities are more often amongst the poorest households in the study sample. In an already saturated employment market, in a country where the unemployment rate is as high as 35% of the labour force (BIT, 2010), the time that a family member devotes to income generating activities is sometimes limited, because the person with disabilities requires constant support. The situation is all the more difficult in households where the person with a disability is a child and requires intensive, continuous care. This study found households with children with disabilities to be the most vulnerable. The situation is even more critical for single mothers. The direct family (parents or siblings) therefore constitute a safety net, but they are not always themselves in a position to help.

However, the opposite can also be true. Although young people or the elderly do not directly contribute to the household's income, they do not always constitute a burden. An older relative can, for example, join a household to look after a child with a disability, and thus free up the other members to work.

Out of all the households visited, 51.6% had female heads of households. A recent study showed that 47% of families in Haiti were single parent families with a female head of household, who had an average of six children, with different fathers who had abandoned them so as to avoid their financial responsibility to the family. In April 2012, the Haitian Senate voted unanimously in favour of a law on paternal responsibility and parent-child relationships (Haiti Libre, 2012).

7.4 Education

- **Observed results**

Out of all the children aged between 5 and 16 years old, 71.6% were attending school and 28.4% were not. However, these percentages conceal major disparities between children with disabilities and their counterparts. At the same age, 94.4% of the controls were attending school whereas only 48.6% of children with disabilities were enrolled in school at the time of the survey. Additionally, children with disabilities seemed to have more learning difficulties, so that at the same age, there are more children with disabilities attending school in the first cycle but their attendance is rare at higher levels. They also more frequently reported having to repeat a school year. Children with disabilities also more often reported a need for personal help in school. In total, 28.4% of children included were not attending school at the time of the survey. At the same age, 5.6% of children without disabilities were not attending school at the time of the survey, this figure reached 51.4% for children with disabilities. The main reasons stated were the child's disability and the lack of funds in the household to cover school fees.

Across all adults over 16 years old, 22.4% reported never having been to school, mainly due to the refusal of the family, a lack of money or a lack of educational infrastructure in the area. People with disabilities represented 54.5% of this group. Among those who had attended school, at the same age, people with disabilities reported having stopped attending school earlier than the controls (as from the first cycle). Finally, the study has highlighted the fact that the reading level differed significantly between the people with disabilities and the control group: 22.9% of people with disabilities reported not knowing how to read (vs. 8.9% of people in the control group) and less than half (47.0%) thought they could read well (vs. 68.9% of people in the control group). Women appear to be worse affected than men.

- **Comparison with other data**

The observed trends (lower school attendance, shorter duration of schooling, higher levels of illiteracy, etc.) are confirmed by other studies in the region (ECLAC, 2011). The statistics are however far higher than the available data. Education in Haiti is renowned as a sector in which there are numerous challenges still to be met. Indicators for the general population are generally low, according to the latest data from the UNDP, the crude rate for school attendance is 27.0%³¹, only 20% of children continue their education through elementary to secondary school. Almost 92.0% of schools are private which makes it difficult for the poorest sections of the population to access education (CCMU, 2006). General data on adults indicated that 72% of the population only attended school to primary level and the

³¹ United Nations Development Programme, <http://hdrstats.undp.org/en/countries/profiles/HTI.html>

literacy rate for Haitians has not exceeded 48.7%³², for over 15 years, with gender disparities.

The data is even more alarming when considering the situation of children with disabilities. In 1998, a study carried out by the Ministry of National Education's Commission on Educational Adaptation and Social Support found that, out of the 120,000 young people of school age with disabilities, only 2,019 had access to education (1.7%). This figure rose to 3.5% in 2008, but remained very low in comparison with the rate of school attendance for children without disabilities (74%) (MAST and SEIPH, 2009) The same study showed that there was very little provision for special education (adapted infrastructure, trained teachers etc.)

The differences in findings may come from the sampling methods, because as already explained, neither the camps nor the institutions were included. Furthermore, this data is presented at national scale, which includes urban and rural areas. However, this study was carried out exclusively in urban areas.

7.5 Employment

Major discrepancies were found between people with disabilities and the controls. Indeed, 48.7% of the full sample reported that they were unemployed: 61.6% of people with disabilities reported being unemployed compared to 35.9% of their counterparts. This lack of employment was due to health, and had lasted for 7 days for 88.7% of the people with disabilities who reported being unemployed, and for a year for 74.5% of them. Only 7.1% of people with disabilities reported being salaried employees, compared to 19.4% of the controls.

The general unemployment figures found were above the national unemployment figures (41%)³³, but this trend seems logical in the wake of the 2010 earthquake. Numerous people lost their jobs (temporary or permanent) following the earthquake (total or partial destruction of the place of work, equipment, stock etc.).

At the same time, people with disabilities are particularly prone to unemployment and this trend has also been found in other studies carried out in other developing countries by Handicap International (Trani and Bakhshi, 2006; Mounier et al., 2010; Pilleron and Brus, 2012). The unemployment figures given here are lower than those presented in the study carried out in 2009 by the FHAIPH (CRD and FHAIPH, 2009) (around 90%). There is very little recent data available on employment of people with a disability.

³² United Nations Development Programme, <http://hdrstats.undp.org/en/countries/profiles/HTI.html>

³³ United Nations Development Programme, <http://hdrstats.undp.org/en/countries/profiles/HTI.html>

7.6 Health

This study found that as many people with disabilities had used health services over the past year as people from the control group (57.7% and 54.7% respectively), but also that they had done so more frequently: 59.4% of them had used them 3 times or more, compared with 34.4% of the controls.

However, people with disabilities had significantly more difficulties when using these services notably the financial cost: lack of funds to purchase medical products (or charms and talismans etc.), lack of funds to pay for post-visit follow-up care, and being refused services due to lack of funds represented 49.9% of responses; and transport: difficulties finding the money to pay for transport and the unavailability of transport represented 39.9% of responses. The qualitative interviews also revealed difficulties related to the attitudes of health professionals.

Difficulties with financial access to care are a general problem. A study conducted by Médecins Sans Frontières in 2005, found that nearly half the families in rural areas paid for health care using short-term strategies, such as selling their assets. The study highlighted the fact that these strategies were more frequently used by the poorest families (MSF, 2005). At the same time, people with disabilities are more affected by these issues, not least due to their repeat visits to health centres.

The World Report on Disability (WHO and World Bank, 2011), has already identified the main barriers to accessing health services which include the difficulties reported by the people with disabilities interviewed for this study. The same issues are raised in other studies carried out in other developing countries. A survey was conducted, for example in seven countries in West Africa in 2010 (Pilleron and Brus, 2012). Significantly, people with disabilities reported difficulties in the same domains (paying for health services and for medicines; accessing the health centre, getting around within the health service).

7.7 Needs and specific support

- **Dedicated Services**

The study of people with disabilities found that whilst they are aware of the existence of dedicated services, the level of use of these services was nevertheless, relatively low. Over half of the people with disabilities were aware of five services offered, all in the health sector (health services, traditional healers, information on health, specialised health services and functional rehabilitation services), but only two services scored over 50% for need (health services and information on health) and neither of them was found to have been used by more than half of the people with disabilities interviewed. The best-known

services were health services and traditional healers; at the other end of the spectrum the least cited services were professional training and legal advice.

Similar studies have been carried out in developing countries on the African continent and have revealed similar trends (Eide et al., 2003; Loeb and Eide, 2003, 2004; Eide and Loeb, 2006). In Mozambique for example, health services and traditional healers were commonly used, while professional training and technical aids had the lowest level of coverage (Eide and Kamaleri, 2009).

In that study, the services with the best coverage (i.e. with the smallest gap between need and use) were those linked to health: health services, traditional healers, and information on health have the highest percentages of coverage with 70.7%, 69.4% and 62.9% respectively. On the other hand, coverage falls below 50% for other services, notably for medical rehabilitation (46.3%) For example, nearly 70% of people interviewed expressed a need for a technical aid but had not yet received one. The figure rose to more than 80% non-coverage for social and legal services.

A study carried out by the International Centre for Evidence in Disability (ICED) and the NGO CBM on the rehabilitation response to the 2010 earthquake shows that some of the people that visited rehabilitation centres had a disability which was not caused by the earthquake, which highlights the need in this specific sector for the whole of the population with disabilities in Port-au-Prince (Tataryn and Blanchet, 2012).

Finally, two major barriers to the use of these different services were raised: the excessively high cost of the services, but also the lack of information on the geographical location of the services and consequently how to access and sign up for or be referred to these services.

- **Technical and functional aids**

Nearly 70% of people met expressed a need for a technical aid but had not yet received one. This may explain the small number of respondents in the section of the study on technical and functional aids. Few people reported having access to technical aids. The best-known and most frequently used were glasses, wheelchairs and walking sticks. Special devices such as hearing aids, Braille or walking frames were rarely mentioned. The same trend was apparent in the study by Schmid et al. (2008), carried out in four other countries in the Caribbean.

The provision of technical aids also differed according to the type of device: glasses were mainly supplied by the private sector, wheelchairs by state-run services (excluding the Health Ministry), and walking sticks by family and friends.

7.8 Informal services

The interviews shed light on the importance of two types of support, outside those proposed by the State, by NGOs or by other associations.

- **The family:** The respondents answers to the interview questions revealed the immediate family to be the main source of support and providers of the different types of aid needed by people with disabilities to ensure their independence, (personal and social support, financial aid, etc.). However, this dedication is not without constraints or consequences: the extent of obligation was expressed in what those concerned said and as detailed above, the time devoted to the person with disabilities makes it difficult for the carers to work and inhibits them from contributing to the household's income.
- **Faith:** God features as a key provider of support for an individual in their daily life: he comforts, strengthens and even heals. This hope constitutes a means for escaping a reality that is sometimes too harsh and their flagrant lack of resources. The possible influences of voodoo should not be ignored. This is characterised by a complex cosmology, and combines Christian elements and ancient African and Arawak beliefs (Métraux, 1958), which see disability as a "punishment" from offended spirits (Poizat, 2008).

8. Stigma and discrimination

The people with disabilities interviewed said that the attitudes of others at home, at school and at work limited their involvement in activities that were important to them. They also reported suffering prejudice more frequently than the controls. The responses of people with disabilities and their friends and family interviewed as part of the qualitative study were used to study the reactions of individuals in the community towards people with disabilities, in terms of behaviour and attitudes or prejudice towards people with disabilities. Three types of reaction in the community were revealed, reactions which people with disabilities report as being repeat occurrences: verbal attacks, intended to better set themselves apart; avoiding contact, to avoid contamination; and ignoring their existence.

This negative behaviour contributes to the persistence of discrimination within all the domains of activities studied in this project: education, employment, health, or even within one's own family circle.

In the area of employment, for example, Pean (2011) highlights that even today all people with disabilities are grouped under the reductive label of invalid, and are therefore considered incapable of work. Begging is, therefore, the only accepted means of earning acknowledged by the community. Often people with disabilities themselves are also convinced others are right in this regard. As regards rehabilitation the family's participation is essential. Sometimes, the parents themselves constitute a barrier to the diagnosis and treatment of a child because they attribute the behaviour of their child to idiocy or to a curse. Hence, the magic, religious and supernatural causes of disability remain very present to some people (Poizat, 2008; WHO and PAHO, 2010).

IV. RECOMMENDATIONS

- 1. Recommendations for politicians (local and national) p. 88**
 - 1.1 Inform and raise the awareness of all the people p. 88
 - 1.2 Continue with physical and financial accessibility initiatives p. 88
 - 1.3 Inform and support people with disabilities p. 88
 - 1.4 Build capacity and support professionals p. 89
 - 1.5 Have reliable data on disabilities p. 89

- 2. Recommendations for organisations that represent people with disabilities (with the support of NGOs, if necessary) p. 89**
 - 2.1 Support and advise the government p. 89
 - 2.2 Inform and raise the awareness of all the people p. 89
 - 2.3 Support people with disabilities and their families and friends p. 90
 - 2.4 Do advocacy work p. 90

- 3. Recommendations for service managers (including NGOs) p. 90**
 - 3.1 Adapt provision p. 90
 - 3.2 Facilitate access p. 90
 - 3.3 Build capacity and support professionals p. 91
 - 3.4 Promote and support the economic inclusion of people with disabilities p. 91
 - 3.5 Respect the national agenda p. 91

The recommendations made here are based on the results of this study but are also the result of a participatory workshop held in Port-au-Prince by Handicap International and the BSEIPH (Office of the State Secretary for the Inclusion of Disabled People) on 24 January 2013.

Representatives of state services (the Institute for Social Wellbeing and Research (IBESR), the Ministry for Social Affairs and Employment (MAST), the Bioethics Committee, the Ministry of Education), a range of disabled people's organisations, international organisations and other non-governmental organisations were therefore able to make their different contributions and give the proposals presented a more practical and operational slant.

At this participatory workshop, discussions focused on five areas for action, each of which is linked to an article of the International Convention on the Rights of Persons with Disabilities and the Law on the Integration of Disabled People in Haiti: healthcare and rehabilitation, education, work and employment, a set standard of living, and protection, the family and disability. Using the 'ambassador' facilitation technique meant the five work areas could be worked on simultaneously. Five groups were formed, comprised of people from different professional backgrounds. Five people were appointed as 'ambassadors' at the same time. Each ambassador was responsible for an area and was tasked with leading the discussion about their theme with each group and was therefore able to add to the recommendations on this area. The recommendations were grouped into three categories based on stakeholder type: politicians (national and local), organisations that represent people with disabilities and NGOs and service managers. Each participant then highlighted the recommendations that they felt to be most relevant leading to an initial ranking of priority recommendations.

The recommendations made therefore reflect the proposals put forward by the workshop participants. Some of the recommendations made match areas already contained in the Law on the Integration of People with Disabilities and initiatives launched by the BSEIPH which are currently underway.

Moreover, in this study, people with disabilities were considered as a whole and as a heterogeneous group, combining different types of disabilities, levels of severity, genders and ages. This means that the recommendations mirror this approach. It is understood that the needs of the population are not uniform or standardised and this diversity needs to be taken into account when devising and implementing adapted and effective actions. Potential activities could be implementing according to the target population, the type of impairment, the level of severity and even the target area or sector. Particular attention was paid to the three groups that appeared to be most vulnerable over the course of the study: women, children and the elderly.

1. Recommendations for politicians (local and national)

The enactment of the Law on the Integration of People with Disabilities in 2012 gave a fresh boost to programmes and activities for people with disabilities. Numerous initiatives have been launched in accordance with a national agenda: adapting labour law, setting up a National Solidarity Fund for the Integration of Disabled People with the aim of “guaranteeing their right to protection against poverty and social exclusion”, creating support centres for people with disabilities in the districts and Disabled People’s Departmental Centres are all projects currently underway.

The recommendations proposed at the participatory workshop for politicians are as follows.

1.1 Inform and raise the awareness of all the people

- Continue developing information and awareness raising campaigns in order to improve perceptions of disability and combat certain prejudices about people with disabilities (with sessions in schools, religious communities and professional organisations, for example).
- Make laws and decrees accessible to ensure they are understood and applied by the relevant stakeholders (notably with regard to accessibility).

1.2 Continue with physical and financial accessibility initiatives

- Incorporate disability into building standards and improve the accessibility of new buildings, public spaces (roads and pavements) and emergency shelters.
- Facilitate access to public transport for people with disabilities.
- Increase the financial accessibility of people with disabilities to services:
 - by improving access to the Social Security (the CAS).
 - by creating a free health insurance card.

1.3 Inform and support people with disabilities

- Set up a reception, information and referral service for people with disabilities (referral to the education system, follow-up and coordination of the therapeutic pathway, for example) and schemes to help people with disabilities find employment.
- Facilitate the provision of adapted equipment by the specialised departments (abolish customs duties on this type of equipment, promote research on the production of adapted equipment using local components, stock some rehabilitation equipment and components in the PROMESS (Programme on Essential Medicine and Supplies) store...).

- Facilitate provision in existing refuges and care units for disabled women and children who are victims of violence.

1.4 Build capacity and support professionals

- Promote the emergence of disabled people's services professionals (including rehabilitation professionals, translators, sign language and Braille teachers).
- Incorporate modules on disabilities into training for professionals working in the fields of healthcare, education, professional training and for all training courses for reconstruction professionals (architects and engineers) in order to encourage optimal service provision for people with disabilities.

1.5 Have reliable data on disabilities

- Promote sector-specific studies (education, health care and employment) of the most targeted groups in order to have reliable information about the situation of people with disabilities.

2. Recommendations for organisations that represent people with disabilities (with the support of NGOs, if necessary)

2.1 Support and advise the government

- Provide the government with expert advice in order to ensure that the needs of people with disabilities are better incorporated into the country's development process.

2.2 Inform and raise the awareness of all the people

- Develop information and awareness raising campaigns targeting:
 - The community as a whole supporting inclusive initiatives run by associations, for example, in order to improve perceptions of disability and combat certain prejudices.
 - The friends and family of people with disabilities (children or adults) in order to debunk the myths about disabilities, change their attitudes and avoid rejection or neglect.
 - People with disabilities themselves, to improve their understanding of their rights and potential.
 - Professionals in the fields of education, employment, health care, training, justice, protection and law enforcement in order to give advice and enhance the understanding of disabilities and improve provision for people with disabilities.

- Create forums for discussion, exchanging good practices and providing support for teachers and other professionals who may work with people with disabilities.

2.3 Support people with disabilities and their families and friends

- Set up places offering inclusive leisure activities and social activities that are open to all, free and accessible at district level, which would help to foster the social life and combat the isolation of people with disabilities.
- Support the friends and families of people with disabilities:
 - Offer training to relatives and friends in order to share technical expertise so as to improve disabled people's quality of life.
 - Create discussion forums via associations, workshops and discussion groups in order to give friends and family the chance to discuss their everyday lives, share good practices, realise that they are not alone and draw on their peers' experience.

2.4 Do advocacy work

- Do advocacy work in order to strengthen certain health care sectors: rehabilitation, mental health, psychiatry, geriatrics and gerontology.

3. Recommendations for service managers (including NGOs)

3.1 Adapt provision

- Develop service provision for people with disabilities. For example:
 - Provide home care services.
 - Set up inclusive convalescent homes.
- Create support services for families, for example by providing a day-care system for children, particularly for single women.

3.2 Facilitate access

- Develop infrastructure and transport accessibility and access to information:
 - Through building design.
 - By developing inclusive and specialised transport.
 - By developing sign language and Braille schools.
- Create a dedicated service in order to offer improved information, support and monitoring to people with disabilities undergoing therapy.

3.3 Build capacity and support professionals

- Strengthen or create jobs in the disability sector:
 - Support the emergence of a physiotherapy school.
 - Continue training orthopaedic technicians.
- Create forums in which professionals (from the health, education and professional training sectors) can listen to each other and exchange good practices.

3.4 Promote and support the economic inclusion of people with disabilities

- Develop the economic inclusion of people with disabilities
 - By raising awareness about the economic potential of people with disabilities.
 - By creating professional training schemes that are adapted to, and match needs in, the labour market.
 - By developing support and training on loans and entrepreneurship.
 - By developing employment access schemes.

3.5 Respect the national agenda

- Coordinate the activities proposed by the NGOs with the agenda of government initiatives

APPENDICES

1. Bibliography	p. 93
2. Detailed recommendations (in French)	p. 97
3. Profiles of people interviewed in Port-au-Prince in 2012 during the qualitative phase (in French)	p. 109
4. Questionnaires	p. 112

1. BIBLIOGRAPHY

Barnes, C. (2011). **Understanding disability and the importance of design for all**. Journal of accessibility and design for all, 1(1): 55-80.

BIT (Bureau International du Travail) (2010). **La promotion du travail décent dans la reconstruction et le développement d'Haïti après le tremblement de terre de 2010**. Genève, BIT (Bureau International du Travail) : 160 pages.

CCMU (Caribbean Country Management Unit) and Latin America and the Caribbean Region (2006). **Social Resilience and State Fragility in Haiti: A Country Social Analysis**. World Bank: 116 pages.

CDC (Centers for diseases control) and NCHS (National Center for Health Statistics) (2010). **Census Questions on Disability Endorsed by the Washington Group**. Atlanta, CDC/National Center for Health Statistics.

Clormeus, L. A. (2012). **La démonstration durkheimienne de Jean Price-Mars : faire du vodou haïtien une religion**. Archives de sciences sociales des religions 3(n°159) : 153-170.

CRD (Centre de Recherche pour le Développement) et FHAIPH (Fédération Haïtienne des Associations et Institutions des Personnes Handicapées d'Haïti) (2009). **Étude sur les Conditions de Vie des Personnes Handicapées en Haïti**. Port-au-Prince, Haïti, Fédération Haïtienne des Associations et Institutions des Personnes Handicapées d'Haïti (FHAIPH) : 89 pages.

ECLAC (Commission Économique pour l'Amérique Latine et les Caraïbes) (2011). **Availability, collection and use of data on disability in the Caribbean subregion**. United Nations: 45 pages.

Eide, A. H. and Kamaleri Y. (2009). **Living conditions among people with disabilities in Mozambique: a national representative study**. Oslo, Norway, SINTEF: 99 pages.

Eide, A. H. and Loeb M. E. (2006). **Living conditions among people with activity limitations in Zambia. A national representative survey**. Oslo, Norway, SINTEF: 178 pages.

Eide, A. H., et al. (2003). **Living conditions among people with activity limitations in Zimbabwe. A representative regional survey**. Oslo, Norway, SINTEF: 132 pages.

Eide, A. H., et al. (2003). **Living conditions among people with activity limitations in Namibia. A representative, National survey.** Oslo, Norway, SINTEF: 123 pages.

Goffman, E. (1975). **Stigmate. Les usages sociaux des handicaps.** Paris, Les éditions de Minuit.

Haïti Libre (2012). **La loi sur la Paternité responsable enfin votée.**

Handicap International (2011). **18 mois d'action en Haïti.** France, Handicap International : 22 pages.

Hurbon, L. (2005). **Le statut du Vaudou et l'histoire de l'Anthropologie.** Gradhiva, 1: 153-163.

IHSI (Institut Haïtien de Statistique et d'Informatique) (2003). **Enquête sur les conditions de vie en Haïti.** Haïti, FAFO, PNUD.

IHSI (Institut Haïtien de Statistique et d'Informatique) (2003). **Recensement Général de la Population et de l'Habitat (RGPH).**

INSERM (Institut National de la Santé et de la Recherche Médicale) (2004). **Déficiences et handicap d'origine périnatale.** 245 pages.

International Centre for Eye Health (2007). **Rapid assessment of avoidable blindness (RAAB) - software and tools,** International Centre for Eye Health.

Kirkwood, B. R. (1988). **Essentials of Medical Statistics.** Oxford, Blackwell Science.

Knowlton, L. M., et al. (2011). **Consensus statements regarding the multidisciplinary care of limb amputation patients in disasters or humanitarian emergencies: Report of the 2011 humanitarian action summit surgical working group on amputations following disasters or conflict.** Prehospital and Disaster Medicine, 26(6).

Loeb, M. E. (2012). **A White Paper on Disability Measurement.** Disability and International Development, 1: 4-11.

Loeb, M. E. and Eide A. H. (2004). **Living conditions among people with activity limitations in Malawi. A representative study.** Oslo, Norway, SINTEF: 179 pages.

MAST (Ministère des Affaires Sociales et du Travail) et SEIPH (Secrétairerie d'État à l'Intégration des Personnes Handicapées) (2009). **Politique Nationale du Handicap, Les grandes Orientations**. Haïti, Presses Nationales d'Haïti : 216 pages.

Métraux, A. (1958). **Le Vaudou Haïtien**. Paris, Gallimard.

Metts, R. L. (2000). **Disability issues, trends and recommendations for the World Bank**. World Bank: 97 pages.

Milligan, P., et al. (2004). **Comparison of two cluster sampling methods for health surveys in developing countries**. International Journal of Epidemiology, 33(3): 469 -476.

Mont, D. (2007). **Measuring disability prevalence**. SP Discussion Paper, World Bank, n°0706: 54 pages.

Mounier, E. (2010). **People with disabilities in the suburban areas of Maputo and Matola: Social representation of disability, Socio-economic situation, Access to health and social services, Local stakeholders system**. Handicap International, RAVIM (Réseau d'Assistance aux Victimes de Mines): 192 pages.

MSF (Médecins Sans Frontières) (2005). **Les soins de santé de base hors de portée pour la population rurale d'Haïti : exclusion et appauvrissement des vulnérables**. Bruxelles.

MSPP (Ministre de la Santé Publique et de la Population) (1998). **Analyse de la Situation Sanitaire, Haïti 1998**. Port-au-Prince, Haïti, OPS (Organisation Panaméricaine de la Santé) OMS (Organisation Mondiale de la Santé).

Olivier de Sardan, J.-P. (2009). **La rigueur du qualitatif : Les contraintes empiriques de l'interprétation socio-anthropologique**. Belgique, Academia Bruylant.

OMS (Organisation Mondiale de la Santé) et OPS (Organisation Panaméricaine de la Santé) (2010). **Culture et santé mentale en Haïti : une revue de littérature**. Genève, OMS : 27 pages.

Pean, M. A. (2011). **Haïti: un modèle d'exclusion, un échantillon de lutte pour l'inclusion des Personnes Handicapées dans le Tiers Monde**. Intervention à la Commission des Affaires Sociales et de l'Environnement du Parlement Européen.

Phillips, C. (2011). **Aller vers le "cocobai" : la reconstruction et les personnes handicapées en Haïti**. Cahier de politique. FOCAL, Agence canadienne de développement international : 14 pages.

Pierre, A., et al. (2010). **Culture et santé mentale en Haïti : une revue de littérature.** Santé mentale au Québec, 35(1): 13.

Pilleron, S. and A. Brus (2012). **Access to services for people with disabilities in 7 West African countries.** Handicap International: 52 pages.

Poizat, D. (2008). **Le Vaudou, la déficience, la chute.** Reliance, 29(9-17).

Ravaud, J.-F., et al. (2002). **Les méthodes de délimitation de la population handicapée : l'approche de l'enquête de l'Insee Vie quotidienne et santé.** Population, 57 : 541-565.

Redmond, A. D., et al. (2011). **A Qualitative and Quantitative Study of the surgical and Rehabilitation Response to the Earthquake in Haiti, January 2010.** Prehospital and Disaster Medicine, 26(6): 1-8.

Schmid, K., et al. (2008). **Disability in the Caribbean. A study of four countries: a socio-demographic analysis of the disabled.** Studies and Perspectives, ECLAC (United Nations): 71 pages.

Schulze, M. (2010). **Understanding the UN Convention on the Rights of Persons With Disabilities.** France, Handicap International: 211 pages.

Shakespeare, T. and Watson N. (2002). **The social model of disability: an outdated ideology?** Research in Social Science and Disability, 2: 9-28.

Stiker, H.-J. (1982). **Corps infirmes et sociétés.** Paris, Auvier-Montaigne.

Tataryn, M. and Blanchet K. (2012). **Evaluation of Post-Earthquake Physical Rehabilitation Response in Haiti, 2010 - a systems analysis.** ICED (International Centre for Evidence in Disability), CBM: 24 pages.

Trani, J.-F. and Bakhshi P. (2006). **Understanding vulnerability of Afghans with disability: livelihoods, employment, income: National Disability Survey in Afghanistan 2005.** Handicap International: 105 pages.

UNDP (United Nations Development Programme) (2011). **Human Development Report 2011.**

Vonarx, N. (2012). **Le Vodou haïtien. Entre médecine, magie et religion.** Rennes, Presses Universitaires de Rennes.

WHO (World Health Organization) and Word Bank (2011). **World report on disability.** WHO, Word Bank: 360 pages.

2. DETAILED RECOMMENDATIONS (in French)

1- Recommandations générales, transversales	Les populations cibles	Les porteurs
L'attitude des proches à la maison et des personnes à l'école ou au travail était ressentie comme un frein à la pleine participation sociale par les personnes handicapées		
<ul style="list-style-type: none"> Des campagnes d'information et de sensibilisation sur le handicap menées auprès de la communauté permettraient d'améliorer l'image du handicap et lutter contre certains préjugés. Ces campagnes pourraient prendre plusieurs formes et s'appuyer sur divers supports : <ul style="list-style-type: none"> - Proposer des séances de sensibilisation dans les écoles, utilisant des moyens de communication participatifs (danses, musique, forums, théâtre, séances de contes,...), - Soutenir le tissu associatif dans les domaines artistiques qui proposent des activités inclusives, montrant une image positive et capable, - Approcher les communautés religieuses et les utiliser comme vecteurs d'un message positif, - Utiliser les médias (au niveau national, départemental et communal) pour valoriser les compétences et potentiels des personnes handicapées comme l'émission radio proposée par le SEIPH. 	Communauté	Société civile / OPH ONG Gouvernement
Les problèmes liés à l'accessibilité ont été régulièrement évoqués, dans tous les lieux de la vie quotidienne (logements privés, bâtiments publics, établissements scolaires, services de santé). L'accessibilité recouvrait ici deux dimensions principales : la circulation dans les bâtiments, et le déplacement entre les lieux de vie		
<ul style="list-style-type: none"> Faire du plaidoyer pour intégrer une dimension inclusive dans le Plan d'action pour le relèvement et le développement national d'Haïti et pour améliorer l'accessibilité des nouveaux bâtiments et des espaces publics (rues, trottoirs,...). 	Gouvernement	Société civile / OPH ONG
<ul style="list-style-type: none"> Faciliter l'accès aux transports en commun (physique et financier) (voir LIPH, art. 29 et 31). 	Personnes handicapées (tous genres, âges, incapacités)	Gouvernement

<ul style="list-style-type: none"> • Adapter les abris d'urgence et les sanitaires. • Définir des normes et des outils de vulgarisation. 	Personnes handicapées (tous genres, âges, incapacités) Personnes handicapées (tous genres, âges, incapacités)	Gouvernement Société civile / OPH Gouvernement
Les personnes handicapées rencontrées avaient peu d'informations sur les services spécifiques, et reconnaissaient ne pas savoir où s'adresser pour avoir des renseignements		
<ul style="list-style-type: none"> • Recenser et diffuser les services spécifiques et les diffuser. • Mettre en place de structures permettant d'accueillir, informer et diriger les personnes handicapées vers les services adaptés (voir la LIPH, art. 22). 	Personnes handicapées (tous genres, âges, incapacités) Personnes handicapées (tous genres, âges, incapacités)	Société civile / OPH Gouvernement Gouvernement
2- Recommandations centrées sur la personne handicapée et la famille	La population cible	Les porteurs
Un des éléments marquants de cette étude est l'absence de référence par les personnes handicapées à leurs droits et libertés et leur méconnaissance de l'existence de services spécifiques		
<ul style="list-style-type: none"> • Proposer des séances d'information et de sensibilisation, voire de coaching, auprès des personnes handicapées elles-mêmes, qui leur permettraient de prendre conscience de leurs droits, mais également de leurs capacités, leur redonnant ainsi confiance. 	Personnes handicapées (tous genres, âges, incapacités)	Société civile / OPH ONG
Les personnes handicapées rencontrées lors de l'entretien qualitatif ont exprimé leur gratitude pour l'espace de discussion inespéré ouvert lors des entretiens		
<ul style="list-style-type: none"> • Mettre en place des lieux d'échanges et de loisirs, ouverts à tous, gratuits et accessibles, à l'échelle des quartiers, qui permettraient de créer une dynamique de vie sociale et de lutter contre l'isolement des personnes handicapées. 	Personnes handicapées (notamment les seniors)	Société civile / OPH ONG
Les familles sont apparues comme un des piliers de soutien majeur dans la prise en charge des personnes handicapées		
<ul style="list-style-type: none"> • Proposer des séances de sensibilisation aux proches et familles de personnes handicapées 	Proches et familles de	Société civile / OPH

(enfants ou adultes) pour démystifier le handicap, faire évoluer l'attitude des proches et éviter des réactions de rejet ou des négligences.	personnes handicapées	ONG
<ul style="list-style-type: none"> Proposer des formations aux parents et proches afin de partager des gestes techniques qui permettraient d'améliorer la qualité de vie de la personne handicapée au quotidien et d'impliquer positivement les proches dans la prise en charge. 	Proches et familles de personnes handicapées	Société civile / OPH ONG
Si les familles sont apparues comme le principal soutien financier des personnes handicapées, cette aide n'était pas sans conséquence sur l'équilibre économique du foyer		
<ul style="list-style-type: none"> Proposer des pensions spéciales pour les proches de personnes handicapées, notamment avec des handicaps lourds, pour améliorer les conditions de vie du foyer. 	Proches directs des personnes handicapées (parent, conjoint)	Gouvernement
<ul style="list-style-type: none"> Renforcer l'accès des personnes handicapées à la CAS (Caisse d'Assistance Sociale), ce qui permettrait aux personnes handicapées d'apporter des revenus dans le foyer. 	Personnes handicapées (tous genres, âges, incapacités)	Gouvernement
La prise en charge d'une personne handicapée au sein de la cellule familiale pouvait également avoir un impact sur les proches		
<ul style="list-style-type: none"> Créer des espaces d'échanges, à travers des associations, des ateliers ou des causeries pour donner l'occasion aux proches d'échanger sur leur quotidien, partager des bonnes pratiques, réaliser qu'ils ne sont pas seuls et s'appuyer sur l'expérience de pairs. 	Les proches directs de personnes handicapées	Société civile / OPH ONG
Le temps dévolu à la prise en charge d'un enfant handicapé éloignait les parents du marché du travail (notamment dans le cas des foyers monoparentaux)		
<ul style="list-style-type: none"> Créer un système de garderie pour les enfants, afin que les femmes célibataires puissent avoir des activités génératrices de revenus. 	Les parents d'enfants handicapés ; Focus sur les mères célibataires	Société civile / OPH ONG Gouvernement
3- Recommandations centrées sur la personne handicapée et la famille	La population cible	Les porteurs
Un des éléments marquants de cette étude est l'absence de référence par les personnes handicapées à leurs droits et libertés, et leur méconnaissance de l'existence de services spécifiques		
<ul style="list-style-type: none"> Proposer des séances d'information et de sensibilisation, voire de coaching, auprès des 	Personnes handicapées	Société civile / OPH

personnes handicapées elles-mêmes, qui leur permettraient de prendre conscience de leurs droits, mais également de leurs capacités, leur redonnant ainsi confiance.	(tous genres, âges, incapacités)	ONG
Les personnes handicapées rencontrées lors de l'entretien qualitatif ont exprimé leur gratitude pour l'espace de discussion inespéré ouvert lors des entretiens		
<ul style="list-style-type: none"> Mettre en place des lieux d'échanges et de loisirs, ouverts à tous, gratuits et accessibles, à l'échelle des quartiers, qui permettraient de créer une dynamique de vie sociale et de lutter contre l'isolement des personnes handicapées. 	Personnes handicapées (notamment les seniors)	Société civile / OPH ONG
Les familles sont apparues comme un des piliers de soutien majeur dans la prise en charge des personnes handicapées		
<ul style="list-style-type: none"> Proposer des séances de sensibilisation aux proches et familles de personnes handicapées (enfants ou adultes) pour démystifier le handicap, faire évoluer l'attitude des proches et éviter des réactions de rejet ou des négligences. 	Proches et familles de personnes handicapées	Société civile / OPH ONG
<ul style="list-style-type: none"> Proposer des formations aux parents et proches afin de partager des gestes techniques qui permettraient d'améliorer la qualité de vie de la personne handicapée au quotidien et d'impliquer positivement les proches dans la prise en charge. 	Proches et familles de personnes handicapées	Société civile / OPH ONG
Si les familles sont apparues comme le principal soutien financier des personnes handicapées, cette aide n'était pas sans conséquence sur l'équilibre économique du foyer		
<ul style="list-style-type: none"> Proposer des pensions spéciales pour les proches de personnes handicapées, notamment avec des handicaps lourds, pour améliorer les conditions de vie du foyer. 	Proches directs des personnes handicapées (parent, conjoint)	Gouvernement
<ul style="list-style-type: none"> Renforcer l'accès des personnes handicapées à la CAS (Caisse d'Assistance Sociale), ce qui permettrait aux personnes handicapées d'apporter des revenus dans le foyer. 	Personnes handicapées (tous genres, âges, incapacités)	Gouvernement
La prise en charge d'une personne handicapée au sein de la cellule familiale pouvait également avoir un impact sur les proches		
<ul style="list-style-type: none"> Créer des espaces d'échanges, à travers des associations, des ateliers ou des causeries pour donner l'occasion aux proches d'échanger sur leur quotidien, partager des bonnes pratiques, réaliser qu'ils ne sont pas seuls et s'appuyer sur 	Les proches directs de personnes handicapées	Société civile / OPH ONG

l'expérience de pairs.		
Le temps dévolu à la prise en charge d'un enfant handicapé éloignait les parents du marché du travail (notamment dans le cas des foyers monoparentaux)		
<ul style="list-style-type: none"> Créer un système de garderie pour les enfants, afin que les femmes célibataires puissent avoir des activités génératrices de revenus. 	Les parents d'enfants handicapés ; Focus sur les mères célibataires	Société civile / OPH ONG Gouvernement
4- Recommandations centrées sur la personne handicapée et la famille	La population cible	Les porteurs
Un des éléments marquants de cette étude est l'absence de référence par les personnes handicapées à leurs droits et libertés, et leur méconnaissance de l'existence de services spécifiques		
<ul style="list-style-type: none"> Proposer des séances d'information et de sensibilisation, voire de coaching, auprès des personnes handicapées elles-mêmes, qui leur permettraient de prendre conscience de leurs droits, mais également de leurs capacités, leur redonnant ainsi confiance. 	Personnes handicapées (tous genres, âges, incapacités)	Société civile / OPH ONG
Les personnes handicapées rencontrées lors de l'entretien qualitatif ont exprimé leur gratitude pour l'espace de discussion inespéré ouvert lors des entretiens		
<ul style="list-style-type: none"> Mettre en place des lieux d'échanges et de loisirs, ouverts à tous, gratuits et accessibles, à l'échelle des quartiers, qui permettraient de créer une dynamique de vie sociale et de lutter contre l'isolement des personnes handicapées. 	Personnes handicapées (notamment les seniors)	Société civile / OPH ONG
Les familles sont apparues comme un des piliers de soutien majeur dans la prise en charge des personnes handicapées		
<ul style="list-style-type: none"> Proposer des séances de sensibilisation aux proches et familles de personnes handicapées (enfants ou adultes) pour démystifier le handicap, faire évoluer l'attitude des proches et éviter des réactions de rejet ou des négligences. 	Proches et familles de personnes handicapées	Société civile / OPH ONG
<ul style="list-style-type: none"> Proposer des formations aux parents et proches afin de partager des gestes techniques qui permettraient d'améliorer la qualité de vie de la personne handicapée au quotidien et d'impliquer positivement les proches dans la prise en charge. 	Proches et familles de personnes handicapées	Société civile / OPH ONG

Si les familles sont apparues comme le principal soutien financier des personnes handicapées, cette aide n'était pas sans conséquence sur l'équilibre économique du foyer		
<ul style="list-style-type: none"> Proposer des pensions spéciales pour les proches de personnes handicapées, notamment avec des handicaps lourds, pour améliorer les conditions de vie du foyer. 	Proches directs des personnes handicapées (parent, conjoint)	Gouvernement
<ul style="list-style-type: none"> Renforcer l'accès des personnes handicapées à la CAS (Caisse d'Assistance Sociale), ce qui permettrait aux personnes handicapées d'apporter des revenus dans le foyer. 	Personnes handicapées (tous genres, âges, incapacités)	Gouvernement
La prise en charge d'une personne handicapée au sein de la cellule familiale pouvait également avoir un impact sur les proches		
<ul style="list-style-type: none"> Créer des espaces d'échanges, à travers des associations, des ateliers ou des causeries pour donner l'occasion aux proches d'échanger sur leur quotidien, partager des bonnes pratiques, réaliser qu'ils ne sont pas seuls et s'appuyer sur l'expérience de pairs. 	Les proches directs de personnes handicapées	Société civile / OPH ONG
Le temps dévolu à la prise en charge d'un enfant handicapé éloignait les parents du marché du travail (notamment dans le cas des foyers monoparentaux)		
<ul style="list-style-type: none"> Créer un système de garderie pour les enfants, afin que les femmes célibataires puissent avoir des activités génératrices de revenus. 	Les parents d'enfants handicapés ; Focus sur les mères célibataires	Société civile / OPH ONG Gouvernement
5- Recommandations centrées sur la personne handicapée et la famille	La population cible	Les porteurs
Un des éléments marquants de cette étude est l'absence de référence par les personnes handicapées à leurs droits et libertés, et leur méconnaissance de l'existence de services spécifiques		
<ul style="list-style-type: none"> Proposer des séances d'information et de sensibilisation, voire de coaching, auprès des personnes handicapées elles-mêmes, qui leur permettraient de prendre conscience de leurs droits, mais également de leurs capacités, leur redonnant ainsi confiance. 	Personnes handicapées (tous genres, âges, incapacités)	Société civile / OPH ONG
Les personnes handicapées rencontrées lors de l'entretien qualitatif ont exprimé leur gratitude pour l'espace de discussion inespéré ouvert lors des entretiens		
<ul style="list-style-type: none"> Mettre en place de lieux d'échanges et de loisirs, ouverts à tous, gratuits et accessibles, à l'échelle des quartiers, qui permettraient de créer une dynamique de vie sociale et de lutter contre 	Personnes handicapées (notamment les seniors)	Société civile / OPH ONG

l'isolement des personnes handicapées.		
Les familles sont apparues comme un des piliers de soutien majeur dans la prise en charge des personnes handicapées		
<ul style="list-style-type: none"> Proposer des séances de sensibilisation aux proches et familles de personnes handicapées (enfants ou adultes) pour démystifier le handicap, faire évoluer l'attitude des proches et éviter des réactions de rejet ou des négligences. 	Proches et familles de personnes handicapées	Société civile / OPH ONG
<ul style="list-style-type: none"> Proposer des formations aux parents et proches afin de partager des gestes techniques qui permettraient d'améliorer la qualité de vie de la personne handicapée au quotidien et d'impliquer positivement les proches dans la prise en charge. 	Proches et familles de personnes handicapées	Société civile / OPH ONG
Si les familles sont apparues comme le principal soutien financier des personnes handicapées, cette aide n'était pas sans conséquence sur l'équilibre économique du foyer		
<ul style="list-style-type: none"> Proposer des pensions spéciales pour les proches de personnes handicapées, notamment avec des handicaps lourds, pour améliorer les conditions de vie du foyer. 	Proches directs des personnes handicapées (parent, conjoint)	Gouvernement
<ul style="list-style-type: none"> Renforcer l'accès des personnes handicapées à la CAS (Caisse d'Assistance Sociale), ce qui permettrait aux personnes handicapées d'apporter des revenus dans le foyer. 	Personnes handicapées (tous genres, âges, incapacités)	Gouvernement
La prise en charge d'une personne handicapée au sein de la cellule familiale pouvait également avoir un impact sur les proches		
<ul style="list-style-type: none"> Créer des espaces d'échanges, à travers des associations, des ateliers ou des causeries pour donner l'occasion aux proches d'échanger sur leur quotidien, partager des bonnes pratiques, réaliser qu'ils ne sont pas seuls et s'appuyer sur l'expérience de pairs. 	Les proches directs de personnes handicapées	Société civile / OPH ONG
Le temps dévolu à la prise en charge d'un enfant handicapé éloignait les parents du marché du travail (notamment dans le cas des foyers monoparentaux)		
<ul style="list-style-type: none"> Créer un système de garderie pour les enfants, afin que les femmes célibataires puissent avoir des activités génératrices de revenus. 	Les parents d'enfants handicapés ; Focus sur les mères célibataires	Société civile / OPH ONG Gouvernement

6- Recommandations dans le secteur de l'éducation	Les populations cibles	Les porteurs
L'étude proposée était une étude en population générale, proposant une analyse de divers secteurs, dont l'éducation		
<ul style="list-style-type: none"> Des études supplémentaires permettraient d'apporter des données complémentaires, notamment sur des populations plus ciblées (comme par exemple la scolarisation des enfants sourds, déficients intellectuels ou en institution) 	Enfants handicapés, Selon le type de déficiences	Société civile / OPH Gouvernement ONG
L'étude a mis en évidence des difficultés d'accès à l'école chez les moins de 16 ans, plusieurs types d'activités permettraient de favoriser une scolarisation des enfants handicapés dans les établissements de proximité		
<ul style="list-style-type: none"> Informers les parents sur les possibilités de scolarisation, en milieu régulier et spécialisé : mettre en place une structure d'orientation académique dans ce sens. Constituer des équipes volantes de sensibilisation pour les professionnels de l'éducation afin de démystifier le handicap et les difficultés liées à la scolarisation des enfants handicapés (présenter par exemple les aides fonctionnelles existantes), prioritairement dans les établissements publics et au niveau primaire (accès gratuit). Favoriser l'accessibilité physique des établissements : <ul style="list-style-type: none"> Proposer des diagnostics d'accessibilité des établissements et des solutions raisonnables pour faciliter la circulation dans les bâtiments (voir LIPH, art. 41), Mettre en place des transports adaptés. Favoriser l'accessibilité financière en mettant en place des bourses d'études pour les élèves handicapés (voir LIPH, art. 40). 	<p>Les parents et les enfants handicapés</p> <p>Les directeurs et les enseignants des établissements scolaires</p> <p>Les directeurs des établissements scolaires Les enfants handicapés Les enfants handicapés</p>	<p>Gouvernement, Ministère de l'Éducation Nationale</p> <p>Société civile / OPH ONG Gouvernement</p> <p>Gouvernement</p> <p>Gouvernement</p>
L'étude a mis en évidence que les enfants handicapés redoublaient plus régulièrement, manquaient plus souvent l'école et étaient moins nombreux dès le 2 ^{ème} cycle, soulignant des difficultés d'apprentissage		
<ul style="list-style-type: none"> Proposer des modules de renforcement des capacités aux enseignants (sur des bonnes pratiques, les bases de la communication pour les malentendants, l'utilisation de matériel adapté, la gestion d'une classe avec un enfant handicapé,...). 	Les enseignants en activité	Gouvernement
<ul style="list-style-type: none"> Proposer des modules sur le handicap intégrés dans le cursus des futurs enseignants, primaire et 	Les futurs enseignants	Gouvernement, Ministère de

secondaire (voir LIPH, art. 37).	(universités publiques et privées)	l'Éducation Nationale
<ul style="list-style-type: none"> Créer des espaces de paroles, d'échanges de bonnes pratiques et de soutien pour les enseignants. Faciliter l'accès à l'enseignement et favoriser l'apprentissage : <ul style="list-style-type: none"> Proposer un soutien scolaire pour les enfants handicapés en primaire pour faciliter l'acquisition des savoirs de base, Employer des facilitateurs éducatifs pour accompagner parents et enfants dans le projet éducatif, et notamment faciliter la communication avec le monde scolaire et les ruptures dans le cursus (inter-cycle), Créer des classes spécialisées dans les établissements (voir LIPH, art. 38). Proposer des cours du soir d'alphabétisation dans les établissements scolaires, pour personnes handicapées, et notamment pour les femmes. 	<p>Les enseignants</p> <p>Les enfants handicapés scolarisés Les parents et les enfants handicapés</p> <p>Les enfants handicapés Les adultes handicapés, focus sur les femmes</p>	<p>Société civile / OPH</p> <p>Société civile / OPH Gouvernement</p> <p>Gouvernement Société civile / OPH Gouvernement</p>
7- Recommandations dans le secteur de l'emploi	Les populations cibles	Les porteurs
L'étude proposée était une étude en population générale, proposant une analyse de divers secteurs, dont l'emploi		
<ul style="list-style-type: none"> Des études supplémentaires permettraient d'apporter des données complémentaires, notamment sur les conditions de travail des personnes handicapées, la réalité du chômage, la fréquence du travail informel, le respect de la loi sur les quotas (LIPH, art. 44). 	Personnes handicapées en âge actif	Société civile / OPH Gouvernement ONG
L'étude a mis en évidence que les personnes handicapées étaient plus souvent sans activités, et ce sur du long terme		
<ul style="list-style-type: none"> Favoriser l'embauche des personnes handicapées grâce à des équipes volantes de sensibilisation pour communiquer sur le handicap, lutter contre les préjugés associés aux personnes handicapées et informer sur les aménagements possibles (lieux de travail, temps de travail,...). Faire prendre conscience aux personnes handicapées de leurs compétences et capacités. 	<p>Professionnels, employeurs des secteurs public et privé</p> <p>Les personnes handicapées</p>	<p>Société civile / OPH ONG Gouvernement</p> <p>Société civile / OPH ONG</p>

<ul style="list-style-type: none"> • Développer les compétences des personnes handicapées en mettant en place des filières professionnelles, en adéquation avec le marché. • Valoriser les compétences des personnes handicapées en proposant des formations sur les crédits et sur l'entrepreneuriat. 	<p>Les personnes handicapées, focus sur femme</p> <p>Les personnes handicapées, focus sur femme</p>	Gouvernement
8- Les recommandations dans le secteur de la santé	Les populations cibles	Les porteurs
Lors de l'atelier, la dimension prévention est apparue comme une priorité (voir LIPH, art. 12)		
<ul style="list-style-type: none"> • Proposer des journées de sensibilisation thématiques sur divers aspects de prévention de la santé (maladies transmissibles, chroniques, sécurité routière,...) afin d'améliorer les connaissances et favoriser des changements d'attitudes/de pratiques. • Former le personnel soignant des maternités au dépistage précoce du handicap. 	<p>Population générale, Focus personnes handicapées Focus femmes Enfants handicapés</p>	<p>Société civile / OPH Gouvernement</p> <p>Gouvernement</p>
L'étude a mis en évidence des difficultés d'accès aux services de santé à plusieurs niveaux (information, accueil, prise en charge,...)		
<ul style="list-style-type: none"> • Informer, soutenir et renforcer les compétences des professionnels de santé : <ul style="list-style-type: none"> - Constituer des équipes volantes de sensibilisation pour intervenir auprès des professionnels (éducation, santé) afin de démystifier le handicap et les difficultés liées à l'accueil des personnes handicapées, - Créer des espaces d'écoute et d'échanges de bonnes pratiques pour les professionnels au sein des structures de santé, - Proposer des modules de renforcement des capacités sur des thématiques précises : <ul style="list-style-type: none"> * Enfance et handicap lourd * Santé mentale * Psychiatrie * Gériatrie / Gériatologie - Intégrer des modules sur le handicap dans le cursus des futurs médecins et autres personnels médicaux (dans les universités et écoles publiques et privées) - Créer des écoles sur les métiers de la réadaptation (voir LIPH, art. 15). 	<p>Les professionnels de santé</p> <p>Les professionnels de la santé</p> <p>Les professionnels de santé en activité</p> <p>Les futurs professionnels de la santé</p> <p>Les futurs professionnels de la réadaptation</p>	<p>Société civile / OPH ONG Gouvernement</p> <p>Société civile / OPH</p> <p>Gouvernement</p> <p>Gouvernement</p> <p>Gouvernement</p>

<ul style="list-style-type: none"> Faire du plaidoyer pour renforcer certains secteurs de la santé : réadaptation, santé mentale, gériatrie / gérontologie. Accompagner et suivre les personnes handicapées dans leur parcours thérapeutique en créant un service d'accueil et de référencement dans les structures de santé (voir LIPH, art. 18). Favoriser l'accessibilité des établissements : <ul style="list-style-type: none"> Créer une clinique mobile Mettre en place des journées d'accueil avec des traducteurs (langue des signes par exemple) Proposer des diagnostics d'accessibilité des établissements et des solutions raisonnables pour faciliter la circulation dans les bâtiments. Favoriser l'accessibilité financière des établissements en créant une carte d'assurance santé gratuite (voir LIPH, art. 19). 	Gouvernement	Société civile/ OPH ONG
	Les personnes handicapées et leurs proches	Gouvernement
	Personnes handicapées (tous genres, âges, incapacités)	Gouvernement
	Personnes handicapées (tous genres et âges, incapacités sensorielles)	Société civile Gouvernement
	Les directeurs des établissements de santé Personnes handicapées (tous genres, âges, incapacités)	Gouvernement Gouvernement
L'étude a également mis en évidence des difficultés d'accès aux traitements et aides fonctionnelles		
<ul style="list-style-type: none"> Créer une pharmacie communautaire. Rendre PROMESS inclusif. 	Personnes handicapées (tous genres, âges, incapacités)	Gouvernement
	Personnes handicapées (tous genres, âges, incapacités)	Gouvernement
Les entretiens avaient enfin souligné des lacunes dans le suivi post-visites médicales		
<ul style="list-style-type: none"> Mettre en place des services de soins à domicile. 	Personnes handicapées (tous genres, âges, incapacités)	Secteur Privé Société civile/ OPH
<ul style="list-style-type: none"> Créer des maisons de convalescence inclusive. 	Communauté, Focus personnes handicapées	Gouvernement

9- Recommandations dans le secteur de la protection	Les populations cibles	Les porteurs
L'étude proposée était une étude en population générale, proposant une analyse de divers secteurs ; cependant, lors des entretiens, les problématiques liées à la protection sont apparues majeures		
<ul style="list-style-type: none"> Des études supplémentaires permettraient d'apporter des données complémentaires, notamment auprès des groupes plus vulnérables (femmes et enfants). 	Femmes et enfants handicapés	Société civile / OPH Gouvernement ONG
<ul style="list-style-type: none"> Proposer des journées de sensibilisation pour les professionnels juridiques, les policiers et les équipes médicales pour améliorer l'accueil des personnes handicapées victimes de violence. 	Professionnels juridiques, policiers, et équipes médicales	Société civile / OPH ONG
<ul style="list-style-type: none"> Faciliter l'accueil des femmes et des enfants handicapés victimes de violence par les refuges et les cellules d'accueil existants. 	Femmes et enfants handicapés	Société civile / OPH Gouvernement

3. PROFILES OF PEOPLE INTERVIEWED IN PORT-AU-PRINCE IN 2012 DURING THE QUALITATIVE PHASE (in French)

Identification Individu	Sexe	Classe d'âge ³⁴	Limitation fonctionnelle principale	Personnes répondant lors de l'entretien	Lieu de l'entretien
Individu 1	Homme	Adulte	Se déplacer	Personne handicapée	Pétionville
Individu 2	Homme	Sénior	Se déplacer	Personne handicapée + 1 proche	Pétionville
Individu 3	Homme	Enfant	Voir, se concentrer	1 proche	Port-au-Prince
Individu 4	Femme	Enfant	Voir	Personne handicapée + 1 proche	Port-au-Prince
Individu 5	Femme	Enfant	S'habiller Communiquer	1 proche	Delmas
Individu 6	Femme	Enfant	Se concentrer Epilepsie	1 proche	Delmas
Individu 7	Homme	Enfant	Communiquer	Personne handicapée + 2 proches	Port-au-Prince
Individu 8	Homme	Enfant	Se déplacer et communiquer	1 proche	Port-au-Prince
Individu 9	Femme	Adulte	Se déplacer	Personne	Port-au-Prince

³⁴ Enfant : personne handicapée âgée de moins de 18 ans,
Adulte : personne handicapée âgée de 19 à 59 ans,
Sénior : personne handicapée âgée de plus de 60 ans.

				handicapée + 1 proche	
Individu 10	Homme	Adulte	Se déplacer	Personne handicapée	Port-au-Prince
Individu 11	Homme	Sénior	Se déplacer	Personne handicapée	Carrefour
Individu 12	Homme	Enfant	Se déplacer, communiquer	1 proche	Delmas
Individu 13	Homme	Sénior	Voir, entendre	Personne handicapée + 4 proches	Delmas / Tabarre
Individu 14	Homme	Adulte	Voir	Personne handicapée + 1 proche	Port-au-Prince
Individu 15	Homme	Sénior	Voir	Personne handicapée	Port-au-Prince
Individu 16	Femme	Sénior	Se déplacer, prendre soin de soi	Personne handicapée	Pétionville
Individu 17	Homme	Sénior	Voir	Personne handicapée	Pétionville
Individu 18	Homme	Sénior	Se déplacer, prendre soin de soi	Personne handicapée + 1 proche	Pétionville
Individu 19	Femme	Adulte	Se déplacer	Personne handicapée	Port-au-Prince
Individu 20	Femme	Enfant	Entendre, communiquer	1 proche	Port-au-Prince
Individu 21	Homme	Enfant	Communiquer	Personne handicapée	Port-au-Prince

Individu 22	Femme	Enfant	Prendre soin de soi	Personne handicapée	Port-au-Prince
Individu 23	Homme	Enfant	Se déplacer	1 proche	Port-au-Prince
Individu 24	Homme	Adulte	Voir	Personne handicapée + 1 proche	Port-au-Prince
Individu 25	Femme	Adulte	Entendre	Personne handicapée	Port-au-Prince
Individu 26	Femme	Sénior	Voir, prendre soin de soi	Personne handicapée + 1 proche	Delmas
Individu 27	Femme	Adulte	Se souvenir	Personne handicapée	Delmas / Tabarre
Individu 28	Femme	Sénior	Entendre, se souvenir	1 proche	Delmas / Tabarre
Individu 29	Femme	Sénior	Voir	Personne handicapée + 1 proche	Carrefour
Individu 30	Homme	Sénior	Voir	Personne handicapée	Carrefour

4. QUESTIONNAIRES

A. COVER SHEET

Cluster name

--	--

--	--

7

Total number of eligible household members aged 5+ years

7

7

IDs of disabled person	Availability for interview 1 = available, 2 = Not available 3 = Refused		
	1	2	3
	1	2	3
	1	2	3
	1	2	3

B. HOUSEHOLD ROSTER

	1. First make a full list of all household members who have lived in the household for at least 3 months of the previous year	2. Gender	3. What is [name]'s relationship to head of household	4. What is age?
ID No.	Person's Name <i>List first name and family name</i>	1=Male 2=Female	<div> <div>1 = head</div> <div>2 = Husband/wife</div> <div>3 = son/daughter</div> <div>4 = Son/daughter in law</div> <div>5=Parent of head/spouse</div> </div> <div> <div>6 = Grandchild of head/spouse</div> <div>7 = Brother/sister of head/spouse</div> <div>8=other blood relation</div> <div>9 = Domestic worker</div> <div>10 = other unrelated</div> </div>	Enter age in completed years
1		1 2		
2		1 2		
3		1 2		
4		1 2		
5		1 2		
6		1 2		
7		1 2		
8		1 2		
9		1 2		
10		1 2		
11		1 2		
12		1 2		
13		1 2		
14		1 2		
15		1 2		
16		1 2		

C. SCREENING QUESTIONS

ID no	Initials	Because of a health problem.....					Screening			13. Mark with X person who is a 'case' (=Yes to Q11 and 12)
		5. Does [name] have difficulty seeing, even if wearing glasses?	6. Does [name] have difficulty hearing, even if using a hearing aid?	7. Does [name] have difficulty walking or climbing stairs?	8. Does [name] have difficulty remembering or concentrating?	9. Does [name] have difficulty with self-care such as washing all over or dressing?	10. Using your usual (customary) language does [name] have difficulty communicating for example understanding or being understood?	11. Does this person have a disability [some difficulty] with two activities or 'alot/unable' to do one activity]	12. Aged 5 or more years?	
1		1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	0 1	0 1	
2		1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	0 1	0 1	
3		1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	0 1	0 1	
4		1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	0 1	0 1	
5		1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	0 1	0 1	
6		1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	0 1	0 1	
7		1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	0 1	0 1	
8		1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	0 1	0 1	
9		1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	0 1	0 1	
10		1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	0 1	0 1	
11		1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	0 1	0 1	
12		1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	0 1	0 1	
13		1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	0 1	0 1	
14		1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	0 1	0 1	
15		1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	0 1	0 1	
16		1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	0 1	0 1	

D. SOCIO-ECONOMIC QUESTIONS

14 What is the major construction material of the external walls
[Observe, don't ask]

- 1 = Brick
2 = Concrete
3 = Unbaked brick, adobe
4 = Wood, logs
5 = Iron/Tin/zinc sheeting
6 = Mud

- 7 = Bamboo
8 = Canvas, felt
9 = Pierre/enduit
10 = Bâche/Toile
11 = Other, Specify:

15 What is the major material of the roof?
[Observe, don't ask]

- 1 = Concrete
2 = Tiles/shingles
3 = Asbestos sheets
4 = Metal sheets
5 = Wood

- 6 = Unbaked bricks
7 = Thatch
8 = Bache/toile
9 = Vetiver/palme
10 = Other, Specify:

16 What is the primary material of the floor?
[Observe, don't ask]

- 1 = Parquet/linoleum
2 = Painted wood
3 = Tile/ceramique
5 = Adoquin

- 5 = Concrete
6 = Clay/earthen floor
7 = Other, Specify:

17 How many rooms are there in your household (excluding bathrooms, kitchens, balconies and corridors)?

--	--

18 What type of toilet that is used in your household?

- 1 = Flush toilet
2 = Traditional latrine
3 = Ventilation improved pit latrine

- 4 = Bowl/Bucket
6 = No toilet
5 = Other, Specify:

19 Where is the toilet?

- 1 = Inside dwelling
2 = Outside dwelling – in compound
3 = Outside dwelling – outside compound

20 What is the main source of drinking water used by your household?

- 1 = Private pipeline
2 = Private well
3 = Public taps/standpipe
4 = Public well
5 = Neighbours

- 6 = Water vendor
7 = Spring
8 = River/stream/lake
9 = Rainwater
10 = Other, specify:

21 What is the main source of lighting in your dwelling?

- 1 = Mains power
2 = Generator/battery/inverter
3 = Kerosene/oil/petrol lamps

- 4 = Candles/lampe de poche
5 = No lighting
6 = Other, specify:

22 Does any member of your household own the following :
(in working order)

	0 = No	1 = YES
a Radio/HiFi/Stereo	0	1
b TV/VCR/DVD	0	1
c Fridge/Freezer	0	1
d Telephone/Cell phone	0	1
e Cupboard	0	1
f Sofa set/armchair	0	1
g Table	0	1
h Motor vehicle incl cars	0	1
i Motorbike	0	1

	0 = No	1 = YES
j Washing machine	0	1
k Sewing machine	0	1
l Air conditioner	0	1
m Bicycle	0	1
n Stove with gas	0	1
o Stove with electric	0	1

Survey of disability Haiti: Disability questionnaire

Cluster Number:

--	--

Household number:

--	--

Individual number:

--	--

Interviewer Number

--

1	Who is being interviewed?	ID no (from HH qre)
	1 = Person with disability	N/A
	2 = Someone else on behalf of person with disability	
	3 = Person with disability together with someone else	

		Difficulty level			
2	Because of a health problem....	No	Some	Alot	cannot do
a	Do you have difficulty seeing, even if wearing glasses?	1	2	3	4
b	Do you have difficulty hearing, even if using a hearing aid?	1	2	3	4
c	Do you have difficulty walking or climbing stairs?	1	2	3	4
d	Do you have difficulty remembering or concentrating?	1	2	3	4
e	Do you have difficulty with self-care such as washing all over or dressing?	1	2	3	4
f	Using your usual (customary) language do you have difficulty communicating for example understanding or being understood?	1	2	3	4

(INSTRUCTION TO THE NUMERATOR): [Don't read the control question out loud]

3 Based on the responses in Q.2, where will you categorize the respondent? Did the person answer:		
a "A LOT" or "UNABLE" in ONE of the questions	1	
b "SOME" difficulty in TWO or more questions	2	
c None of the above	3	STOP

4 What is the cause of the difficulty doing the activities (disability) (tick all that apply)

1 = From birth/congenital

2 = Accident (Domestic/work)

3 = Accident (Road crash)

4 = Earthquake

5 = Communicable disease/illness. Specify _____

6 = Non communicable disease/illness. Specify _____

7 = Psychological/Mental disorder

8 = Spiritual

9= Violence - armed

10 = Violence - sexual

11 = Violence - other

12 = Drugs/tablets

13 = Others, specify:

14 = Don't know

5 How old were you when it started

--	--

years

00 = from birth

99 = Don't know/refused

B. REHABILITATION SERVICES

I am now going to ask you some questions about some services that you may or may not be aware of or have used now or in the past

	Are you aware of this type of service?	Have you ever felt this service could be of benefit to you?*	Have you ever recieved this service?	If yes, are you currently receiving it?	If reported needing (Yes to QX) but not receiving a service (No to QX), ask why have you not recieved it?	If reported once receiving service (Yes to QX) but not receiving it now (No to QX), ask why are you no longer receiving it?
	0 = No 1 = Yes	0 = No 1 = Yes	0 = No 1 = Yes	0 = No 1 = Yes	1 = Too expensive 2 = Too far/no transport 3 = Discriminating 4 = Communication barriers 5 = Don't know where to access 6 = Service not available 7 = Not satisfied with services	1 = Too expensive 2 = Too far/no transport 3 = Not longer available 4 = Communication/language barriers 5 = Don't know where to access 6 = Not really helping me 7 = Not satisfied with services
a	0 1	0 1	0 1	0 1		
b	0 1	0 1	0 1	0 1		
c	0 1	0 1	0 1	0 1		
d	0 1	0 1	0 1	0 1		
e	0 1	0 1	0 1	0 1		
f	0 1	0 1	0 1	0 1		
g	0 1	0 1	0 1	0 1		
h	0 1	0 1	0 1	0 1		
i	0 1	0 1	0 1	0 1		
j	0 1	0 1	0 1	0 1		
k	0 1	0 1	0 1	0 1		

C. ASSISTIVE DEVICES**1 Read list of devices that are relevant to difficulty category according to Washington Group Questions**

		I am going to read you a list of assistive devices. For each please tell me if you use it, need it but don't use it, or don't need it	If used, is it in good working order?	If used, where did you get the assistive device?
Difficulty category	Device	1 = Use it 2 = Need it, but don't use it 3 = Don't need/NA 4 = Don't know what it is	1 = Yes 2 = No 3 = N/A	1 = Private 2 = Government health service 3 = Government service (not health) 4 = NGO 5 = Other 6 = Friend/relative 7 = Don't know
Seeing	Eye Glasses			
	Magnifying glass			
	Telescoping Lenses/glasses			
	Enlarge print			
	Braille			
	Other, specify			
Hearing	Hearing aids			
	Sign language interpreter			
	Other?			
	Computer?			
Mobility	Wheelchairs			
	Crutches			
	Walking stick			
	White cane			
	Guide			
	Standing Frame			
	Other, specify			

2 Do you use any other assistive devices

0 = No

Go to Q4

1 = Yes

Go to Q3

3 If yes, please tell me what they are:

List devices

Code:

4 Are there any assistive devices you think you need but do not have?

0 = No

End

1 = Yes

Go to Q 5

5 If yes, please tell me what they are:

List devices

Code:

HAITI DISABILITY STUDY 2012 - COVER SHEET (English)									
TO BE FILLED IN BY INTERVIEWER									
Cluster Name: _____		Cluster No. <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>		House No. <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>					
Subjects Name _____		Subjects No. <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>		Interviewer No. <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>					
Language of Interview:		Subject:		Date (Day/Month/Year): ____ / ____ / ____					
1 = Creole		1 = Case (Person with a disability)		Start Time ____ : ____ : ____					
2 = French		2 = Control		Finish Time ____ : ____ : ____					
Person interviewed									
1 = Direct interview with case/control				ID of proxy from household roster: <input type="text"/> <input type="text"/>					
2 = Interview with proxy				ID of proxy from household roster: <input type="text"/> <input type="text"/>					
3 = Interview with proxy and case/control together									
		Tick as appropriate		COMMENTS					
Interview completed									
Problem with interview									
TO BE FILLED IN BY FIELD SUPERVISOR									
This involves more than simply collection the questionnaires at the end of the day! The field supervisor and project manager are to make sure that each questionnaire is scanned over. Ensure that appropriate coding has been used and that all questions are answered and legible.									
Supervisor Name									
Date checked									
Remarks									
TO BE FILLED IN BY DATA ENTRY CLERK									
		ENTRY 1				ENTRY 2			
Data entry name									
Remarks									

B Control subjects only: Washington Group Screening questions

		Difficulty level			
2	Because of a health problem....	No	Some	Alot	Cannot do
a	Do you have difficulty seeing, even if wearing glasses?	1	2	3	4
b	Do you have difficulty hearing, even if using a hearing aid?	1	2	3	4
c	Do you have difficulty walking or climbing stairs?	1	2	3	4
d	Do you have difficulty remembering or concentrating?	1	2	3	4
e	Do you have difficulty with self-care such as washing all over or dressing?	1	2	3	4
f	Using your usual (customary) language do you have difficulty communicating for example understanding or being understood?	1	2	3	4

(INSTRUCTION TO THE NUMERATOR): [Don't read the control question out loud]

3	Based on the responses in Q.2, where will you categorize the respondent? Did the person answer:		
a	"A LOT" or "UNABLE" in ONE of the questions	1	
b	"SOME" difficulty in TWO or more questions	2	
c	None of the above	3	

B. Cases/Controls >16 years only: Marital status and education for respondents >16 years

1 What is your marital status?

- 1 = Married or living together
 2 = Divorced/seperated
 3 = Widowed
 4 = Never married/living together

2 Have you ever attended School

- 0 = No
 1 = Yes

3 What is the highest level of education you completed

--	--

(develop code list)

4 Can you read well, a little or not at all?

- 1 = Well
 2 = A little
 3 = No at all

5 Why did you receive no formal education?
[For participants with no education]

- 1 = absence of school
 2 = Lack of money
 3 = Needed to work
 5 = Education not very useful
 6 = Being disabled was refused
 7 = Doesn't like school
 8 = Too much household work
 9 = Family does not allo
 10 = No transport
 11 = Other

[Response options to be adapted to
 Haiti context]

C. Cases/Controls ≤16 years only: Education Questions

1 Are you currently enrolled in school?

0 = No Go to Q12

1 = Yes Go to Q7

2 In what grade are you currently enrolled

--	--

(develop code list)

3 Is the school you are currently enrolled
in private or public

1 = Public

2 = Private secular

3 = Private religious

4 In the last month how many days have
you missed from school

--	--

days

5 Have you ever repeated a grade at
school?

0 = No Go to next section

1 = Yes Go to Q11

6 If yes, how many times have you
repeated a grade at school

--

7 If not currently enrolled, have you ever
attended school?

0 = No Go to Q14

1 = Yes Go to Q13

8 If yes, what is the highest grade you
completed

--	--

(develop code list)

9 If you have never attended/are currently
not attending school, what is the reason?

1 = Not enough money

2 = Failing/underachieving

3 = Illness

4 = Because of disability

5 = Lack of interest

6 = School not accessible

7 = Other, Specify: _____

D. All cases/controls: Health

1 During the past one year how many times have you used health facilities	<input type="text"/>	<input type="text"/>	Times
2 Have you faced any difficulties accessing any health facility	0 = No 1 = Yes		
3 What kind of difficulties did you face? (3 answers possible)	Financial difficulties 1 = I was refused because I had no money (or not enough) 2 = I had difficulty to get food for myself during my stay 3 = I didn't have money for fees/donation after treatment 4 = I didn't have money for medication/amulates/objects Transport, access difficulties 6 = there was no available transportation/it's very far away 7 = I had difficulty to find the money for transportation 8 = No transport - refused travel on public transport 9 = I had difficulty to find someone to go with me because nobody had time to take me 10 = I did not ask anybody because I felt that it was a waste of time 11 = I had difficulty to find somebody to go with Difficulties at the health service 12 = there was no available medication 13 = there was no service available for my need (condition) 14 = I was refused because I am disabled 15 = attitude of medical staff was negative 16 = The equipment that they gave is not very useful 17 = there is no female professional 18 = no difficulty 19 = other, specify _____		
4 How do you get to the closest available health care facility	1 = by foot 2 = by motorise vehicle 3 = by bicycle 4 = on an animal (donkey....) 5 = other, specify _____		

E Women aged 15-49 years only: Reproductive health.

1 Do you have any children?	0 = No 1 = Yes	
2 How many children do you have today (excluding those who have died)?	<input type="text"/>	<input type="text"/>
3 Did you have any pregnancies that ended before term (i.e. Still birth, miscarriage or abortion)?	0 = No 1 = Yes	
4 If yes, how many pregnancies ended before term?	<input type="text"/>	

E2 Women with Children only: Pregnancy care

I would now like to ask you some questions about your children born in the last 5 years.

Please answer questions about the most last child born in this period

5 Did you see anyone for antenatal care during this time?	0 = No 1 = Yes
6 Whom did you see? Anyone else? <i>Probe to identify each kind of person and record all mentioned</i>	1 = Health personnel/Doctor 2 = Nurse/midwife 3 = Auxiliary Midwife 4 = Traditional Birth Attendant 5 = Community/village health worker 6 = Other (please specify_____)
7 Where did you give birth to [name]? <i>Probe to identify source. If unable to determine if public/private sector write the name of the place</i> _____	1 = Home (Your home) 2 = Other home 3 = Public sector Govt. hospital 4 = Public sector Govt. health centre 5 = Public sector Govt health post 6 = Other public sector (specify_____) 7 = Private medical sector/private hospital clinic 8 = Dispensaire 9 = Other private medical sector (specify_____) 10 = Other (specify_____)
8 Who assisted with the delivery of [Name]? Anyone else? <i>Probe for the types of person(2) and record all mentioned.</i> <i>If respondent says no one assisted, probe to determine whether any adults were present at delivery</i>	1 = Doctor 2 = Nurse/Midwife 3 = Auxillary Midwife 4 = Traditional birth attendant 5 = Relative/friend 6 = Other (specify_____) 7 = No one assisted
9 Did [name] ever have any vaccinations to prevent him/her getting diseases, including vaccinations recieved in a national immunization coverage day	0 = No 1 = Yes

F. Cases/controls aged ≥16 years only: LIVELIHOODS

- 1** What is your work status?
- 1 = Paid work (go to Q2)
 2 = Self employed e.g. Own a business (go to Q2)
 3 = Non-paid work e.g. Volunteer/charity (go to Q2)
 4 = Student (go to Q3)
 5 = Keeping house/homemaker (go to Q3)
 6 = Retired (go to Q3)
 7 = Unemployed (health reasons) (go to Q3)
 8 = Unemployed (other reasons) (go to Q3)
- 2** What is your occupation, _____ Code
 that is, what kind of work do you mainly do?
- 3** Have you done any work in the last seven days?
- 0 = No Go to Q4
 1 = Yes Go to Q6
- 4** Although you did not work in the last 7 days, do you have any job or business from which you were absent from leave, illness, vacation, or any other such reason
- 0 = No Go to Q5
 1 = Yes Go to Q6
- 5** What is the main reason that you did not work in the last seven days?
- 1 = Sick
 2 = Maternity
 3 = Household member ill
 4 = Vacation/strike
 5 = Suspension
 6 = Temporary work load reduction
 7 = Student
 8 = Too old/retired
 9 = Disability
 10 = Waiting for recall/reply from employer
 11 = Lack of experience/qualifications
 12 = Lack of access/money for transport
 13 = Other (Please specify _____)
- 6** Have you done any work in the last 12 months?
- 0 = No
 1 = Yes

G. All cases and controls: Activity limitations and participation restrictions(SINTEF)**1 ACTIVITY LIMITATION**

How difficult is it for you to perform this activity WITHOUT any kind of assistance at all?

(Without the use of assistive devices - either technical or personal)

	No difficulty	Moderate difficulty	Severe difficulty	Unable to do
a	1	2	3	4
b	1	2	3	4
c	1	2	3	4
d	1	2	3	4
e	1	2	3	4
f	1	2	3	4
g	1	2	3	4
h	1	2	3	4
i	1	2	3	4
j	1	2	3	4
k	1	2	3	4
l	1	2	3	4
m	1	2	3	4
n	1	2	3	4
o	1	2	3	4
p	1	2	3	4
q	1	2	3	4
r	1	2	3	4

PARTICIPATION RESTRICTION**2 Do you have any difficulty performing this activity in your current environment?**

[Current environment where you live, work and play etc for the majority of your time,
and with the use of any assistive devices, either technical or personal]

	No difficulty	Moderate difficulty	Severe difficulty	Unable to do
a	1	2	3	4
b	1	2	3	4
c	1	2	3	4
d	1	2	3	4
e	1	2	3	4
f	1	2	3	4
g	1	2	3	4
h	1	2	3	4
i	1	2	3	4
j	1	2	3	4
k	1	2	3	4
l	1	2	3	4
m	1	2	3	4
n	1	2	3	4
o	1	2	3	4
p	1	2	3	4
q	1	2	3	4
r	1	2	3	4
s	1	2	3	4
t	1	2	3	4
u	1	2	3	4
v	1	2	3	4

H. **All cases and controls: Environmental Factors (Sintef)**

Being an active, productive member of society includes participating in such things as working, going to school, taking care of your home, and being involved with family and friends in social, recreational and civic activities in the community. Many factors can help or improve a person's participation in these activities while other factors can act as barriers and limit participation.

First, please tell me how often each of the following has been a barrier to your own participation in the activities that matter to you. Think about the past year and tell me whether each item on the list below has been a problem daily, weekly, monthly, less than monthly, or never. If the item occurs, then answer the question as to how big a problem the item is with regard to your participation in the activities that matter to you.

(Note: if a question asks specifically about school or work and you neither work nor attend school, check not applicable)

<i>Please circle only one</i> In the past 12 months how often:	Daily	Weekly	Monthly	Less than monthly	Never	N/A	When problem occurs, has it been a	
							Big problem	Little Problem
a. has the availability/accessibility of transportation been a problem for you?	1	2	3	4	5	6	1	2
b. has the natural environment – temperature, terrain, climate – made it difficult to do what you want or need to do?	1	2	3	4	5	6	1	2
c. have other aspects of your surroundings – lighting, noise, crowds, etc – made it difficult to do what you want or need to do?	1	2	3	4	5	6	1	2
d. has the information you wanted or needed not been available in a format you can use or understand?	1	2	3	4	5	6	1	2
e. has the availability of health care services and medical care been a problem for you?	1	2	3	4	5	6	1	2
f. did you need someone else's help in your home and could not get it easily?	1	2	3	4	5	6	1	2
g. did you need someone else's help at school or work and could not get it easily?	1	2	3	4	5	6	1	2
h. have other people's attitudes toward you been a problem at home?	1	2	3	4	5	6	1	2
i. have other people's attitudes toward you been a problem at school or work?	1	2	3	4	5	6	1	2
j. did you experience prejudice or discrimination?	1	2	3	4	5	6	1	2
k. did the policies and rules of businesses and organizations make problems for you?	1	2	3	4	5	6	1	2
l. did government programs and policies make it difficult to do what you want or need to do?	1	2	3	4	5	6	1	2

i: Children <16 years only: QoL/Activities

Pediatric Quality of Life Inventory CHILD REPORT (ages 8-12) PedsQL12						
In the past ONE month, how much of a problem has this been for you ...						
ABOUT MY HEALTH AND ACTIVITIES (problems with...)	Never	Almost never	Sometimes	Often	Almost always	
1. It is hard for me to walk more than one block	0	1	2	3	4	
2. It is hard for me to run	0	1	2	3	4	
3. It is hard for me to do sports activity or daily exercise	0	1	2	3	4	
4. It is hard for me to life something heavy	0	1	2	3	4	
5. It is hard for me to take a bath or shower by myself	0	1	2	3	4	
6. It is hard for me to do chores around the house	0	1	2	3	4	
7. I hurt or ache	0	1	2	3	4	
8. I have low energy	0	1	2	3	4	

ABOUT MY FEELINGS (problems with...)	Never	Almost never	Sometimes	Often	Almost always	
1. I feel afraid or scared	0	1	2	3	4	
2. I feel sad or blue	0	1	2	3	4	
3. I feel angry	0	1	2	3	4	
4. I have trouble sleeping	0	1	2	3	4	
5. I worry about what will happen to me	0	1	2	3	4	

HOW I GET ALONG WITH OTHERS (problems with ...)	Never	Almost never	Sometimes	Often	Almost always	
1. I have trouble getting along with other kids	0	1	2	3	4	
2. Other kids do not want to be my friend	0	1	2	3	4	
3. Other kids tease me	0	1	2	3	4	
4. I cannot do things that others kids my age can do	0	1	2	3	4	
5. It is hard to keep up when I play with other kids	0	1	2	3	4	

ABOUT SCHOOL (problems with ...)	Never	Almost never	Sometimes	Often	Almost always	
1. It is hard to pay attention in class	0	1	2	3	4	
2. I forget things	0	1	2	3	4	
3. I have trouble keeping up with my schoolwork	0	1	2	3	4	
4. I miss school because of not feeling well	0	1	2	3	4	
5. I miss school to go to the doctor or hospital	0	1	2	3	4	

i: Children <16 years only: QoL/Activities

Pediatric Quality of Life Inventory PARENTAL REPORT for CHILDREN (ages 8-12) PedsQL2						
In the past ONE month, how much of a problem has your child had with ...						
PHYSICAL FUNCTIONING (problems with...)	Never	Almost never	Sometimes	Often	Almost always	
1. Walking more than one block	0	1	2	3	4	4
2. Running	0	1	2	3	4	4
3. Participating in sports activity or exercise	0	1	2	3	4	4
4. Lifting something heavy	0	1	2	3	4	4
5. Taking a bath or shower	0	1	2	3	4	4
6. Doing chores around the house	0	1	2	3	4	4
7. Having hurts or aches	0	1	2	3	4	4
8. Low energy levels	0	1	2	3	4	4

EMOTIONAL FUNCTIONING (problems with...)						
Never	Almost never	Sometimes	Often	Almost always		
1. Feeling afraid or scared	0	1	2	3	4	4
2. Feeling sad or blue	0	1	2	3	4	4
3. Feeling angry	0	1	2	3	4	4
4. Trouble sleeping	0	1	2	3	4	4
5. Worrying about what will happen to him or her	0	1	2	3	4	4

SOCIAL FUNCTIONING (problems with ...)						
Never	Almost never	Sometimes	Often	Almost always		
1. Getting along with other children	0	1	2	3	4	4
2. Other kids not wanting to be his or her friend	0	1	2	3	4	4
3. Getting teased by other children	0	1	2	3	4	4
4. Not been able to do things that other children his or her age do	0	1	2	3	4	4
5. Keeping up playing with other children	0	1	2	3	4	4

SCHOOL FUNCTIONING (problems with ...)						
Never	Almost never	Sometimes	Often	Almost always		
1. Paying attention in class	0	1	2	3	4	4
2. Forgetting things	0	1	2	3	4	4
3. Keeping up with schoolwork	0	1	2	3	4	4
4. Missing school because of not feeling well	0	1	2	3	4	4
5. Missing school to go to the doctor or hospital	0	1	2	3	4	4



Representation and evaluation of disability in Haiti (Port-au-Prince, 2012)

Handicap International and the International Center for Evidence in Disability (IDED), of the London School of Hygiene and Tropical Medicine (LSHTM) joined forces to propose a cross-sectional study to analyse the situation in which people with disabilities find themselves in Port-au-Prince in 2012, and thereby identify the operational mechanisms by which the needs of people with disabilities can be best met.

This document provides :

- (1) statistically reliable data on disability and people with disabilities in Port-au-Prince (prevalence, reported causes, profile of people with disabilities identified);
- (2) a snapshot of the situation for people with disabilities and compare it to a control group without disabilities in order to reveal restrictions on participation and barriers that specifically affect the study population (family environment, living standards, education, employment and health);
- (3) a perspective of people with disabilities' difficulties in terms of inclusion, access and social participation.

HANDICAP INTERNATIONAL

14, avenue Berthelot

69361 LYON Cedex 07

France

T. +33 (0) 4 78 69 79 79

F. +33 (0) 4 78 69 79 94

publications@handicap-international.org