Local Strategies in a Global Network: Disability Rights Advocacy in Jamaica

by

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Dedication

This dissertation is dedicated to my wonderful husband Ransford Tucker who has supported my every endeavor, my amazing daughters Teresa and Kimberly, and in loving memory of my Father Cyril Cole and my mother Virginia Alveranga who imparted to me the dedication and determination that guided me through this journey.
Acknowledgements

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Local Strategies in a Global Network: Disability Rights Advocacy in Jamaica

Joan Adina Tucker

ABSTRACT

The declaration of the International Year of Disabled Persons in 1981 and the international activism of persons with disabilities resulted in the globalization of disability, which involved a new framework for the treatment of PWDs. Although disability activism was being played out globally, it has been about PWDs gaining equality and full participation in their local societies. Therefore, at the heart of an international movement was the strategic organization of PWDs, most of who live in the developing world. This dissertation is based on a case study of activism for disability rights in one particular developing society, Jamaica. The Jamaican movement is spearheaded by the Combined Disabilities Association (CDA), which has been at the forefront of disability rights activism locally and regionally. The primary research question: how does CDA organize strategically to meet the needs of the broader disabled population of Jamaica is broken down into the following four sub-questions: 1) how is “disability” constructed in the context of Jamaican culture, 2) how did CDA members negotiate their original involvement and level of participation with the organization, 3) what is the nature of the linkage between the CDA and Disabled People International, and how does this relationship affect CDA’s policies and procedures, and 4) what strategies does CDA employ to mobilize PWDs in Jamaica to participate in advocacy
activities? These questions are explored using participant observation, semi-structured interviews, survey, and document review. Findings reveal a complex construction of disability as Jamaicans negotiate between various beliefs and ideas to understand the meaning of disability. Furthermore, the negotiation of movement involvement by PWDs is based on the connections they have with fellow members as well as the personal benefits that they receive. Although the CDA has been influenced by the international disability movement, it has also contributed to the global activism, especially in the Caribbean. In a local environment overwhelmed by limited financial resources and social inequalities, the CDA by default addresses some social welfare of PWDS, while pursuing its primary commitment to advocacy, resulting in numerous challenges.
Chapter One

Introduction

When the United Nations (UN) declared the International Year of Disabled Persons (IYDP) in 1981, disability became a global issue that involved a new framework for the treatment of persons with disabilities (PWDs) as well as the passage of new laws and policies, mandating equal rights for such persons. However, these changes did not occur because of the good will of policy makers; rather, the “self organization of PWDs has been a major catalyst behind these changes” (Priestly 2001:9). PWDs were traditionally viewed as suffering from a “limitation of competence” (Ingtstad and Whyte 1995), and so they were often isolated from the rest of society and were characterized by having the “lowest income, lowest education, and lowest workforce participation” (Scotch 1988). That they could mobilize for collective action came as a surprise to many who worked in the field of disability services.

Although this activism for disability rights was being played out on the global stage, it has been a movement about PWDs gaining full participation in the societies in which they live (Priestly 2001). Therefore, at the heart of the international movement was the strategic organization of PWDs from several countries, 80 percent of whom lived in the developing world (WHO 1980). This dissertation is based on a case study of activism for disability rights in one particular developing society, Jamaica. The Jamaican movement is being spearheaded by the Combined Disabilities Association (CDA), an organization operated by PWDs. The CDA has led Jamaica to the forefront of both regional and international disability rights advocacy. According to the International Disability Rights Monitor, Jamaica is ranked fifth in the Americas and foremost in the
Caribbean in disability rights policies and services. Nevertheless, this accomplishment does not mean that Jamaica is adequately meeting the needs of its disabled population. In fact, both activists and researchers argue that PWDs have relatively low priority in Jamaican society, which is evidenced not only by the lack of a national disability act (Gayle and Palmer 2005) but also by the limited number of services for PWDs. Furthermore, most of the available services to PWDs are being provided by nongovernmental organizations (NGOs), which rely largely on private donations.

**Research Questions**

Using the Combined Disabilities Association (CDA) as an ethnographic case, I explored the strategies used by a local advocacy group to mobilize Jamaicans diagnosed with a variety of disabilities and coming from different socioeconomic backgrounds. Ethnographic research is focused on the local organization; however, a full understanding of its organizational strategy required that the relationship between the local and the global be given due attention. Since the CDA is primarily an advocacy organization that faces the task of addressing advocacy and social services needs, within a cultural context of limited resources, the following question will guide the research: How does CDA organize strategically to meet the needs of the broader disabled population of Jamaica? In order to understand its mobilization strategies, I have broken that primary question into the following four sub-questions:

1. How is “disability” constructed within the context of Jamaican culture?

2. How did CDA members negotiate their original involvement and level of participation with the organization?
3. What is the nature of the linkage between the CDA and Disabled Peoples
   International (DPI), and how does this relationship affect the CDA’s policies and
   procedures?

4. What strategies are employed by the CDA to mobilize PWDs in Jamaica to
   participate in advocacy activities?

My choice of topic and research site represents the intertwining of my personal
and professional interests. I grew up in Jamaica as the child of a parent with a physical
disability; and I am also the parent of a child with a developmental disability. Although
my father was physically disabled and needed crutches to walk, I never thought of him as
“disabled” until I took my first disability studies class in college. Although he was not
employed in the “formal” sector, my father found ways to help support his family such as
repairing shoes, or making paper bags and selling them at the market. In retrospect, my
father was hindered more by social and economic factors than by his disability.

My interest in disability advocacy is influenced by my own involvement with
disability advocacy organizations in the United States. Accessing services in a country
with vast human and financial resources has not only made me aware of the challenges
that PWDs experience but also the overwhelming task that NGOs face, especially those
operating in countries with relatively limited resources. This has shaped my interest in
advocacy in the developing world and the challenges that local organizations face. I
chose the CDA as the case for study because 1) it is the first cross-disability organization
in Jamaica, 2) it is a part of a grassroots movement started by PWDs, and 3) it is involved
in advocacy at the national and international levels. As a founding member of Disabled
Peoples International (DPI), the CDA is a recognized leader in disability rights advocacy in the Caribbean.

Disability Legislation and Policies

Although Jamaica has not passed a national disability act, which is often seen as the “gold standard” for disability rights, its level of commitment to the rights of PWDs is demonstrated in passing the National Policy on Disability in 2000. Designed based on the requirements of United Nations Standard Rules, this document provides guidelines for providing opportunities to PWDs. However, the National Policy is not enforceable because it lacks legal sanctions (www.dip.org). The policy has the following purposes: 1) to set guidelines and direction for the Jamaican Government as it seeks to provide equal opportunities for PWDs, 2) to assist the government in strengthening its capacity to address disability issues within its area of functional responsibility, 3) to provide a framework for governmental agencies to incorporate in developing and implementing policies designed, 4) to provide equal opportunity for PWDs in all aspects of life, and 5) to assist government in implementing the United Nations Standard Rules on the Equalization of Opportunities for PWDs (JCPD 2001). The goal of the policy document is to “improve the status and conditions of PWDs, so that they can enjoy a better quality of life in areas such as education, employment, health, housing, transportation, and accessibility to all areas of the society” (JCPD 2001:20).

The CDA has been working with the Jamaican government to pass a national disabilities act. A moral document has been drafted, although it has been tabled in Parliament. If passed, this groundbreaking and comprehensive legislation would be the
first of its kind in the Caribbean (JIS 2004) because it not only mandates equal rights but also provides legal sanctions.

In the absence of a comprehensive legislation, local advocates continue lobbying efforts to secure rights and benefits by other means. For example, there have been amendments to the building code, modification to the National Traffic Act, changes in housing allocations, and revision to the income tax statutes as well as provide concessionary bus fares. These changes were intended to benefit all PWDs, but because of various limitations, many do not share them. For example, income tax concessions and the housing allocations only benefit those who are employed and concessionary bus fares only benefit residents in the urban areas of Kingston, St. Andrew, and St. Catherine.

**Definition of Terms**

The World Health Organization’s (WHO) attempts to universalize the meaning of disability, resulted in the International Classification of Impairments, Disabilities, and Handicaps (ICIDH), which was established in 1980. This version, of the ICIDH highlights the following three terms: impairment, disability, and handicap. *Impairment* refers to any “loss or abnormality of psychological, physiological, or anatomical structure of function” (WHO 1980, Ingstad and Whyte 1995). *Disability* refers to any lack or restriction, resulting from impairments. *Handicap* speaks of social disadvantages that persons experience because of their impairments. In 2001, the WHO revised the ICIDH to the International Classifications of Functions and Health (ICF). This document deals with body functions and activity limitations, and uses *functioning* as an umbrella term for both. It further defines *disability* as an umbrella term for impairments, activity limitations, or participation restrictions (WHO 2001).
The CDA and Jamaica Council for Persons with Disabilities (JCPD), the local governmental agency that implements Jamaica’s national disability policy, define disability as “any restriction or lack of ability to perform an activity in the manner or the range considered normal as a human being” (JCPD 2001:4). Such restrictions or lack of ability should be the result of an impairment (JCPD 2001). This definition will be adopted for the purposes of this study.
Chapter Two

Background

Overview of Jamaican History

Jamaica is the largest and most populous English-speaking island in the Caribbean. It was part of the British Empire from 1655 until its independence in 1962 and it remains a part of the British Commonwealth. Under British rule, thousands of Africans were brought to Jamaica to work as slaves on the island’s sugar plantations. Their descendants comprise the majority of the population of contemporary Jamaica. When slavery ended in 1938, “it left thousands of sugar cane workers without adequate means of support” (Payne 1995:16).

In addition to the thousands of former slaves left without adequate means of support, emancipation had other consequences for Jamaica. For example, free trade destroyed the monopoly of the sugar industry and peasant farming became the main means of subsistence. Many of these farms existed in some of the most remote areas of the country, often located on mountain slopes and not easily accessible. Some farmers took jobs with the sugar industry because their farms could not provide them adequate economic support. Facing dire economic conditions, many former slaves left Jamaica to seek employment overseas. Over the years, rural residents have migrated to the city of Kingston and have come to see it as the place to go in search of better opportunities.

Jamaica is divided into fourteen parishes and three counties. Kingston, the capital, is a modern city. Kingston and the urban areas of St. Andrew form the Kingston and St. Andrew Corporation (KSAC), the municipal body that governs the corporate area. Over the years, Kingston’s boundaries have extended northwards to include some areas
of St. Andrew, such as Half Way Tree and New Kingston, which is a hub for finance and business. The city of Kingston continues to expand in all directions for both residential and industrial reasons.

A significant development has been westward into the parish of St. Catherine in the area of Greater Portmore, a large residential development that is a “bedroom community” whose residents commute daily to Kingston for employment. Another urban area is Spanish Town, the capital of St. Catherine, located approximately 13 miles west of Kingston. Both Portmore and Spanish Town are connected to the municipal transportation system in Kingston, thus giving residents access to the city’s educational and employment opportunities. The development of these areas by the Jamaican government through the National Housing Trust (NHT), have made home ownership possible for many Jamaicans including several PWDs. Most of these PWDs were able to acquire homes in these areas because of a government policy that stipulates that five percent of all homes built by the NHT must be allocated to PWDs. The CDA considers this one of its advocacy achievements.
CDA and the Jamaican Movement

The disability rights movement in Jamaica started in the 1970s and spread to other parts of the Caribbean (Gayle and Palmer 2005). It began with the Progressive Blind Association (PBA), led by blind persons who had been dissatisfied with the leadership at the Jamaica Society for the Blind (JSB), the agency that oversaw the welfare of blind persons. The JSB excluded blind persons from participating in the decisions of the organization. However, through activism, they assumed leadership of the organization and were successful in improving services for persons who were blind and/or visually impaired. Although the JSB and other similar organizations were successfully advocating for blind persons, all PWDs were experiencing discrimination and exclusion from fully participating in society. As a result, the Combined Disabilities Association (CDA) was formed to advocate for Jamaica’s wider disabled population, in 1981. The emergence of the Jamaica’s disability movement, the formation of the CDA and its
subsequent role in the international disability rights movement were attributable to a combination of factors that occurred locally and internationally.

The 1970s was a tumultuous time as various movements were emerging. In Jamaica, for example, PWDs were influenced by the success of the American Civil Rights Movement of the 1960s and the asserting of rights of the Black Power Movement of 1970s and saw it as time to assert their rights. Activists were further strengthened by the democratic socialism ideology of the former Prime Minister, the late Michael Manley. He “urged Jamaicans to be active in their development by partaking in the decision-making process, particularly on matters affecting them” (Gayle and Palmer 2005:6). Many PWDs found this to be relevant to their experiences with charitable organizations that were providing services to them. These organizations had adopted a charity approach, which excluded PWDs from participating in the decisions that affected their lives.

In addition, Manley’s administration instituted numerous social reforms, transforming the standard of living and the expectation of the Jamaican people. For example, programs such as “a minimum wage for all workers, free secondary and university education (to the extent that it was available), paid maternity leave, though mild by the standards of advanced capitalist countries, were far-reaching for a Third World country” (Kauffman 1985:1-2). As Kauffman (1985:2) asserts, “this was a genuine attempt at profound social reform.” These policies also had implications for disability rights activism in Jamaica. Manley’s ideology, therefore, influenced disability rights activists to participate in changing the conditions of their lives (Gayle and Palmer
When blind persons gained leadership of the JSB, it also helped to strengthen the resolve of other persons with disabilities.

On an international level, the United Nation’s declaration of the IYDP incited much activity from PWDs around the world. In addition, to the declaration of a new framework, it brought support to help with the formation of national groups. DPI was also formed in 1981, and the CDA became one of the founding members. Their support helped to strengthen the Jamaica movement, bringing them to the forefront of disability activism in the Caribbean (Gayle and Palmer 2005). As a member of DPI, the CDA is part of the Caribbean and North American region and represented on the DPI World Council which meets with the United Nations.

As the first cross-disability group to be formed in the Caribbean, the formation of the CDA brought national attention to the issues affecting PWDs throughout the Caribbean. As a non-governmental organization, the CDA receives a small subvention from the Jamaican government and relies largely on grants and donations. It is governed by a 12-member board led by a chairperson who oversees board activities. Board members are elected by the general membership to include persons from the four major disability groups: deaf and/or hearing impaired, physically impaired, blind and/or visually impaired, and mentally or cognitively impaired. Finding a representative for cognitively impaired individuals is often difficult; therefore these persons are usually represented by a non-disabled individual and sometimes the positions remain vacant. The CDA also has a staff of four managed by the coordinator/director who is responsible for the organization’s administrative functions.
The CDA is primarily an advocacy organization and claims several advocacy accomplishments. These include greater accessibility to public building, concessionary bus fares in the city, five percent housing allocation, and income tax exemption. However, many disabled Jamaicans cannot access benefits because they are unemployed. The CDA is lobbying for the passage of legislation to give deaf people the right to have driver’s licenses without restrictions as well as appropriate accommodations during testing. Currently, deaf persons can receive driver’s licenses but they have to be retested annually, which is unacceptable to activists, especially because deaf visitors from other countries do not have any driving restrictions when they visit Jamaica (Jamaica Information Service 2004).

Without duplicating the services of other agencies, the CDA provides a limited number of social services to its members. Over the years, these have included distribution of a limited number of grocery items, the provision of personal loans, and referral services. However, some of these are no longer available. In 1983, the CDA also established Diversified Economic Enterprises for Disabled Self-help (DEEDS) Industries, Limited, a company that manufactured wooden arts and craft items. This provided employment for approximately 65 persons, most of whom were PWDs.

**The Prevalence of Disability in Jamaica**

Though believed to be significant, the extent of need among persons with disabilities in Jamaica is unknown, largely because there is no accurate estimate of the total disabled population. Data on this population comes from the two main sources: the World Health Organization (WHO) estimate, and the 2001 Population Census. However, those two sources are in dispute with each other.
According to WHO’s estimate, 260,763, or 10 percent of Jamaica’s population is disabled. Both activists and researchers agree that this is an overestimation because the formula used is based on the assumptions about the causes of disabilities that are outdated (Ingstad 2001). According to the 2001 Population Census, the number there are 161, 673 PWDs or 6.2 percent of the population. According to researchers at the Statistical Institute of Jamaica, this number is inaccurate because of several limitations with the last census which prevented several persons from being counted. For example, it was difficult to gain access to PWDs living in institutions (Bartley 2001) or in some remote rural communities. Moreover, these figures are hampered by the inconsistencies in the definition.

**Services for Persons with Disabilities**

The two main areas in which disability services are provided are health and education. Jamaica was one of the first countries to develop a national system, starting as early as 1921. However, it was not until the early 1970s that the contemporary health care delivery system was developed (Leavitt 1992). In 1974, Ministry of Health and Environmental Control green papers entitled “The Health of the Nation, Proposal for a National Health Service” defined health as the attainment of all citizens of a state of complete physical, mental, and social well being and not merely the absence of disease and infirmity. This expanded the system to include preventative care through the institution of Primary Health Care (PHC). Currently, primary health care is provided through public health clinics located in communities across the island. As Leavitt (1992) states, the health system did not provide any specific services for PWDs. Rehabilitation services are administered by a different agency other than the health care system (Leavitt
1992). However, these services are usually limited to the corporate area of Kingston and St. Andrew.

Unlike the health system, the education system was not accessible to most Jamaicans until the early 1970s. Prior to 1944, a dual system of education existed as the government ran primary schools but secondary schools were operated by private institutions such as churches (Moore and Johnson 2004). This meant that only the upper and middle classes were able to attend secondary schools. In 1953, the Ministry of Education was established, leading the way for the development of a national education policy. Although the government’s goal in the 1960s was to build an adequate number of primary and secondary schools, it was not until the 1970s that the education system began providing adequate educational opportunities for the majority of Jamaicans. For example, in 1973 the government, as part of its social reform policies, instituted universally free secondary and college education. While at the secondary level Jamaica was providing education for all Jamaican students, the tertiary level, which included the College of Arts Science and Technology (now called University of Technology) and the University of the West Indies, were serving the needs of students in the entire Caribbean. In 1982, the government expanded post secondary education by establishing the Human Employment and Resource Training Program (HEART) to provide skills and employment training for unemployed youth after they completed high school (www.moec.gov. 20005). However, most of these services were not available for PWDs.

Historically, services for PWDs in Jamaica were provided by charitable organizations. Most of these services have been concentrated in Kingston, which made them largely inaccessible to persons in the rural areas. One of the first government
facilities to provide rehabilitation services was the Sir John Golding Rehabilitation Centre (formerly Mona Rehabilitation Centre) which was established in 1953 and located in Kingston, adjacent to the University of the West Indies. This was established in response to the polio outbreak and served only the most severe cases of individuals with physical disabilities. In 1956, the School of Hope for children with mental retardation was established. Non-governmental agencies such as the Jamaica Association for the Deaf, which was established in 1938, operated schools for deaf children and the Salvation Army School for the Blind operated schools for blind children. However, these services were usually located in major urban areas. And even so, they did not prepare individuals for participating in community life. Although there are many adults with disabilities, most services have been aimed at children and young PWDs.

In recent years, the government has assumed a larger responsibility for disability services; however, many services are still being provided by NGOs that rely largely on private donations. In 1973, the government made a major step toward providing for PWDs by establishing the Jamaica Council for Persons with Disabilities (formerly Jamaican Council for the Handicapped). This agency, which is an arm of the Ministry of Labor and Social Security, is responsible for implementing the National Policy on Disability which includes the provision of limited rehabilitation services such as a guidance and training center in Kingston that accommodates 45 students, one sheltered workshop in Kingston that employs 12 persons, and two training workshops in the parishes of Clarendon and Hanover. It also operates a hostel for girls and young women with disabilities who need residential accommodations in order to access training and employment opportunities in the corporate area of Kingston and St. Andrew.
The Ministry of Education began implementing a project to establish a formal special education program in Jamaica in 1989; to that end, the Special Education Administrative Unit was established to supervise special education services across the island. In 1998, the first module on special education was introduced to all teachers’ colleges in Jamaica, providing teachers with a basic understanding of children with special needs (www.moec 2005). Currently there are three institutions offering training in Special Education: University of the West Indies and Mico Teachers’ College in Kingston, and Sam Sharpe Teachers’ College in Montego Bay. Training programs were all designed to prepare teachers to accommodate special needs students.

Educational services for children with disabilities have improved considerably since the 1970s. There are now schools for children with mental retardation, schools for the deaf, and schools for the blind and some students with impairment are being accommodated in the regular classroom. In addition, there are early stimulation programs for children of preschool age. These programs are provided through the Ministry of Education along with the assistance of NGOs. Special education services are now available to some children with special needs at the primary school level, albeit mostly in the larger urban areas.

In an effort to address the educational needs of children in the rural parishes, the government has established six special education units, five of which are in rural parishes. Funded by the Dutch government, these units act as resource facilities for the schools that are attached to them and to schools located nearby.
### Table 1- List of Agencies Providing Services for Persons with Disabilities

<table>
<thead>
<tr>
<th>NAMES OF AGENCIES</th>
<th>SERVICES OFFERED</th>
<th>LOCATION</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Non-Governmental Agencies</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3D Project</td>
<td>Education, Advocacy and Support</td>
<td>St. Catherine, Clarendon, St. Thomas</td>
</tr>
<tr>
<td>Abilities Foundation</td>
<td>Vocational Education</td>
<td>Kingston</td>
</tr>
<tr>
<td>Caribbean Christian Center for the Deaf</td>
<td>Education</td>
<td>Manchester</td>
</tr>
<tr>
<td>Christian Deaf Fellowship Center</td>
<td>Education</td>
<td>Kingston</td>
</tr>
<tr>
<td>Clarendon Group for the Disabled</td>
<td>Advocacy and Support</td>
<td>Clarendon</td>
</tr>
<tr>
<td>Combined Disabilities Association</td>
<td>Advocacy and Support</td>
<td>Kingston</td>
</tr>
<tr>
<td>Covenant Christian Academy and Children’s Centre</td>
<td>Education</td>
<td>Kingston</td>
</tr>
<tr>
<td>Danny Williams school for the deaf</td>
<td>Elementary level education for deaf children</td>
<td>Kingston</td>
</tr>
<tr>
<td>Disabled Peoples Organization of the Caribbean</td>
<td>Advocacy</td>
<td>Kingston</td>
</tr>
<tr>
<td>Eastern Disabilities Association</td>
<td>Advocacy and Support</td>
<td>Portland</td>
</tr>
<tr>
<td>Genesis Learning Centre</td>
<td>Education</td>
<td>Kingston</td>
</tr>
<tr>
<td>Jamaica Association for Children with Learning Disabilities</td>
<td>Advocacy</td>
<td>Kingston</td>
</tr>
<tr>
<td>Jamaica association for Mental Retardation</td>
<td>Operates the School of Hope facilities</td>
<td>Kingston</td>
</tr>
<tr>
<td>Jamaica Paraplegic Sports</td>
<td>Recreational</td>
<td>Kingston</td>
</tr>
<tr>
<td>Jamaica Society for the Blind</td>
<td>Advocacy</td>
<td>Kingston</td>
</tr>
<tr>
<td>Lister Mair Gilby School for the Deaf</td>
<td>Education</td>
<td>Kingston</td>
</tr>
<tr>
<td>National Parent Advocacy Group</td>
<td>Advocacy</td>
<td>Kingston</td>
</tr>
</tbody>
</table>
Table 1 Continued

<table>
<thead>
<tr>
<th>NAMES OF AGENCIES</th>
<th>SERVICES OFFERED</th>
<th>LOCATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>School of Hope</td>
<td>Education for children with mental retardation</td>
<td>Kingston and 29 satellite sites</td>
</tr>
<tr>
<td>St. Christopher’s School for the Deaf</td>
<td>Education</td>
<td>Kingston</td>
</tr>
<tr>
<td>Western Disabilities Association</td>
<td>Advocacy and Support</td>
<td>St. Ann</td>
</tr>
<tr>
<td>Woodside School for the Deaf</td>
<td>Education</td>
<td>Clarendon</td>
</tr>
</tbody>
</table>

**Governmental Agencies**

| Jamaica Council for Persons with Disabilities | Implements national disability policy; offers rehabilitation services | Kingston, St. James, Manchester, and Clarendon |
| Mico Care Center (Ministry of Education)     | Educational assessments and placements           | Kingston                           |
| National Children’s Home                    | Orphanage                                       | Kingston                           |
| Olstends Hostel for Girls (JCPD)            | Housing                                         | Kingston                           |
| Sir John Golding Rehabilitation Center      | Rehabilitation and a variety of support services | Kingston                           |
| Special education Unit, Ministry of Education | Coordinates special education services           | Kingston                           |
Chapter Three

Review of Literature

The study of disability has traditionally been interdisciplinary, encompassing a wide range of academic literature. However, this area of study has consistently held a marginal place in the social sciences. These works mostly reflect the disability experiences of North America and Europe; moreover, they offer a limited perspective on PWDs because they tend to present them in terms of deficits or incompetence. There is a noticeable absence of research on the disability rights movement even when the social movement literature is taken into account. Disability studies as a recognized interdisciplinary field emerged during the 1980s as the academic counterpart to disability rights advocacy (Longmore 2003). Longmore suggests that “the danger is not that we [academics] will ignore disability, but that we will reach intellectual, socio-cultural, ethical, political, and policy conclusions about disabled people without examining the ignorance, fear, and prejudice that deeply influence our thinking” (Longmore 2003:3). He further argues that paradigms such as the medical model of disability have influenced the academic considerations of disability. However, the emergence of disability studies is an example of how interests are re-focused.

Models of Disability

The Medical Model

Like most Western societies, Jamaica approached disability using the framework of the medical model. The establishment of the Sir John Golding Rehabilitation Center in the 1950s to treat persons who were victims of the poliomyelitis epidemic of the 1950s and 1960s became the major rehabilitation facility of the Caribbean. Focusing primarily
on persons with physical impairment, rehabilitation mainly involved medical services, including numerous surgeries some of which were experimental.

According to many former residents and patients of the Mona facility, they were not taught anything about advocacy or rights and did not expect society to accommodate them; instead, they had to adapt to the inaccessibility of the societal physical environment. Therefore, many of these individuals were unable to access public buildings or public transportation without assistance from others. As Longmore (2003) suggested, the medical approach to disability was a barrier to the social integration of PWDs in society because service providers focused on treating the impairment but ignored the societal barriers that excluded PWDs from fully participating in society.

The Charity Model

Likewise, the charity model assumes that PWDs need to be cured or pitied (Kluth 2006). By presenting these individuals as helpless and deserving pity, proponents of the charity model often solicit money to support organizations that provide services to disabled individuals. In Jamaica, the charitable model has its roots in the country’s colonial past. During this period, several charitable organizations were established to care for the indigent and the disabled. Most of these were operated by the wives of colonial officers from England whose responsibility was to perform charitable work. The Salvation Army School for the Blind and the Jamaica Society for the Blind were both established as charitable organizations to care for blind persons. Many blind persons were given a secondary education and very limited job skills. These job skills were often utilized in sheltered workshops where they received little or no compensation. As a
result, some of these persons depended on begging for income; while others used their musical talents to perform on the roadside for donations from passersby.

The charity model has been internalized by many Jamaicans. As a result, some people continue to see disabled persons as needy and requiring someone to take care of them. For example, some people are often eager to assist and do not see PWDs as individuals who might take some initiative for themselves.

The Social Model

The social model challenges both of these perspectives because rather than viewing disability as a “problem” stemming from within the individual, it views disability as a consequence of social structures and processes that hinder people with impairments from fully participating in society (Priestly 2003). This model, which originates from the British disabled people’s movement, distinguishes disability from impairment; thus, claiming that “disability is something that is imposed on top of impairment” (Priestly 2003:14, UPIAS 1976). According to this perspective, the deliberate and unnecessary exclusion and isolation of persons with impairments from participating in society is a direct result of this negative treatment. Therefore, the social model emerges as correction and considers persons with impairments as a minority or oppressed group (Priestly 2003) rather than victims of individual and tragic circumstances (Oliver 1990). This model has been adopted by contemporary practice and study of disability; and though not always explicitly stated, it is foundational to the work of social scientists and many applied scientists addressing the topic of disability.

For example, scholars such as La Grow and Daye (2005) used the social model as a point of reference in investigating the challenges that persons with impairments
experience as they seek to fully participate in society. In exploring the barriers to employment experienced by blind and visually disabled people in New Zealand, these authors found that 90 percent of participants believed that their impairment prevented them from finding a job. Accessible work environment, discrimination from employers and coworkers, and underestimation of their capabilities were some of the primary barriers that they highlighted. This is significant considering that New Zealand has adopted a national policy to promote the full inclusion of PWDs.

Kohrman (2003), while investigating the definition of disability in China, found that in an effort to ensure that PWDs receive equal access to employment, the government instituted a quota system that stipulates that businesses hire a specific percentage of disabled persons. This is enforced through the issuing of identification cards to persons who fit the state’s definition of disability. However, the state’s definition is often baffling as individuals who are obviously disabled are often denied disability status. Kohrman’s work demonstrates the challenges that arise as societies seek to define and codify standards for equality of these persons. As Kohrman concludes, “the people who formally codify disability and create government assistance programs for the disabled” usually have no experiential knowledge of impairments.

Estoff (1997) also addressed a similar issue in the United States as she studied the barriers that persons with severe persistent psychiatric disorders encounter when they apply for Social Security and Disability Income. This study reveals the societal treatment of persons with psychiatric disorders who receive “doubly marginal” treatment by being “unwelcome both in the non-disabled and the disabled communities” (Estoff 1997:1). Her work not only clarifies the reasons why persons apply for disability income; but it
also demonstrates that the denial of these benefits combined with discrimination prevent
them from having a viable role in the society.

Pawlowski’s (2001) work portrays persons with impairments as staff in a medical
rehabilitation hospital. In this facility, they occupy various roles such as rehabilitation
counselors, nurses, and aides. However, this does not mean that they are fully accepted
by non-disabled colleagues and coworkers. This work demonstrates that persons with
impairments are viable contributors to society, even positions not typically held by
PWDs. Pawlowski does not suggest that these individuals are fully accepted without
resistance. In fact, she found that despite their achievement of professional status, they
“constantly struggle to prove their competence to colleagues and coworkers without
disabilities” (Pawlowski (2001:72).

Although the disability movement has exposed society to the social model, various
aspects of the medical and charity models still exist in Jamaican society. Arguably, as
individuals seek to understand the meaning of disability, they negotiate between the
approaches depending on what they are trying to accomplish. For example, many rural
residents who express the belief that disability is the result of supernatural causes still
turn to medical professionals for answers and cures to their disabling conditions. Others
believe that persons with certain disabilities such as blindness should not live
independently; instead they should have someone to care for them.

Constructivist Theory

The constructivist perspective is central to the social model of disability and it has
been influential in both academic disability studies and in the disability rights movement,
the major accomplishment of which was the reconceptualization and reframing of

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disability. This perspective is predicated on the idea that “everyday life and social phenomena are socially constructed” (Berger 1966:1). In other words, individuals interpret their daily experiences by employing subjective meanings based on the “coherent social world within which they exist” (Berger 1966:22). Although often treated as objective facts, these meanings not only differ from culture to culture but they are also changeable within a culture. For example, Groce (1985) in her study of heredity deafness in Martha’s Vineyard found that although deaf persons were marginalized in most of American society, they were fully integrated in this community. Deaf residents were so much a part of the community that when older Vineyarders were asked to name some of the deaf persons they could not remember who were deaf and who were not because “everyone spoke sign language.” The extent to which hearing persons in this community went to accommodate deaf persons was very different from the rest of American society. In fact, when tourists who did not know sign language started coming to the Vineyard, they treated deaf persons differently from the community members.

Brogan and Taylor (1989) studied institutionalized persons with severe or obvious disabilities in the United States and found that non-disabled persons in contact with them did not “stigmatize, stereotype, or reject” them. Because of their bond with the disabled individuals, these family members and workers alike understood them even though in some cases, they were only able to use limited gestures and sounds. In some cases the non-disabled individuals developed such close bonds with the disabled individuals that they were able to understand them by imagining how they would feel if they were in a similar situation.
The ways in which PWDs are treated within a culture are dictated by the beliefs, attitudes, and values of that culture. In fact, cross cultural studies (Ingstad and Whyte 1995) reveal the various ways that disability is constructed and the cultural beliefs and values that dictate these treatments. For example, Devlieger (1995:95) found that “whereas the concern of Western societies is to improve the lives of PWDs, among the Songye of Zaire, their primary interest is explaining why they are as they are [disabled].” In order to find answers to the causes of disability, the Songye look to their physical environment, to their social relationships, or to God. For example, they believe that “the non-observation of food prescriptions and sexual taboos by expectant mothers may results in their child being born with a disability” (Devlieger 1995:99). Disability that is obvious at birth is usually attributed to sorcery, but only if the mother remembers having bad relations with a family member or close relative. For example, “the cause of spasticity in a child was attributed to sorcery because the mother remembers having an argument with her brother-in-law while she was pregnant. He told her that she would vomit out her child instead of delivering it in a normal way. The disability occurred because the mother never forgot the incident; instead, she believed that she was the victim of sorcery” (Devlieger 1995:100).

The Songye also has a very strong belief in reincarnation. Therefore, if a child is born with certain characteristics, he/she is often considered an ancestor or a friend who has returned to the family (Devlieger 1995). In this case, the child is believed to have the “spirit of the ancestor.” In the case of a child born with a clubfoot, an ancestor was assumed not to have been properly buried; his coffin was too small, for example, so that his legs were pressed too much. Disability as caused by God is the most widely used
explanation among the Songye. According to Devlieger, when the cause of disability cannot be deciphered in social-familial terms, God, an absolute and unknown force, remains as the only possibility and final cause.

According to Devlieger (1995:94), these traditional beliefs, which are rooted in the Songye’s worldview, “have to be understood before the implementation of any kind of services. The understanding of cultural beliefs provides a basis for dialog between service providers and persons with disability.” Devlieger’s findings among the Songye are similar to those of Leavitt (1992) and Thorburn (1998). These authors investigated the meaning of disability in several, mostly rural Jamaican communities. The studies focused on the beliefs and attitudes of parents and community members about childhood disability. The findings were to be used in the implementation of a community-based rehabilitation project. Thorburn (1998) worked in three different communities, one urban, and two rural, where she conducted a survey to assess local attitudes toward disability prior to embarking on a public education program. Her findings revealed that a significant minority of Jamaicans in these communities believed that disabled children are sent from God (40 percent), that the disabling conditions were caused by evil spirits (18 percent), were punishments, or were the results of a pregnant woman looking at a disabled person. Like the Songye, residents of these communities were more concerned with the etiology of the disability than with living with the disability.

Thorburn’s study was primarily concerned with the implications of these beliefs and program implication. However, Gayle and Palmer (2005) elaborate on the effects of attitudes on the disability experiences in Jamaica. These authors claim that negative attitudes from the public, including family, community, and government devalue the
humanity of PWDs resulting in their isolation and exclusion. They also suggest that the local interpretation of the source of disability determines acceptance and treatment of PWDs which may result in negative or positive attitude. The existence of negative attitudes has implications for the CDA, the premier disability rights group in Jamaica, because it promotes the full inclusion of PWDs in society. However, taking into account the existence of negative beliefs and attitudes, this study also looks at the Jamaican class structure as a factor that prevents these individuals from achieving equality and full participation in their society.

**Disability and Social Class**

Class is a term often used to describe a group of persons who share a common relation to the means of production and one of the factors that might determine the stratification of society. In societies where there is a class structure, individuals with weak relations to the means of production are usually part of the lower classes. Conversely, those who control land, capital, and labor are considered part of the ruling class.

Although disability is not usually discussed in terms of class, a mutual relationship exists between poverty and disability (UN 2006). According to the UN, while the risk of impairment is greater for the poverty stricken, the converse is also true. People living in poverty tend to become disabled because of aggravating factors. According to the UN, these factors include malnutrition, sub-standard housing, hazardous occupations, and heightened exposure to violence. On the other hand, PWDs are more likely to become impoverished because they lack jobs or access to income, basic social and medical services, and rehabilitation. Disability also has an economic
impact not only because it creates additional hardships for people who are already poor (Marfo 1994), but also because PWDs are disproportionately unemployed and underemployed and their incomes are below those of non-disabled individuals (Schriner and Scotch 2001).

In spite of the relationship between disability and poverty and the discrimination experienced by PWDs, there are considerable differences in the quality of life of disabled persons depending on their socioeconomic statuses. As Charlton (1998) points out, PWDs with adequate financial resources have no problem procuring the most modern assistive devices, services, and personal aids. These differences are evident in Jamaica as some PWDs who have the economic means travel to the United States and England for medical care or attend college while others have never attended school or received any rehabilitative services. Some persons with physical disabilities are able to acquire motorized wheelchairs through their own resources while others wait for several months to get a manual wheelchair from Food for the Poor, a charitable organization in Jamaica. However, the social and economic structure in Jamaica combined with lack of opportunities for PWDs have forced many of these individuals into a cycle of poverty.

Class structure in Jamaica

Understanding social class in Jamaica requires looking back at its colonial past. Starting with the enslavement of thousands of Africans and the establishment of a plantation economy, the highest rewards from the market went to those Jamaicans who controlled extensive investments in both land and capital” (Austin 1984:3). During this period, a color-based class structure was established where blacks were considered inferior to whites. When slavery was abolished, “it left thousands of sugar cane workers
without adequate means of support” (Payne 1995:16), leading to the social and economic hardships. Many of these individuals became peasant farmers. In addition; they seek alternate employment within the sugar industry. In search of better opportunities many migrated to Kingston and those who could afford it migrated to foreign countries such as England and later on the US and Canada. Traditionally, living conditions in the rural communities were characterized by lack of modern amenities, and social services such as health care, educational facilities, electricity, and clean drinking water.

Contemporary Jamaica inherited a color-based class structure that is beneficial to white and light skinned Jamaicans while detrimental to the darker skinned Jamaicans. This inequality permeated all aspects of the society preventing darker skinned Jamaicans from gaining access to education and employment. This was also evident in the leadership of the most prominent disability organizations that predate the disability rights movement. An activist, Walker, explains

“In those days Society for the Blind was run by Lady V. a whole lot of them Lady so and so. They were white people from England as part of the Royal Society for the Blind. Their husbands were professionals [in Jamaica] and their wives wanted something to do so they let them run it (Tucker 2006:10 n).

Although the “social class-color hierarchy is no longer rigid, white and light skinned persons are generally of higher social status” (Leavitt 1992:57). As Leavitt explained, this condition occurs mostly in big cities and the superiority of whites and inferiority of blacks are continually reinforced. In addition to white or light skin color, level of education, occupation, neighborhood of residence, and the type of car that one drives are all status indicators. As a consequence of this hierarchy, persons who are in
middle or upper classes had access to the best schools which were only available to those who could pay for it. Over the years, there have been several legislative changes that have been instituted to offer equal opportunities to all Jamaicans. These included free education from primary to the tertiary level which was instituted in the 1970s. This has resulted in the changes of faces in private and public sectors as most of these jobs are held by dark skinned Jamaicans. This serves as evidence to many that with education they can achieve economic success. Consequently, Jamaicans see education as a means of advancement and a marker of high status. However, with changes in Jamaica’s politics and economics, benefits such as free education have been curtailed making education beyond the primary level unaffordable for many poor families, especially those living in the rural areas. This value for education and economic advancement is shared by PWDs in Jamaica. For example, most of the PWDs whom I met, if they were educated they were very proud of their achievements and if they did not have the opportunity they were still trying to become educated.

In promoting “equality and full societal participation,” CDA attempts to offer educational and training opportunities to PWDs. However, limited funding allows these opportunities to be made available to only a limited number of persons, most of who live in urban areas.
Chapter Four

Methodology

In order to understand how the CDA organizes strategically to meet the needs of the broader disabled population of Jamaica, the following questions were explored:

1. How is “disability” constructed within the context of Jamaican culture?
2. How did CDA members negotiate their original involvement and level of participation with the organization?
3. What is the nature of the linkage between the CDA and Disabled Peoples International (DPI), and how does this relationship affect CDA’s policies and procedures?
4. What strategies are employed by the CDA to mobilize PWDs in Jamaica to participate in advocacy activities?

I conducted an ethnographic case study of the CDA using participant observation, semi-structured interviews, open-ended group interviews, informational survey, and document review. This study was conducted in two phases. The first phase involved establishing rapport and laying the groundwork for second phase of data collection.

My fieldwork in Jamaica took place over a seven-month period from December 2005 to July 2006. My tenure with the CDA involved balancing the roles of researcher, volunteer, and sometimes friend and confidant. As researcher, I was committed to following the regulations of the university’s Institutional Review Board (IRB) and the ethical code of the discipline of anthropology to “do no harm” not only to my informants which included the entire community of disabled persons who were all potential informants, if not in my study, in future studies. I considered it a privilege that these
individuals allowed me to share in their experiences and tried to give back as much as I could by volunteering my time wherever I was needed. This involved staying late to work on projects, helping out at CDA events and assisting with transportation when it was needed.

I reported to the CDA’s office most days except when I was out conducting interviews. While at the office, I assisted with various duties ranging from the preparation of grant proposals to the distribution of food items. Sometimes my activities would include helping someone to prepare a resume, or to access email. I also accompanied the staff and board members to seminars and workshops. I tried to immerse myself into the lives and experiences of the CDA and its members, as much as a non-disabled person could. This involved sharing in their joys, tragedies, and personal losses such as the death of a beloved advocate for the cause of the deaf. One of the most striking experiences was learning that a CDA member had been raped. The empathy and support expressed by the other members revealed the closeness and commitment that they share. By participating in these activities, I became acquainted with the CDA and the JCPD staff members, many of whom are disabled.

**Entering the Field**

During this phase (December 2005 to March 2006), I established rapport with CDA members by attending CDA events. This included traveling with staff and board members across the island to conduct training seminars on disaster preparedness, designed specifically for PWDs. I also started conducting participant observation at the CDA office, selected study sites, and identified participants for individual and group interview.
**Study Sites**

This research was conducted in four sites in Jamaica: Kingston, and the parishes of Portland, St. Catherine, and Clarendon. From the outset, I knew that I would be working in Kingston but I was not sure in what other areas I would be collecting data. In fact, my selection of sites was made based on the availability and the willingness of persons to participate. However, as best as possible I tried to include both rural and urban communities and persons with all different types of disabilities.

I first made contact with the CDA in Kingston in the summer 2005, through the Caribbean regional representative of DPI, who is also a member of the organization. I found her contact information at the DPI website and contacted her by telephone. After explaining my research to her, she suggested that I contact the director, in Kingston. I met with her in May 2005 and discussed my interest in making the CDA the focus of my study. During our meeting, she gave me background information on disability rights movement in Jamaica and the origin of the organization. Then she shared some of her experiences with the movement and her subsequent employment with the CDA. She was excited that I wanted to conduct research there because although students had interned with the organization in the past, they were local individuals; I would be the first doctoral candidate.

I began volunteering with the CDA in December 2005, and continued there until June 2006. Upon my arrival in December, I was introduced to the CDA staff as well as the employees of the JCPD, whose office is located on the same premises as the CDA. Both agencies work in close collaboration. I was also introduced to the canteen staff as a CDA worker. This afforded me the privilege of paying the employee price for lunch.
During this period, I attended activities for the annual Disability Awareness Week, monthly rap sessions, and Christmas social.

Through the help of the CDA’s director, staff, and board members, I made contact with members and other disability service organizations. This included having a staff person accompany me on visits to rural communities to help me navigate rural terrain. The CDA did not have any stipulations about whom I could talk to or where I could go; instead, the staff gave me access to members and expected me to honor their trust. Persons were very open and frank with me and if they did not want to participate, they would let me know.

Portland was selected because it has a CDA affiliate group called the Eastern Disabilities Association (EDA). The EDA covers three parishes, Portland, St. Mary, and St. Thomas. However, only Portland residents were included in the study. I first became involved with members in this area during a regional workshop held by the CDA in St. Mary. At the end of the workshop, the coordinators requested my assistance in networking with national and international disability organizations. I stayed in contact with them but did not begin my research there until June 2006.

My first involvement with the Clarendon group began when I attended a CDA outreach event in May Pen, the capital of the parish. This visit allowed me to establish contact with the JCPD field officer in the area. My initial plan was to get a list of PWDs living in the parish; I would then contact the listed persons individually. However, after meeting with the field officer, I received a few names of individuals who were scattered throughout the May Pen area. After spending a day visiting homes, I was unable to contact many of the individuals. I was to able to schedule a focus group for a week later
but only one person attended. Finally, with the help of the CDA’s field officer, I was able to establish other contacts in the District of Milk River, which is located at a different part of the parish. I made about three visits to this community which is located several miles outside of May Pen. With the exception of one resident, these persons had no affiliations with the CDA. Some of them had never heard of the organization or the JCPD.

St. Catherine, on the other hand, was selected because although it is largely a rural parish, it has two major urban areas, Spanish Town, the capital, and Portmore. In addition, a large number of disabled persons reside there, including several CDA members. Most of the participants in the study who live in this parish are from the areas of Portmore, Spanish Town, and Old Harbor. On my visits to Spanish Town and Old Harbor, I conducted interviews with CDA members. I did not conduct any focus groups in St. Catherine, but several of the participants in the Kingston group reside in the Portmore area.

**Data Collection Plan**

In order to answer the research questions, I conducted an ethnographic case study of the CDA, using multiple data collection techniques. These included: informational survey, open-ended group interviews/focus groups, semi-structured interviews, participant observation, and document review. Ethnography is about understanding a local situation from the perspectives of the people living there. However, with the involvement of various actors, there are often multiple perspectives that sometimes appear to be in conflict with each other. However, the use of multiple methods allowed me to check and recheck the validity of responses by using my understanding of what I
was learning in the field. My study only spans a single period in 2006 but the CDA has
been in existence for 25 years. By reviewing the organization’s records, I saw the
various strategies that they used in the past, some of which are no longer being utilized.
This verified some of the information that I received from informants, who had been with
the organization for several years.

Informational Survey

The informational survey was designed to collect information on the social
composition of the CDA and the involvement of CDA members with the organization.
The instrument was divided into two parts with the first part eliciting demographic data
including gender, area of residence, type of impairment, and socioeconomic status (SES).
SES was measured using the participant’s response to three questions. Firstly,
participants were asked to select one of the seven responses to the question: Please
indicate your highest education level that you attained. These included primary or
elementary, secondary, high school, undergraduate degree, college certificate, graduate or
post graduate degree, and other. The other option allowed participants to write in a
response that was not indicated on the survey. Secondly, they were asked to write-in
their responses to the question: What is your occupation? Thirdly, they were asked to
indicate “yes” or “no” to the question: Are you employed? For the purposes of this
research, SES was defined as a component concept with multiple measures of education
level, employment, and occupation (Bollen et al). The second part consisted of five
open-ended questions aimed at assessing member involvement and level of participation
with the organization. The areas covered were: 1) length of membership, 2) volunteer
positions held with the CDA, 3) participation in the CDA activities, 4) prior involvement with the CDA, and 5) how they learned about the organization.

The initial idea was to administer the survey to all CDA members. However, an exact number of CDA members were not known. For example, although the CDA believes that there are over 2000 members, the membership forms and attendance sheets only accounted for 289. From reviewing both documents and my knowledge of the organization, I could account for approximately 300 members. These included individuals who had attended the last two annual general meetings, had a membership application on file, or who were referred to me by CDA members and staff.

My intention was to distribute these forms to members at the CDA events such as the Annual General Meeting (AGM), an event attended by most CDA members, and monthly rap sessions. However, this strategy proved to be unsuccessful because the AGM was not held in 2006 and because the CDA events were not always conducive to completing the survey. The survey would also be administered to members who visited the CDA office. Although I completed some surveys using this method, the majority of CDA members did not visit the office. I also completed some of the surveys by telephone; but this strategy proved to be too costly. Nevertheless, I was able to complete 55 questionnaires. However, only the second part of the survey will be analyzed as demographic information was acquired from the membership forms, which yielded a total of 289 members. The results of the completed surveys were used to help determine member involvement with the organization.
Open-ended Group Interviews/Focus Groups

Group interviews were conducted in three locations: Kingston, Portland, and Clarendon. The purpose of these group interviews was to gain a better understanding of the local ideas and attitudes about disability. This method was chosen because it offers the opportunity to identify a range of responses and opinions on the topics (Schensul et al 1999). This method also afforded me the opportunity of collecting a large amount of data in a relatively short period from a large number of people than would be possible in a single interview.

Since the ideas about disability tended to vary between urban and rural areas, the initial idea was to conduct four group interviews: two in the urban area of Kingston and two in the rural areas of Portland and Clarendon. Because ideas about disability are believed to be different between urban and rural areas, I ensured that interviews included participants from both areas. In addition, based on the assumption that CDA members would be exposed to various educational seminars about disability, it is possible that their views about disability would be different from that of non-CDA members. Therefore, non-CDA members were included. The Clarendon group consisted of 10 participants with one CDA member present. In the Portland and Kingston group interviews, all of the participants were members of the CDA. The aim was to obtain norms, behaviors, and cultural domains (LeCompte and Schensul 1999). The initial idea was that each group would include a combination of persons with various types of disabilities. However, after observing the communication difficulties faced by hearing impaired individuals in other group discussions, I decided to conduct a separate group for these persons.
The group interview with hearing impaired persons was different from the other group in several ways. For example, the meeting was organized and facilitated with the help of two the CDA staff who acted as co-facilitators. One staff member was also the sign language interpreter. The attendance at the meeting was 16 instead of the prescribed number of persons 10; however, most of these persons did not participate in the discussion.

The group interviews were scheduled to be formal with a specified list of questions, prearranged time and place, and a prepared list of questions (See Appendix 6). However, only one group followed the prearranged format. Neither of the rural groups followed the prearrangement. For example, in Portland, the participants decided on the location of the meeting as well as who would be in attendance. It was difficult to stick to the topic as participants wanted to discuss other issues. Participants were given a gift to compensate them for participation.

After receiving verbal or written consent, each group interview was audio taped and later transcribed verbatim. With the help of the CDA secretary and field officer, I was able to record notes of the responses at three of the groups. Transcriptions and notes of the group interviews were analyzed and a list of “beliefs,” “attitudes,” “ideas,” and “myths” about disability was compiled along with the treatment that disabled persons received. A comparison was done to see if there were differences or similarities between rural and urban beliefs.

*Semi-structured Interviews*

The semi-structured format of interviewing was used because it “combined the flexibility of the unstructured, open-ended format” (LeCompte et al 1999:149) with
some direction and agenda. This format was chosen because it allowed me to explore new information while providing the flexibility to explore different topics with different individuals (LeCompte et al. 1999; Weller 1998). This format was very useful because while interviewing CDA members, I realized that several individuals not only had multiple roles in the organization but also many who were currently inactive had previously served in various capacities with the CDA.

I conducted about twenty interviews with CDA members, using an interview guide to cover topics pertinent to relevant research questions. Two types of interview guides were used, one for board members and another for general members. The board members’ interview guides included approximately twenty-one (21) open-ended questions covering five general areas 1) participant’s personal experience with disability, 2) ‘knowledge of the disability rights movement, 3) local attitude toward disability, 4) involvement with the CDA, and 5) funding for the CDA (See Appendix 4).

The interview guide for general members included ten open-ended questions covering three areas, 1) personal experience with disability and 2) involvement and level of participation with the organization (See Appendix 5). Although not included in the interview guide, I asked both groups what they perceived as the primary need among PWDs in Jamaica. The interviews lasted between 60 to 90 minutes and were tape-recorded.

Interviews were conducted in the participant’s home, workplace, the CDA office, or at a location chosen by the informant. In a few instances, the interview was conducted over the telephone. Most of the rural interviews were conducted at the informants’ homes. At the very beginning, the informant was given the informed consent forms; in
some cases I read the informed consent document and they signed to show that they gave permission for me to do the interviews. Later on in the study, I received approval from IRB to use a verbal consent. This exception made it easier for me to include individuals whom I could only reach by telephone. Interviews were tape recorded with the exception of a few instances when the environment was too noisy or if I conducted interviews over the telephone.

Interviews were transcribed and analyzed for common themes and patterns to build a theoretical explanation of informants’ participation in and level of involvement with the organization. During the analysis, a recurring theme was that many of the older members were closely connected to others in the organization which kept them involved. Furthermore, some informants continually made distinctions between themselves and others with different types of the disabilities.

**Participant Observation**

Ethnographic research is typically based on the ability of the field worker to learn through exposure to or involvement in the day-to-day routine of activities of participants in the research setting (LeCompte et al 1999). I conducted participant observation with the CDA for a period of six months (December 2005 to June 2006). During this period, I worked in a volunteer capacity on a part-time basis; I also attended various organization events (i.e. monthly rap sessions, social events, monthly meetings, training seminars, visits to rural communities). These events helped me to understand the dynamics between the members of the organization. The type of data to be collected included a description of events, such as location, persons in attendance, topics discussed, order of activities, interaction between attendees, and the recording of statements and
conversations. I recorded my observations and impressions in field notes, which were analyzed and used as descriptive data.

Document Review

I also gained permission from the CDA director to review documents, from the CDA’s archives, including newspaper clippings, minutes, and brochures. My expectation was to look back at records from the last 25 years of their existence. After a lengthy search over several months, many of their records could not be found. Instead, I reviewed some of the documents that were available in the CDA office; these covered the period from 1992-2000. These documents were reviewed mainly for evidence of strategies used by the CDA and its link with international disability movement. While reviewing these documents, I discovered that the CDA had utilized various strategies over the years. Many of these included working with limited funds while adjusting to the changing and diverse needs of PWDs in Jamaica.

Participant Recruitment

Since this is a case study of the CDA, the majority of the participants were members of the organization. In fact, non-CDA members were only included in the group interviews. The study was open to all members who were willing to participate in the study. During the participant selection process, I sought to gain a balance of participants based on type of disability and area of residence.

Recruitment of CDA members

Several strategies were used to recruit CDA members for participating in the different aspects of the research. For example, the informational survey was used as a recruitment tool for potential interview participants. Survey participants could indicate
whether they would be interested in participating. Twenty (20) of these individuals were to be selected for interviews based on the following criteria: 1) belonging to the various disability groups, 2) their knowledge about the organization, and 3) a positive response to the recruitment question on the survey.

Twenty (20) CDA members were also recruited to participate in the two focus groups, one in the parish of Portland and the other in Kingston. For the Kingston group, I received referrals from the CDA coordinator of individuals who fit the selection criteria and were willing to participate. However, in Portland, all members were invited to participate in the interviews.

Recruitment and Selection of Non-CDA members

Twenty (20) PWDs were recruited to participate in two group interviews, one in the parish of Clarendon and one in Kingston. Through the help of the CDA field officer, I established contact with PWDs the Milk River community where the Clarendon focus group was held. The field officer also helped me to recruited participants for the Kingston focus group with included hearing impaired persons.
Chapter Five

Ethnographic Setting

Although more than half (52 percent) of Jamaica’s population lives in urban areas, Jamaica is mostly rural with a majority of the urban population concentrating in the areas of Kingston and St. Andrew, Montego Bay and the parish capitals. When these areas are not considered, the rural population in most of the fourteen parishes is 70 percent or greater (www.jsdnp.org.jm). This chapter describes the research setting with the aim of shedding light on its people, their environment, and the various circumstances that impinge upon their lives.

There is increasing development in the parish capitals, which includes establishment of many businesses traditionally found in Kingston. For example, branches of most financial institutions, government offices, and medical facilities are located in these capitals. However, the major drawback for these areas is the lack of affordable and reliable transportation; and, many rural villages are remote and often located several miles outside the parish with rough roads and hilly terrain. As a result, many rural residents cannot access these services easily. Furthermore, many services are only available in Kingston; therefore, they are less accessible to poor rural families. For the person who is disabled this creates even greater challenges, especially those with mobility impairments. During my fieldwork in Jamaica, I visited several rural communities in Portland and Clarendon to conduct informant interviews. This includes my visit to Milk River, Clarendon.
Visit to Milk River, Clarendon

I visited Milk River one afternoon in May 2006 accompanied by two CDA employees. Milk River is located several miles from May Pen, the capital of Clarendon. The road from May Pen to the Milk River exit is a two-lane highway which is the main thoroughfare leading from Kingston to the southern part of the island. The road surface was fairly even and offered a comfortable driving experience. Over the years, the Jamaican government has successfully maintained the major highways but has neglected the roads to the smaller rural villages.

After driving for about four miles, we reached the Milk River exit on the left. As I turned on to the road, the surface was still fairly smooth but that was about to change. The road became rougher as it was scattered with potholes or varying sizes. I tried my best to dodge them but this was sometimes unavoidable. The drive was mostly pleasant except when I drove into unexpected potholes or when there was not enough space for me to avoid them. In fact, there were points when the top surface had completely eroded leaving only gravel and stones. With regards to the road surface, driving here was not unlike driving elsewhere on the island because many of Jamaica’s roads are in disrepair. Residents often tell foreigners that driving in Jamaica requires one to have a PHD in driving, which means to be pothole dodger. I had never been to this area before, so I relied on travel companions for direction.

The development in this area was sparse with a few small grocery shops along the way. Major places in the area include the Vernam Field air strip used for drag racing, the
Milk River Bath, JAMALCO bauxite Company, and Garvey-Maceo High School.

However, the high school was the only site that we saw. This high school was named in honor of Jamaica’s Marcus Garvey and Cuba’s Antonio Maceo. This was a gift from the Cuban government that served not only as reminder of the relationship that Jamaica had with Cuba during the leadership of the former Prime Minister, Michael Manley, but also as a reminder of his commitment to the building of high schools in rural areas.

Soon we came to a clearing where there was nothing in sight but sugar cane fields on both sides of the road… just sugar cane. This part of Clarendon was noticeably flat, which is unusual for Jamaica because the island is so mountainous. We soon got to our next intersection, and I was instructed to turn left. The surface was obviously rougher with gravel and dirt as most of the paved surface had eroded. I drove a little while until I was instructed to turn onto another dirt road, to which I hesitated. Then heard the same words “turn here” and I thought, “No, you have to be kidding, on this bad road? It is not my car and I would not drive my car up here.” Anyway, I turned; and drove for a few meters then we stopped at one of the two houses on that road. The area around us was a flat, dry area. There were no trees, just a few houses scattered along the way and some others clustered together further down road.

We stopped and a young man in his mid thirties came out to meet us. I soon learned that was David, our contact who acted as the community gatekeeper. I drove into the front yard and parked. The house was a small structure built with a combination of concrete and wood. It had a porch with red flooring. There was a young woman sitting on the front porch and a toddler playing in the front yard. After the introductions, he took me around the back and showed me the chicken coop with about 100 chickens that he had
CDA had helped him acquire through donations. From the back of the yard, I got a good view of the area and all I could see was brown grass. He was leasing the property from the owner who lived next door. The field officer told him that we wanted to meet with some PWDs. He was excited and took us on a tour of the neighborhood. David seemed to have a sense of responsibility for the people in the neighborhood. He told us “there are a lot of disabled people in the district and I know where all of them live.” Our first stop was his next door neighbor, Mary. As we talked on her front porch, three other women joined us. Then Mary asked us to come inside; I was not sure but we followed her and David inside the house. We passed through the living room and my curiosity was building. I parted the curtains that separated and entered the bedroom. Then Mary showed us her son, who was lying on a mat on the floor with a pillow underneath his head. His legs were bent backwards at the knees in a kneeling position and his arms were bent upwards at the elbow. His eyes were very alert and he looked at us as if he recognized us as visitors. He was no bigger than a two or three year old child. Then Sharon asked, “How old is he?” Mary said that he was twenty five years old. I asked Mary if he could talk and she said no. He followed us with his eyes as we moved around the room.

Mary wanted to know if we could get help for her son. Sharon inquired about his diagnosis and she said that a doctor in May Pen said that he had Downs Syndrome. According to Mary, she had tried but could not get any assistance. Luckily, the office attendant came with us because he said that her son could get help from Missionaries for the Poor in Kingston. But she would have to find her own transportation to Kingston.
So, we left the house and promised to get help for her son and to arrange transportation through the JCPD.

When we went outside a few more ladies had gathered on the porch and only one person had an obvious disability. So, we reminded David wanted to talk to PWDs. I explained to them about my research and that we wanted to have a group discussion about their experiences living with a disability.

After leaving, we went back on to the paved road and down to the primary school. As I looked ahead, the houses and the properties looked different. These structures were bigger and made of concrete. There were many, many fruit trees, especially mango trees, and it was during mango season; we picked many mangoes. David took us around the neighborhood and introduced us to some of the disabled people who lived there. One of the persons we met was Ms. Brown who is physically disabled and wheelchair bound. As David introduced us, Ms. Brown had a few words of caution for us. She told us to be careful; because our presence in the neighborhood would help to build up people’s expectations. Then, if we could not meet those expectations, they would be disappointed. That was a sobering thought that made me think about the type of discussion that might take place in the group interviews. After making plans to return a week later, we left the neighborhood with many mangoes and other produce. The residents in this neighborhood were typical rural residents who were known for their kindness. It is almost impossible to visit a rural community without receiving some kind of produce.

Visit to Hope Bay, Portland.

Portland is different from Clarendon in many ways. First, it is located on the northeastern part of Jamaica and has the beauty of the beach and the mountains. There
are two ways to travel from Kingston to Portland. One way is using the Junction Road, which passes through the parishes of St. Andrew and St. Mary. The other way, which is twice as long, passes through the parish of St. Thomas. Although I had gone to Portland many times, my trip in June 2006 was my first experience as the driver. I remember dreading the experience because the Junction Road is known for its winding, precipitous roads but its breathtaking scenes through the mountains. However, I thought, the shorter distance was enough incentive for me to forget about how scary the drive could be. Then I considered that after passing through St. Andrew, the drive would not be so scary.

I visited Hope Bay, Portland on a Saturday morning in June to attend a rap session of the Eastern Disabilities Association (EDA), a CDA affiliate group. Meetings are usually held on the second Saturday of every month. The coordinators agreed that I could use this time to talk with members about their experiences. I took a driving companion who was not afraid to drive with a novice on the Junction Road. We left Kingston at about 7:30 a.m., not only to make sure that I got there by 10 a.m. but also because there was supposed to be less traffic that early in the morning. The roads were not very busy and it was a comfortable drive with few potholes.

After navigating the hilly terrains, we arrived at Hope Bay, which is a small fishing village of the coast of Portland. There is nothing significant about Hope Bay; it is one of several fishing communities along the Portland coast and one of those places that could be missed in the blink of an eye. Following the directions that I received, I had no trouble finding the road by the old police station. When I turned, I saw the building of the Fishermen's Cooperative, where they were meeting. It was located on the beach. As I drove up, I saw a man sitting in a wheelchair but he was the only one there. There were
no chairs, only an open porch with a long ledge. So, I went and introduced myself and realized that it was Mr. Smith, one of the EDA’s coordinators. We waited for almost an hour before anyone else arrived. At this time, I was wondering how long I should wait. Then two ladies arrived and I realized that they were not going to have chairs. So I sat on the edge of the porch which is what everyone else did except those in wheelchairs. It was a cool morning and very different from my Clarendon experience. While we waited for the meeting to start, we watched the fishermen repair their boats and nets. Our meeting lasted until about 1:30 p.m. At about 1:00 p.m., one of the ladies asked me if I would like something to drink. I was about to tell her that I had brought my own drinks but thought that would be rude. So, I accepted. Then someone went to the store, bought me a soda, and apologized for not having anything else. I was surprised because when I met with the groups in Kingston, I provided refreshments and snacks. Like the people in Clarendon, they were grateful that they mattered enough for me to meet with them.

When the meeting ended, I offered Mr. Smith a ride home. I did this almost instinctively without having any idea how far away he lived. Also, I had not thought about how I would get him and the wheelchair in and out of the car. When one of the ladies heard that I would give Mr. Smith a ride home, she asked, “Are you going to drive all the way to Woodbury?” I wondered why she asked until I started driving there. Luckily, I had a traveling companion; and we both assisted Mr. Smith getting in and out of car. The district of Woodbury was located several miles up a mountain road on the opposite side from the beach. This was a paved road; but like the other interior roads, there were several sections where the surface had completely eroded. Mr. Smith lived in a remote area and my major concern was getting back to Kingston before dark. I was
also wondering how he normally got home after rap sessions, so I asked. That was when he told me that most Saturday afternoons when the meeting ended at 2:00 p.m., he sat out by the old police station, sometimes until 6:00 p.m. before a taxi driver would agree to take him home. According to Mr. Smith, as the drivers passed they would say “next trip,” but that next trip seemed to never come. Saturday was market day and people traveled with groceries and produce so there was not enough room for a man and his wheelchair. So he had to wait until all the other passengers were transported before there was space for him and his chair.

Once we got to his house, we helped him out of the car and into the wheelchair. He was very grateful and apologized for not having anything to give us. As we were leaving, he asked if we liked sugar cane and got some from the neighbors. He also cut cinnamon leaves from his tree and gave them to us. That was something that I could use.

_Rural transportation_

Transportation in rural Jamaica is very different than in Kingston mainly because there is no official transportation system in rural Jamaica. Instead, transportation is provided by private individuals who operate minibuses and taxis between key points. The cost of transportation is twice as much as in Kingston. For example, it costs Mr. Smith JA$100 to go from his house to Hope Bay but in Kingston, the average bus fare is JA$50 and PWDs pay a concessionary bus fare of JA$15. The lack of an official transportation system in the rural areas makes it impossible for concessionary fares to be negotiated.
Kingston, Jamaica

Uptown

Most people think of Kingston as having two areas: uptown and downtown, separated by Cross Roads, which is primarily a traffic junction. The uptown area is located north of Cross Roads and the downtown area is located south of Cross Roads. Over the years, uptown has been characterized as an area of high status while downtown as one of low status. Half Way Tree marks the beginning of the uptown area. It is a major traffic junction which connects commuters to various areas of Kingston and St. Andrew as well as the parishes of St. Catherine, St. Mary, and Portland. Half Way Tree is the center of the uptown commercial district which is characterized by several shopping plazas and malls, the favored shopping area for the middle and upper classes. Half Way Tree Road is the main thoroughfare between Cross Roads and Half Way Tree, and one of the most congested in the corporate area. This road handles two-way traffic until about quarter of a mile before it enters Half Way Tree square; then, it becomes a one way road. At this point, northbound traffic is directed to Maxfield Avenue, another northbound road that leads into the Half Way Tree area.

Beyond Half Way Tree are some of the more affluent neighborhoods located on the foothills of St. Andrew. These include areas such as Norbrook, Havendale, and Manor Park to the north, and Mona Heights, Barbican, Jack Hills, and Beverly Hills to the east. New Kingston is located about half a mile southeast of Half Way Tree and is not only the hub of business and finance but also the site of Kingston’s nightlife. New Kingston is bounded by Trafalgar Road to the north and Oxford Road to the South, Half Way Tree Road to the West and Old Hope Road to the east. Knutsford Boulevard is the
major northbound thoroughfare that runs through New Kingston and runs from Trafalgar Road to Oxford Road. Known as the “hip strip” by residents, Knutsford Road is the site of the major hotel chains, banks, and several local and foreign fast food restaurants. Several businesses and government agencies have relocated from downtown to this area.

Traveling throughout Kingston requires special navigation skills both as a motorist and as a pedestrian. As I traveled along these roads, I am constantly being surprised by the total disregard that pedestrians and motorists have for road rules or for each other. For example, when driving it helps to keep looking out for pedestrians because even if the motorist has the green light pedestrians just walk out into the street. In fact, I noticed that some pedestrians avoid making eye contact with the driver as they go across the street; this result in a lot of honking of horns.

Driving around Kingston, there are some notable scenes worth mentioning, such as the numerous peddlers at major intersections selling car chargers, water, snacks, and other miscellaneous items. They mostly wait for the traffic to stop and then walk up and down the lanes. They are usually not pushy; instead, they wait for motorists to buy their products. Another kind of peddler to be found at these intersections is those who sell their windshield cleaning services. They usually wait for motorists to stop then start cleaning the windshield with or without permission. Usually, a young man walks up to the car with a squirt bottle in one hand and a squeegee in the other. Then he gives that pitiful look that says, ‘life is hard and I am trying to make an honest living.’ Then he starts lifting up the wiper blades and squirting fluid on the windshield. While this is taking place, the motorist has no choice but the sit there until the light changes. My usual response is to signal and say no, without winding down my window because I never, ever
wind down my window in traffic. However, these “no” signals do not usually work because these young men are persistent; but; I never give in. So they squirt liquid and wipe the glass; then they expect to get “paid.” About the time they are finished cleaning the light changes and I drive away with no guilt or remorse.

Waiting at the traffic light is one way to observe street activities and these do include PWDs. Sometimes, I see PWDs encounter dangerous situations while begging. For example, the intersection of Half Way Tree and Oxford Roads is one spot where the same disabled man stands and begs all day, every day. I have passed him there in the morning, late evening and on the weekend. He is physically disabled and he walks with a cane. He does not stand on the curb but in the traffic lane with one outstretched hand and the other holding his walking stick. He rotates his position from time to time so that he can have access to motorists traveling southbound on Half Way Tree Road as well as those traveling along Oxford Road. Of course he does not have access to the cars going north on Half Way Tree Road (Oxford Road dead ends into Half Way Tree Road). The first time that I saw him, I thought, “how dangerous;” and wondered if he was afraid of getting hurt. But then that became less shocking after I saw another disabled man at the Half Way Tree Road and Old Hope Road intersection. This is in the middle of Cross Roads; it makes me anxious just thinking about driving there. But he hangs out there; not on the sidewalk but in the same lane as the southbound traffic. He just sits there in his wheelchair “parked” very close to the curb and waits; the traffic moves on but he waits. One morning, on my way to the CDA office and I passed him in his usual spot but this time he was sleeping and I wondered if he spent the night there. This man still baffles me
because I have never seen him begging; so I am not sure why he is there. I have wanted to take photographs of these scenes but it feels very intrusive.

My scariest intersection experience took place at Oxford Road and Old Hope Road. Again, I was going to the CDA office on Ripon Road, which intersects Oxford Road. However, motorists heading eastbound on Oxford Road were not allowed to turn right onto any of the side streets. So, I drove down to Old Hope Road to make a right turn at the light and then enter Ripon from the other end. As I approached the intersection, I saw a young man who appeared to be in his thirties pushing a woman in a wheelchair. She was well dressed and her hair was nicely done. They were both on the median and they were approaching my direction from behind. I was about fourth in the line of traffic; as I saw them coming, I wanted the light to change and it did. But they kept coming toward me. By this time, the cars ahead of me were moving and there was beginning to be a noticeable gap in the traffic. I did not want to move suddenly for fear that I might hit them, so I honked my horn. But he still came up to the car. I just glanced in their direction to see how close they were to the car before I started to move. When the man realized that I was not going to give them any attention, he made a fist, leaned over, and pounded as hard as he could on my window. I was glad that the light was still green and I drove off. At this point, I was also happy that this was the final week in June and I was completing my data collection.

Downtown Kingston

Parade is the center of the downtown area. King Street, which runs from north to south with East Queen Street on one end and West Queen Street on the other end converge into St William Grant Park (formerly Queen Victoria Park) which is the center
of Parade. The park divides Parade into two areas: North Parade and South Parade. This area is the major municipal transportation terminal; most bus routes end here. This area is bounded by Church Street on the east and Orange Street on the West. From North Parade you can get vehicles to the northern and eastern part of the city and from South Parade passengers can access vehicles traveling to northern and western part of the city.

The KSAC, municipal authority, has designed the parade for minimal use by private vehicles. For example, there are no parking spaces for private vehicles. This part of downtown is crowded, especially on market day, Saturday. In this highly congested area, pedestrians and shoppers vie with buses, taxis, and handcarts for space while watching out for pickpockets. Many of the sellers come as close as possible to the street to sell to persons who do not wish to wander deep into the market area. King Street at South Parade is the location of the few remaining department stores, banks, and other commercial enterprises.

Although the downtown area is mostly commercial, several residential communities are located nearby. With the exception of Ocean Towers, an upscale condominium on the waterfront, south of the Parade area, most of the other residences in the downtown are considered ghettos and slums. Some of these residences have been abandoned by the owners and are now occupied by squatters. These areas are also known for their high incidents of crime and many of the homes are visibly distressed and dilapidated. Some of these residences were once fine middle class homes; while others are just rows of shacks separated by zinc sheets located along unpaved lanes with little or no sanitary facilities.
**Municipal transportation**

The main means of public transportation in the corporate area, Spanish Town, and Portmore is operated by the Jamaica Union Transit Company (JUTC). JUTC is a governmental agency which was established in 1998. It has five bus depots or terminals throughout Kingston and St. Catherine. It has modern Volvo and Mercedes Benz coach buses that seat approximately 55 persons. The cost of a single ride is JA$50 or approximately US$1. Commuters who buy a smart card pay JA$40 per ride. Disabled commuters who have approved identification pay JA$15. Buses operate on a schedule which accommodates employees and students. It is possible to catch a bus to most areas throughout Kingston. Most buses are staffed with a driver and conductor; however, several buses are equipped with an automated fare collection system.

Although these are typically 55-seat coaches with a designated amount of standing capacity, the recommended capacity is usually exceeded, especially during the evening rush hour. For example, sometimes busses are packed two times beyond the recommended capacity. At the very front of the bus are seats designated for PWDs. JUTC provides service on two routes for people who are physically disabled. Route 101 operates from Portmore to Constant Spring Road and services passengers traveling to Abilities Foundation, a vocational facility for PWDs. Route 102 operates from Harbor View in the Eastern Kingston to Papine. These routes offer services to six institutions that provide services for PWDs including Sir John Golding Rehabilitation Center, Jamaica Society for the Blind, and School of Hope. Half Way Tree is a transfer point for both routes.
PWDs experience numerous challenges on the buses. These include the refusal of the conductor to accept identification because persons do not look disabled. This is exacerbated by the fact that JUTC identification cards are often stolen or switched while riding the bus. For example, one PWD explained how his card was switched on the bus. According to him, as he entered a crowded bus and someone offered him a seat; he was asked to pass his card down to the conductor. However, when the card was returned it was not his original card. However, he did not know what had occurred until he went to use his card the next time.

In addition to JUTC buses, commuters in many areas of the city have come to depend on route taxis or minibuses. These are drivers who operate taxis illegally along the bus route. In many cases, their services are not as reliable as the JUTC but they are usually available when the JUTC buses are not. Although I have been warned on many occasions not to take route taxis, I have done so with regret. My most notable occasion was taking a minibus one morning from Constant Spring Road, North of Half Way Tree, to the CDA office on Ripon Road. I entered the minibus because the driver said that he was going downtown which meant that he would have to pass Cross Roads, which is close to the Ripon Road stop. However, when he arrived at Half Way Tree, all the passengers exited the vehicle except me. So, I sat and waited for an indefinite amount of time while the conductor walked up and down the pavement shopping for additional passengers. I considered leaving but since I had already paid my bus fare; I waited. However, after some time, I decided that I could afford to lose JAS$50 dollars. So I got out of the vehicle and took a JUTC bus to Cross Road. Then, I vowed to never take another minibus or route taxi again but I soon broke that vow. This happened to me on
several occasions, so after a while when the minibus reached Half Way Tree, I just got off. Sometimes, I walked from Half Way Tree to Ripon Road, which was less than two miles. I just convinced myself that I needed the exercise.

Figure 2 – Map of Kingston

Description of CDA Office

The CDA’s office is located at 18 Ripon Road on the National Insurance Scheme (NIS) building near the New Kingston area, which is a short distance from Cross Roads.
The NIS is a governmental agency which shares its building with the JCPD and the CDA. There is also another building on the premises, which houses a catering school. This property is completely fenced and located behind an iron gate that is opened during daylight hours but is closed after dark. The premises are staffed with 24-hour security, daily and on weekends. The guards are stationed at the guard house located next to the gate. Most of the parking is located in the back of the NIS building. The main entrance to the CDA office faces the guard station. It is the first entrance that clients see when they enter the premises. As a result, the CDA receives many clients that are looking for the NIS or JCPD office.

Most clients enter the CDA through its main entrance; however, because CDA’s entrance does not have a ramp, clients in wheel chairs use the JCPD entrance and enter the CDA through a connecting door. Approaching the CDA there are several signs on the glass which read “THIS IS NOT THE NIS OFFICE” with arrows pointing in the direction the NIS office. I have often wondered whether or not the signs are helpful because several persons still come in to the CDA thinking that it is the NIS office. To gain entry into the CDA office, persons must press the buzzer located outside. This sounds at the secretary’s desk and she opens the door and allows the person to enter. The buzzer system is a security measure that is used widely in offices throughout the city.

The CDA office is approximately 400 square feet in area. Upon entering the office, clients approach a small makeshift reception area, which is identifiable only by the four chairs along the wall to the right. Most prominent of this area are the bags of groceries awaiting distribution and the ‘grey house’, a large cabinet used for storing miscellaneous office products. Also located in the area and facing the chairs in the
reception is an L-shaped desk with a computer. During the time that I was at CDA, this
desk was not assigned to anyone in particular. However, it has been used by student
assistants, the field officer when she is in office, and sometimes by me. Working at this
desk requires the ability to stay focused in spite of numerous distractions and to be
vigilant, ensuring that items on the desk do not disappear.

The secretary’s desk is the focal point of the office and is located behind a
partition. The upper half of this partition is made of glass. Her desk faces the front door
so that she is able to see everyone who enters the office through the front door or the door
leading to the JCPD office. She is the first person that clients encounter. Part of her job
is to screen these individuals by assessing their needs and then take the appropriate
action.

The CDA’s most valuable equipment is kept in the secretary’s cubicle. These
include a personal computer, the all-in-one printer, telephone and DSL box and cables,
large photocopier and two file cabinets. Some of these items are removed at night and
locked away in the director’s office. This area is partially enclosed with a doorway but
no door. An unwritten rule is that someone should be at this desk at all times, not only to
assist clients but also to keep an eye on the office equipment and supplies.

Beside the secretary’s cubicle, there is a narrow passage which leads to the
director’s office. Space along this passage is very tight because there are shelves with
numerous books, file cabinets and a mix and match of miscellaneous stored office
products. It is possible for two persons to pass at the same time. However, that is not
possible if one person is in a wheelchair. With the exception of the restroom, the
director’s office is the only enclosed space and the only space that can be locked. As a
result, all valuables including small office equipment such as the printer are stored there at the end of the work day and on weekends. Adjoining the director’s office is a single restroom with a toilet and sink. Although this area is bursting with storage items, it is accessible to a wheelchair.

Figure 3 - Diagram of the CDA Office

The CDA’s office hours begin at 8:30 a.m. and ends at 5:00 p.m. Monday through Thursday; the hours are 8:30 a.m. to 4:30 p.m. on Fridays. The CDA workday covers a wide range of planned and unplanned activities. However, the major task being done is providing assistance and support to PWDs. A typical day involves carrying out routine office work which involves extensive telephone calls and visits from PWDs, both members and non-members, and taking care of office paperwork.

The CDA receives several different types of telephone calls from CDA members and non-members. These include a wide range of requests ranging from someone who
wants to know what is on the agenda for the next rap session to a mother calling to
complain that bus a conductor bus refused to accept the concessionary bus fare from her
son who is mentally retarded. Most of these calls are handled by the director partly
because there is only one telephone line and although there is call-waiting, the director’s
phone is the only one where this feature can be accessed.

In addition to the phone calls, the CDA experiences a several persons visit the
office. These include persons who require various types of assistance, as well as sellers
and CDA members who stop by the office to visit. Although there is a lot of people
traffic in the office, the visits are usually uneventful except for the occasional disruption
caused by World Cup Football or Frankie’s visits. He visits the office about one to two
times each month in the afternoon. Frankie usually makes his presence known by
speaking loudly and ignoring the secretary’s request to be quiet or to stay in the reception
area. He tries to wander in the direction of the director’s office. When he does that, the
secretary sternly reminds him to stay in the designated area; he wanders around the office
and asks to speak with the director. If she does not respond to him, he calls out her name
like a nagging child until she responds. When she responds, which she usually does after
ignoring him for a short while, he asks her for various items that he sees in the office.
His favorite is the computer on the front desk. After she explains that she cannot give
away the computer because it does not belong to her, Frankie starts asking for items
randomly.

One day, when no one was noticing, he wandered down to the director’s office
and looked in for a minute to see if there was anything that he wanted. Later on, while
sitting in the waiting area he started asking for one of the dresses that she had in her
office to give to his girl friend. Of course, it surprised her, briefly, that Frankie knew that she had clothes in her office. His visits usually last for about two hours and although he did not get the computer and the other things that he asked for he would always leave with something even if it was bus fare or some food supplies.

Office sellers are another type of visitors that come to the CDA. These are persons who go to various businesses in Kingston and sell products that they think appeal to women, such as underwear. Two of the regular sellers are “FDR” and Janet. To maximize their chances for a sale, these sellers come to the office near the end of each month, which is when the workers get paid. Although their presence may sometimes be disruptive to the office routine, sellers are allowed to come in and sell especially those who are disabled. In order to support these sellers the sometimes buying things that they do not need.

Food distribution time is one of the most stressful for the CDA staff. Once or twice each month, the CDA receives grocery items from Food for the Poor, an international Christian humanitarian aid organization. The CDA arranges for items to be picked up from a warehouse in Kingston and delivered to the CDA office. Some of the items include rice, kidney beans, “vegemince,” and cooking oil. Distribution of these items occurs on an ongoing basis; however, the peak of distribution occurs on the days following their arrival to the office, which changes from month to month. With assistance from a few CDA members, products are then packaged into two to three-pound plastic bags and distributed to CDA members on a first come first served basis. The storage and distribution of these products often contributes to the untidiness of the office and creates extra work for the staff. Despite these challenges, the CDA has become an
oasis for its members, most of who reside in Kingston. Most members seldom come into the office for assistance; instead, they contact the CDA by telephone.
Chapter Six

Data Analysis

This chapter presents my data and an analysis thereof. These will be presented in four sections. In the first section, I will describe the construction of “disability” in the context of Jamaican culture. It will also include the personal histories of key informants who participated in the open-ended group and semi-structured interviews. In the second section, I will describe the way that CDA members negotiate their involvement and level of participation with the organization. The findings will be analyzed using the data from the informational survey and semi-structured interviews. In the third section, I will describe the nature of the CDA’s linkage with DPI. Finally, I will describe the CDA’s strategies for mobilizing PWDs in Jamaica.

Construction of Disability in Jamaican Culture

*Question One: How is “disability” constructed in the context of Jamaican culture?*

The construction of disability was explored by looking at local attitudes and beliefs about disability as well as what it means to be “disabled” in Jamaican society. To this end, semi-structured and open-ended group interviews were used. The following results highlight the responses of selected informants who participated in the open-ended group interviews.

*Selected Key Informants*

Pseudonyms and changes to the names of places are done to obscure the identity of informants. These include three who are physically impaired: two who are deaf, and one who is blind. Four of these informants live in urban areas, and three live in rural
Jamaica. These individuals are selected because their opinions and experiences summarize those expressed by the larger group of participants.

David is in his early thirties and is physically disabled. He became a member of the CDA in 2006. David is a farmer and lives in the parish of Clarendon. At the time of the study, he had recently received assistance through the CDA to start a small project raising chickens.

Mavis is in her early twenties and is visually impaired. She is very involved with the organization and attends most of its activities. She is a school teacher who works and lives in Kingston.

Shirley is in her thirties and is deaf. She is not a member of the CDA. Shirley is self-employed and lives in the Portmore area.

John is in his forties with a physical impairment. He has been an active CDA member. John is currently employed. He lives in St. Catherine but works in Kingston.

Ms. Brown is in her fifties and is an elementary school teacher. She has a physical impairment and uses a wheel chair. Ms. Brown lives and works in Clarendon. At the time of the study, she was not a member of the CDA.

Clara is in her forties and is physically disabled. A year ago she was diagnosed with diabetes and had one of her legs amputated. Clara lives in the parish of Portland and has been a member of a CDA affiliate group for over five years.

Mark is in his twenties and is deaf. He is an active member of the CDA. He is currently employed with a social service agency. He lives and works in Kingston.
Attitudes and Beliefs about Disability

Informants’ ideas about disability were classified into the following categories: 1) disability is the result of supernatural causes; 2) PWDs are not considered normal; and 3) society has low expectations for PWDs.

1. Beliefs about the causes of disability.

Participants agreed that there are common beliefs in Jamaican culture that disability is the result of supernatural causes such as obeah (witchcraft), duppy (evil spirits), and chastisement or retribution from God.

According to Clara,

“When my son was born...some people say its obeah. Later they say it’s because I am a diabetic. They say ‘it’s obeah, then it’s because she have sugar that’s why the child come stay so. But they didn’t talk until I lost the foot. Because is when lost my leg I find out that I have sugar (diabetes). So when them hear now, them say I know, that’s why her son come so...That is why her son born so.

[Some people still have the beliefs about spirits and duppy. They still think about it happening either to the mother while she is pregnant or after the child is born, they say something did set for somebody and it just catch the child.

[It somebody becomes disabled as an adult], sometimes they have it to say; it’s the same concept, that somebody does them something, like its obeah. Yes they have it to say reaction you see them, they are no good you know is reaction following them.”

Clara’s experience reflects the negotiation that occurs by Jamaicans as they try to understand the meaning of disability. In this case, disability is first attributed to a
supernatural cause and then to a natural one, reflecting the complexity of cultural meanings. For example the idea of accepting a supernatural cause shows that these persons still embrace their traditional Creole cultural beliefs about disability discussed by Leavitt (1992) and Thorburn (1998). However, the ascription to a supernatural cause does not preclude other explanations. When someone said that the child’s disability is caused by obeah then later by the mother’s diabetes, it demonstrates that persons adhere simultaneously to both Creole and European beliefs and practices. This is also observed in the general health-seeking behaviors and religious practices of many Jamaicans. For example, when someone is ill, it is common practice to visit both the medical doctor and the spiritual healer. Arguably, this is done because they want the best chance of being cured. In the case of religious practices many Jamaicans participate in Christian religions while holding on to the practices of the Creole religions. Often various aspects of Creole culture is stigmatized and therefore, not socially acceptable by mainstream society; therefore, persons hide their involvement. On the other hand, European influenced institutions and practices are socially acceptable and participating in them brings specific social benefits.

According to David,

“Sometimes you hear some people say that it is wickedness that you do turn back on you. [Because] some people with a disability are stubborn and they are being chastised by God. And the Bible tells us that God chastises those whom he loves. Sometimes he might know that you are going to do something wicked, that might cost your life.”

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Informants also explained that PWDs are considered different from other members of society.

2. PWDs are not considered normal.

According to Mavis,

“What I notice about able-bodied persons is that, they have this tendency to when they see you as a disabled person they act as though you are an alien from Mars, like they are able-bodied so they are the normal creatures of the world and you are so different. You know, they say things like ‘she looks good and she blind’ or ‘how you can cook and you have one the hand’. Or I like to see when they doing that thing with their hands (speaking of sign language) a mean like you are so different, so abnormal or better yet paranormal and that is what they do to disabled persons. They don’t look on us as any normal somebody. They just take us differently from the other people in the society. People do not accept difference. You are like a red crayon in a box of black ones. You know, the worse thing for an able-bodied person to see is a pregnant disabled woman. They say things like, the man who got you pregnant is wicked because they think that you must be pregnant by an able-bodied man for the disabled man is impotent.”

These discussions suggest that although efforts have been made, through legislation and public education, to normalize disability, people still hold to the traditional Western beliefs that disability is an anomaly, characteristic of the medical and charity models. Therefore, it is difficult for them to perceive PWDs participating in so-called normal activities, of which sex relations appears to be the most perplexing to conceive. Therefore, a pregnant disabled woman contradicts societal perceptions of what
it means to be disabled. As Mavis suggests, not only are people shocked that a woman is pregnant but they also conjure up explanations to justify their original belief. As a result, they decide that she must have been taken advantaged of by a man who is not disabled; because, as Mavis suggests, they also believe that the disabled man is not sexual either. The idea that PWDs are not involved sexually is a common but unfortunate misconception. If this idea persists, it may have serious implications for PWDs. In fact, this perceived lack of sexual activity by PWDs has resulted in their exclusion from sex education programs. This is already an issue of concern as the incidence of HIV/AIDS and other STDs are increasing among segments of the disabled population in Jamaica.

Shirley shares a similar experience.

“When I was pregnant, I go to the clinic and I was sitting down because they don’t understand me because I am deaf. At first, they call me dummy. After I had the baby, and I go to see the doctor, she asked, whose baby is it, so I tell the doctor that it’s my baby. She didn’t believe me so the doctor asked the nurse whose it is baby. I know the nurse because she comes to my church. So, the nurse tells her that it’s my baby.”

John states,

“Some persons really and truly see it [disability] as a curse because, they see themselves as normal persons, so you with being blind or paralyzed you appear to them in a different light or from different planet. And you mainly find this with rural area because I mean persons in Kingston and St. Andrew are familiar with the disabled but in rural areas they see it as a curse and sometimes they will say that’s why god give you that. You know, they don’t think that you should be killed
or punished but they think that you should be put up at an infirmary where you
don’t do anything. You are served or being served not being a part of the society,
especially if you are paralyzed.”

Mark also shared his experience,

“I have a friend named Roger. One day we were at home watching TV and his
friends come over but his friends are hearing persons. So they ask if the deaf can
play football and ask what deaf can do. I said yes I can play football. I tell them
that deaf can do plenty things and that they need to move around deaf and see.”

3. Society has low expectations for PWDs

Another theme that emerged from the group interviews is the idea that PWDs are
underestimated and that society has low expectation of them. PWDs expressed their
ideas about the way that non-disabled persons perceive them. For example, most people
in the group stated that able-bodied people believe that they are not capable of managing
their own lives. They also shared that these individuals think that all disabled persons are
beggars and should not speak up when they are being mistreated.

According to John,

“There is the tendency to take away the independence of a disabled person. If a
disabled person is going about their business, people don’t think that they have
the capacity to fend for themselves. Whenever they see them going across the
street or... they just rush to help. It is good to help but there is a tendency of
taking away their independence. For example, you see a person who has lost a
limb or whatever or a member of their body, I think that they can live a normal
life same way. And again, we should say we don’t need pity we just need opportunities."

This discussion reflects the collision of multiple cultural beliefs about disability; specifically, the social model and traditional Western belief that PWDs are incapable of fully functioning in society. This perception is aligned to the charity model and appears to be rooted in Jamaican culture; in that, PWDs are perceived as needy and helpless and always requiring assistance. While multiple ideas about disability co-exist within the culture, the idea that PWDs are incompetent could hinder their integration into society.

The social model, which represents a new paradigm and the official model of the disability rights movement, was intended to replace traditional perceptions and treatment of disability. However, cultural change is often a slow process, subjected to structural barriers. For example, efforts to reduce stereotypical ideas about disability such as public education, passage and implementation of new legislation, and the creation of opportunities for PWDs are hampered by lack of resources. Consequently, the process of changing negative perceptions may take a longer process than PWDs expect.

Mavis explains,

“When you are assertive and you are disabled you are aggressive but when an able-bodied person is being assertive it is ok.” Instead of having empathy for the disabled person, they show us sympathy and I have always had to be saying to able-bodied persons that we don’t need sympathy because anything you can do we can do it too. It’s just that we have to overcome. You understand, and some of us are so much more qualified than they are and they look at us and assume that you are going to have difficulty or just can’t do it. Disabled persons allow
people to think that we cannot manage; we must show that we can manage. I got blind late; [in life] and know more than one blind person who was not born blind. The way I operate as a disabled person shows I can manage. The way some disabled persons act, people tend to offer them help. We allow people to think we need help. For example, if we as blind persons would stop begging, there would be a different perception about the blind.”

These comments triggered a discussion about begging by PWDs. Several PWDs have been mistaken for beggars even when they are well dressed and are not begging.

John argues,

“There is one perception over the years that of blind person begging. But there is a lot of deaf begging. Begging is now a common factor in Jamaican society, but when a disabled person begs it is not seen in the same light. The other day, I went to a Chinese restaurant and they refuse me entry. When I went to purchase lunch, the security said you are coming in to terrorize the patrons. In this society, we stereotype disabled persons. I am not going to beg but if you want to give me something, I won’t refuse it.”

It appears that PWDs are being mistaken for beggars on a regular basis. These experiences were shared with me by several of the interview participants. For example, I was told the story of a CDA member who is blind. He was waiting outside the pharmacy in Half Way Tree while his wife went inside to shop. As he was standing there, someone came to him, took his hand and put some money in it and said “take this” and walked away.
Treatment of Persons with Disabilities

Some informants state that they knew of PWDs who have been physically and verbally abused.

1) Verbal and physical abuse

According to Ms. Brown who lives in a rural community,

“I have seen in this community many disabled people are physically abused especially if they are poor and some of them cannot find any food and they will go around to dances and those places to find food; then, they will be physically abused.”

Shirley also relates a similar experience,

“At my job where I used to work, they ask me my name and I try to explain to them that my name is Shirley and I showed them in the register but they don’t understand and call me dummy. Also at home, when I was about nine or ten, the children in the neighborhood would beat stones together and throw them at me and hit me with it.”

According to Mark,

“My experiences at work before (at my previous job), when I go to work, to iron, I remember at the same time two of my deaf friends came in to communicate with me. So one of the hearing persons started to tease me and say that I love the two deaf girls. I didn’t like it and told them to stop it but they didn’t. So I went to my assistant supervisor and complained, just for him to talk to them. The supervisor talked to them and told them to stop teasing him because the deaf is a normal person. So one of my deaf friends got angry and wanted to hit the guy who was
teasing me. So the supervisor told the staff that he is deaf and cannot hear so ignore him and leave him. But the hearing persons say that they have guns and will shoot him. They don’t like deaf persons. I try to communicate with them but they never know sign language, and can’t understand what I am saying. I try to write on a piece of paper but they still don’t understand, maybe they don’t understand the words because we don’t write straight English. They say that I am stupid. I left that work now anyway.”

2) PWDs are treated unfairly

Ms. Brown states,

“People in the community [parents and others] are saying that I should not be teaching because I am disabled and I cannot move to go around to the children. But, I am positive about myself because if I was not positive, to what people are saying, I would not come out to work. But I know that if I stay at my house people would not offer me anything to support a family, you cannot do that. So I take the positive that say I will go on my wheelchair and work. So I think that people in the community should be happy for me to see that I am in a wheelchair and trying to do my best. I am sure that children that I am teaching know that I am doing my best.”

According to Clara,

“People have a lot to say about people with disability. To me its sometimes like disability is a crime.” Some people will sympathize with you and some will help you, but you have other people who will not help. Yes, they will always have a negative feeling about a person with a disability. The other day, I was trying to
get off the bus and a young man was standing in the way and I said to him could you help me to get down the steps and he said in a loud tone “me naw hold nobody hand.” The conductor says to him you believe she was born like that. She never born like that you know. You know what can happen to you. Him never hold my hand or help me but two weeks later I saw the conductor and he said to me “you know remember the guy that refuse to help you off the bus, him meet in an accident and him lose him two foot [legs].”

Shirley shared the following experiences when both she and her husband were mistreated by their neighbors.

“One day I was at home and my neighbor, a woman, called me and sends me to buy a phone card for her. Why she doesn’t ask her daughter? Why? Why she send me? She always sends me to buy phone card; because I am deaf people always sending me to by phone cards. I tell the woman no, but she still ask me; so I tell my husband but he can’t help me because he is deaf. That is not right the woman must go buy the phone card herself. On Labor Day, people (in the neighborhood) don’t want to work so they call on my husband who is deaf and he outside cutting grass until in the night while all of them stand around talking. That is not right.”

According to Mark,

“I know that my manager does not like deaf persons. I have problem at my work I cannot communicate with him. When I communicate, I ask all the deaf to come. I had a meeting with him, he can’t sign, and there are no interpreters there. So he got up [leave the meeting]. He said that I need to get an interpreter but his boss
is not interested because they don’t have any money to pay an interpreter. He said if I want an interpreter, he will draw the money from my salary to pay an interpreter. Hearing persons treat deaf persons negatively because we communicate with our hands; and the [only] ones who talk with their hands; and they don’t understand us.”

According to informants, negative attitudes and treatments do not prevent them from participating in society. For example, David explains his resolve in the midst of negativity.

“I got disabled in 1991 when I was going to Bible college. And I took sick down there in Westmoreland, and I come up here. People have all type of things saying. But I don’t watch that. I still move on with my life. In 1995, I got my daughter and I still move on. It’s a bit struggling for you to know that your basic things that you need in life because of your disability you not going to reach your goal. You understand. Because you work still, you know, but because you have some hindrances sometimes moving up toward that standard. But, people with disabilities they are humans. They still have to eat drink wear, enjoy pleasure, and do everything like everybody else. So they need the society to come to the realization that the people with disabilities they are not like animals. You understand. Sometimes they don’t treat us right… and the government too.”

Informants responded unanimously that the government needs to do more for disabled persons to inform PWDs about benefits as well as help to educate the public on disability issues.
Ms. Brown suggests that,

“Many people in the country are not educated about disability. There is nothing on television. It’s just lately that the Senator, one of the politicians, who is visually impaired is stressing about it. Because it is just lately that, I know that PWDs who are working must not pay income tax. I wasn’t aware of it because it is not publicized. Many people have heard about it but just lately. I am in the system and I was not aware of it, so imagine people who don’t have the information that I have. But I don’t think it is wholly and solely is the government, you know, because the government is trying to make disability people stay in their jobs. It’s mostly the people in the community, parents and others. Like me, they are saying that I should not be teaching because I am disabled and I cannot move to go around to the children.”

The idea of educating non-disabled persons about disability is a common suggestion of interview participants. For example, Mark suggests,

“*The government should help to educate hearing persons just to let them know that deaf persons are human beings like everybody else. I strongly believe that all every civil servant should have to learn sign language like police, doctor, and lawyer.*”

*Results of Semi-structure Interviews*

This section highlights interviews with two key informants, one physically impaired and one blind. These are descriptions of the challenges faced by PWDs in Jamaica from their perspectives, offering a glimpse of what it is like living with blindness and physical impairment in Jamaican society. Their experiences challenge some of the
stereotypical beliefs held by many Jamaicans that a person with disability cannot manage to take care of themselves. However, amid personal challenges these individuals not only care for themselves but others as well.

*First Informant – Mr. Williams*

“One day I just concluded that...I am ordained to be blind...So I say well then life has to go on; I have to try and do something, to achieve something. I have to survive.”

Mr. Williams is in his sixties and has been a member of the CDA for over six years. Unlike many of the blind persons who are members of the CDA, he became blind late in life. Although he is clear about the medical reasons for his blindness, Mr. Williams believes that blindness was his fate. His story is similar to many PWDs who believe that they became disabled because they did not receive adequate medical attention. His experience also typifies that of many PWDs in Jamaica who have decided to “keep moving.” I have chosen to highlight Mr. Williams’ story because like many Jamaicans, disabled and non-disabled alike, he “struggles” against the social and economic challenges; and he considers himself a survivor.

Mr. Williams was one of my last interviews. We met at the CDA office one evening after work. I was willing to meet at his home in St. Catherine but he suggested that we meet at the CDA office. He said that he could get a ride to the office from downtown Kingston where he was participating in a vocational training program.

I began with a synopsis of my research and explained to him about the details of the informed consent process using the verbal consent. I started by asking how he became blind.
How I became blind - First signs

“I just got home one night and found that my eye was hurting me; my head back
was hurting me and when I wake up next morning, the pain got more and more.
When I went to the doctor, the doctor claimed that my blood pressure was high
and that was causing the headaches. So, he gave me some tablets and I went
home. After taking the tablets, the [blood] pressure came down and the vision
came back. [Because my vision] was kind of blurry and they say that it was
because of the high blood pressure why the vision was that way but not knowing
that it was glaucoma, it was the eye pressure that was building up and not the
normal body pressure. But I was treated for that [high blood pressure].”

Things got worse

“Next time, I went by the Webster Memorial (church in Kingston that operates a
free clinic) to get an eye test because my eyes started to feel a way (unusual).
Although I do the welding, it is not the welding that caused it; because I wear
shield and goggles. You know, normally if you get flashes it can affect you. So
when I went by Webster and they said that I have to see an optician
[ophthalmologist] because my vision was bad. So they give me a paper, but fate
was against me because when I went to the eye place by Gordon Town Road, they
diagnosed me with glaucoma, and the treatment that I was getting was for the
body pressure. They said that they could stabilize the eye pressure and then if
anything they can operate later on. So after three months, when I went back for
my appointment, they say that the doctor was on two weeks leave so I have to
come back. At that time, the prescription had only had one week left and there
was nobody there to write me another prescription; so I had to wait until the two weeks were up. So fate was still unkind to me because after the two weeks, I heard that the doctor’s daughter died so he had to stay in India for another two weeks so the eyes became worse and worse. So, a cousin of mine took me to another doctor and they started to treat it. So, I was using some eye drops and the eyes were stabilizing. But on the first of January 1999, I went to my bed, dropped in the drops as usual because the direction said drop in four times daily in both eyes; next morning when I woke up, I couldn’t see anything. After about an hour, I barely got a little shadow, so I wondered maybe I didn’t drop the drop in correctly; so I waited until the 12 o’clock time to drop the drop in again. I dropped it and I waited to see but my eyes were dark and I could only see a smaller shadow.”

So I called my cousin and told him that I was not seeing anything. So we decided to go back to the doctor. He said that the eye pressure was high and he had to reduce the pressure and that they would have to operate. At that time it was JA$22,000 (approximately US$1,000) per eye. For a man not working, I couldn’t find JA$22,000 and it was already costing me nearly JA$6,000 each month to buy eye drops. They referred me to University of the West Indies hospital (UWI). When I went to UWI, the specialist asked what medications I was using and when I took them out and showed him he said, “my God”; and he said that it was the drops that made me blind. He asked me if I read the paper inside of the box; so I told him no and he read it for me. It states: use for ten days pause for three days then use for another ten days then discard because it becomes
harmful. So I was taking it four times a day; it was even supposed to be put on
the refrigerator and I didn’t even know that because the direction that was written
on the box and even on the bottle said take four times a day. But it is the fine
(print) paper inside the box telling me that after twenty days the drops are no
good it is harmful. So it is that dropping that makes me blind. They said that they
couldn’t operate on it and that they would have to treat it. Then there was some
400 or 500 of us in line waiting to be operated on and its only 30 persons they
operate on each day and they only operate one day each week, every Wednesday.
So you understand the situation.”

Surviving

“One day I just concluded and come to it that it is like I am ordained to be blind
because is not that I am not trying but every time I made a move it is like
something else happened. So I say well then life have to go on; I have to try and
do something, to achieve something. Life have to go on you have to survive; you
have food to find, you have clothes. You have to move because I am not used to
the sit down business; so I am going to do something. So I try to find out what I
can do. I applied to the Jamaica Society for the Blind for some assistance to raise
some chickens and they say for me to get estimates and send it to them. When I
send the estimate and gave them, they send back and said that the estimate is too
high and that they don’t have any money. That’s it. So I just said fine.

Raising chickens

So, I called my friends and said to them, I want to raise some chickens and they
asked me how I am going to raise chickens and I am blind.” And I told them that
someone told me how to do it, and I am going to try it. Some send me cement, some send mesh wire, some carry money and I fix up the coop (with help). Then, I went to find out now the cost of the chicken; so I called Jamaica Broilers and talked to a lady and let her know that I am a blind man and I would like to raise some chickens and what is the cost of the chicken. So she referred me to another woman that would give me some assistance. I called and explained to her that I am blind and I would like to raise some chickens but I only have a small amount of money. So she asked me how much I have, I told her $1000, and she said, that’s nothing but bring what you have and come. So I called another cousin and asked him to go with me to Jamaica Broilers; so we went out there. The woman gave me 100 chickens and two bags of chicken feed and said that the money that I have I should use it to buy additional feed and supplies. So that’s how I started to help myself but people rob me. I will carry 105 pounds of chicken and they still say its only 80 pounds that I carry. They claim say that I am blind so you don’t know how much. But that is not what troubles me. We got notice from where I used to live and I can’t raise chickens at the new place. When I applied for a permit to put up the fowl coop, the sanitary inspector said that the area was not sanitary enough to raise chickens. So I had to find another method of making a living, to find way to help myself.

Although Mr. Williams is independent and resilient, he constantly invokes his identity as a blind man to gain assistance. Here he relies on the aspect of the charity model that considers disabled persons to be needy. This is another example of how persons negotiate between both traditional and contemporary beliefs.
Selling appliances

So, Homelectrix (a home appliance company) used to have a warehouse out nearby where I live. There was a fire and the warehouse got damaged and they were selling out the appliances; so I went out there and bought some stoves – one burner stoves, and start to sell them so that I can keep myself afloat. Because as a man, you know say you have family even as a blind man, you still don’t want to depend on them. And they still look to you because from them see you still moving and you don’t sit down in the house...them say that sometimes them feel that I am not blind because of the way I move."

Inspiration

“I know that there is a supreme being and if you try to help yourself, he will help you at all times. And more time when you pray and ask because you know that he is not going to come and give you because you are blind. You know that you have to make an effort and any effort that you make, and he will assist you. If you do what you are supposed to do, if you do your part at all times, somewhere down the line you will get assistance. Sometimes you don’t even know where it is going to come from; but it come because the effort and that inner spirit that telling you to move now; God is with you. So with me now, I just put my trust in God and I go anywhere. I am not afraid to go anywhere. I just pick up my cane and I just gone. If I feel sick and I want to go to the doctor and I say to the lady, go with me and she hesitate, I just bathe, put on my clothes, take up my cane and I am gone. You understand? I am not waiting on anyone. And I make sure that I keep all of my appointments, if I have an appointment.”
Socializing

“I used to socialize a lot even before I was blind because I played cricket, I played dominoes, and I played football. I used to play dominoes for the island. I represent the island before I was blind. So I am not the type of person to just stay in. I socialize; I go to church. Everything that happens at my church, I am there and at CDA... I am the same person I was before; I don’t change. Moving around comes automatic for me.”

Learning to read Braille

“I just start learning to read Braille. When I approached the JSB to learn to use Braille, they told me that the nature of work that I did, (before I was blind) it would not enable me to use Braille because my hands would be too hard and I wouldn’t be able to feel the symbols. But I told them that is foolishness; and, they should let me try. But fate unkind to me because the same morning when I was supposed to start, I took a taxi and the taxi door shut with my thumb into the door. So the fingers become numb and my whole body became numb. You know she now, I don’t have any feeling and it took over two years to get back that feeling. Although the nail grew back, I did not get the true sense of feeling. But I prove them (JSB) wrong still. Down at the school where I am doing the skills training now, they carried a Braille machine trying to show us. They give me five minutes with the alphabet and the next time they bring the paper to show me and I could identify the alphabet. And they say that’s good.”
The cane

“Since, I have been in this program, about four months, my cane broke one Friday. Without the cane I can’t move. So I called JSB and ask them for a cane and the response was that I must contribute money. So I told them that I don’t have any money because I am in a training program and I am not getting paid. I look at it and said that I am paying my dues and not getting any benefit and if it was someone who went to School for the Blind calling, they would send the cane and give him. They wouldn’t want the student body come down on them. So I went to JCPD, and got a voucher to pick up the cane and when I went up there they still ask me for a contribution. Then I ask myself, why did I join this organization? Remember, my cane broke and I live outside of Spanish Town. And I can’t move. From that time, I just look at it different. I generally buy my cane.

Most blind persons are just like the normal person. They behave same way. So, just watch yourself (laugh). Just like the normal person out there, the blind man and the blind woman do the same thing.”

Treatment by Non-disabled persons

“Most of my friends who I grow up with or who I associate with during my time, them see the blindness and say the man just sick with him eye. They don’t take it for anything. They said that they don’t want me feel too sorrowful. What they love about me is the approach that I take to it, and I still move on. So they respect that so they just treat me as normal same way. So a man [friend] will come to me say, I am going into the town are you coming? Just like when before I wasn’t
blind. Let me tell you something. I might call one of my friends and say lend me a money, and he will say to me come check me later. Remember he is driving and he is telling me to come and check him. He not thinking of me as a blind man, he is thinking of me as a friend; and that is the most important thing to me. If he thinks of me as every time I am to move, somebody have to come move me then I am going to be like a burden and he don’t want me to feel like a burden. I don’t want to be a burden to anyone. So, I just try to move myself.”

Justice

“You have the other people now that glad that you are blind, because they pick and they prey on the weak. That’s all they do. Eight times, they break into my house in one year. The place was filled with dogs but they killed off some of the dogs. And it is hard for a blind person to get justice. I don’t know about any other country but in Jamaica, it is hard for a blind person to get justice. Because when you show the police and can prove that it is your things, they say you can’t see, so how do you know that it’s yours? They stole a king size bed from me; they switched it. When the policeman came, I showed him that the bed in there is not mine. He said, “I know that they take the bed but if anything further, check with me down at the station.” They know who took the bed and them not saying anything to them. A policewoman came when they broke in the place on another occasion. They took two dozen seat cushions, the thermostat out of my six burner stove, and took off the back of the stove. Then when the police woman came, she doesn’t ask anybody anything because if she had just asked, she would find out who took the things. In fact, she never really wanted to come; but it’s because me
and a lady went down to the station together. I was inside, she was outside, and she overheard the policewoman ask, how am I supposed to investigate for a blind man? How is he going to know what he has? So, she didn’t want to come.

Remember this, no justice for the blind person.”

Second Informant – Daniel

Daniel’s experience

Daniel is 49 years old and is physically disabled. He contracted polio when he was three years old. He was born in rural Jamaica but moved to an urban area of St. Catherine in 1983. Daniel is has been a member of the CDA for about six years.

I met with Daniel one morning in October 2006 on the grounds of the church where he is a member. His interview was one of four interviews that I had scheduled in the parish of St. Catherine. I was accompanied by the CDA field officer who introduced me to Daniel. We talked about the neighborhood, the weather, and how hot it was for the month of October. I explained to him about my research and the informed consent process using a verbal consent form. At this point, the field officer left us and went for a walk in the neighborhood. Daniel and I sat outside the church in the driveway. I sat on the pavement and he sat in his wheelchair.

After the formalities of the informed consent and getting permission to record the interview, I explained to him about my research

How did you become disabled?

“My mom said that I went to bed one night and I didn’t wake up at the usual time; so, she woke me up; it was like four or five in the morning; because in Jamaica, if your child slept through the night, you wake him up early to go to the bathroom
so that they don’t wet the bed.” But I didn’t wake up; and, when they tried to get me up, I didn’t have any feelings in my legs and couldn’t walk. So they put me on the donkey and took me to the nearest health center in Cambridge. I am from St. James in a little district that is eight miles away from Cambridge. When I got to Cambridge, they didn’t know what was taking place; so I was taken to Cornwall Regional Hospital in Montego Bay, but, they did not know what was wrong either. So, I was transported to the University Hospital in Kingston and they sent me from there to Mona Rehab.

Daniel stayed at the Mona Rehabilitation Center, in Kingston, until he was seven years old. At Mona, he got medical treatment, physical therapy, and attended school. It was during the polio outbreak in the 1960s; so they discharged him to make room for more severe cases. He went back to St. James and did not receive any further schooling.

According to Daniel, he is self taught. ”Although he has not completed elementary school, Daniel is very intelligent and quite articulate. I asked, about his vocational skills and learned that he repairs shoes and does steel work and went on to describe his steel work experience.

“For instance, like these columns that you see here, the concrete columns. I helped to put in the steel section; and most of the work on this [church] I helped to do it. The steel inside, you know when you cut them, tie them together, and make a column and then you pour the concrete over them. So, I can do that; I do maybe about 80 percent of it along with some of the brethren.”

I did not quite understand about the steel work but I remember seeing construction workers tying steel rods with mesh wire and pouring concrete so I tried to
visualize what he was saying. I was very impressed because this church was a large structure with huge columns towering over us. Also, the steel work on the church gate and parts of the wall was very intricate. So, I asked him how he learned this skill and he explained,

“Well it’s right here that I learn it. When the church started to build, Pastor said that there is nothing wrong with my brain. She said, it’s only your legs so I should get myself involved and I did what I could. She kept telling me that “it’s your feet not your brain.” So from there, I tried to excel. So, I can do steel work; and sometimes I help my friends sand down furniture.”

Later on, I learned that Daniel repaired wheelchairs also but he could not get the parts to repair them. I asked him my burning question: did you learn to read and write? He explained.

“They had a program on television, JAMAL (Jamaica Movement for the Advancement of Literacy). I stayed at home and learn it. It was on the television, but its not there anymore. That’s where I learn it. I do a lot of reading even now, a lot of reading.”

I then asked Daniel what it was like living with a physical disability and he stated,

“The honest truth, it’s horrible. But because you have the will power not to let as Bob Marley say not to let the system get on top of you. That is what drives me and then I know that I can pray and talk to the Lord. So that is inner strength but in the real world its horrible man. Even in the past two weeks, I went to visit a friend of mine (who is disabled) and it was a challenge to go where she lives and when I eventually got there and saw where she lived, (she is in a wheelchair)
when I see the condition she was in you know, because I see myself in a better condition than her, not financially but being able to move around.

According to Daniel all those years in the country, he learned to farm and was good at it. For example, he stated,

“When I was in the country, in St. James, I used to farm. When I left James and came to St. Catherine, I had 6 chains of sugar cane joint that I planted and I had one chain of banana, dasheen, coco (fibrous root crops). I used to go on my knees, cut my stick, and use the fork and plant. Is since I come here I get lazy.”

I asked Daniel why he decided to leave St. James and move to St. Catherine, and he explained,

“The treatment down there [rural area] is worse than up here because there is a myth attached to people with disability down in the country, because somebody would say a duppy lick (hit) him. But the reason why I left is... from I was very small I told myself that there are certain things in life I must accomplish. And down there it was from home to farm, home to farm and it wasn’t working out. I had an uncle that lives nearby here. I wrote him and ask him if he had a place I could stay. He was my favorite person and said yes you can come. But when it was possible for me to come, his job laid him off and he had to go back to the country. I didn’t know so I still came. When I came I found out that I had another uncle here and he said that it was alright to stay for two weeks. His wife said, let him stay and somehow I think that it was the hands of the lord because within that period of time, she took sick. He had to go out and work and I just fit in myself and started to clean, cook, and wash clothes (because I can do those
things from I was in the country). Then, I just fit in; and because their kids were little, when he would come home from work now he didn’t have to do anything.

So my two weeks started in 1983 I am in still in St. Catherine. I live on my own now because I got a house from Food for the Poor, so I am on own since 2000.”

When I asked Daniel how he was being treated, he said,

“Well, basically in here (his neighborhood), I have friends and they will say to me let's go play football, let's go play cricket? So, basically most people see me as one of them. In other words, they don’t see me as a disabled person because I try not to seclude myself. Anything that is happening, I try to be part of it. I don’t try to draw back [because] the more you are involved the less time you have to think about your limitations.”

Like Mr. Williams, Daniel believes that his friends treat him as a normal person because they invite him to take part in so-called normal activities with them. Of course, these are activities in which he is unable to participate. Although this might seem peculiar to an outsider, it has significance for both men because they want to be treated as normal.

When I asked him about his experience at church, he explained,

“Here in St. Catherine where I live, I don’t have a problem with nobody because I make myself very active. On Monday mornings I would go by the high school and lead the school devotions and I did that for maybe five to six years. Then, I met in an accident and someone else took it over. I talked to the principal and she said that it’s going on alright. I just check now and again to see that it’s still functioning. I make myself very active.”
Daniel dreams of learning landscaping and taking some computer training but has not been able to get into the classes that are being offered in the parish of St. Catherine. He talked about his experiences of trying to get enrolled into one of the vocational programs offered by Human Employment and Resource Training (HEART) Trust.

“I tried to get into HEART about three years ago; but, they told me that they did not have anything for disabled persons. The place where I wanted to go, they said that it wasn’t accessible. I also wanted was to do landscaping but they said that was good but the landscaping would be difficult [and wanted to know if rain falls what I would do. I said, don’t you think that I thought about that before...I have it in my mind that before I die landscaping is part of what I want to do. They also said that floral arrangement is good but landscaping wasn’t accessible for a wheelchair person.”

This is another example of how social barriers are more disabling than the person’s impairment. This agency’s decision to exclude Daniel from taking part in certain classes is based on their assumption of what is most suitable for a disabled person. This attitude is rooted in the charity and medical models that limit the range of things that such persons are capable of doing. The attitude of excluding PWDs from educational and training opportunities have resulted in many of them being unemployed.

According to Daniel, there are few training opportunities for PWDs and these do not come around frequently. He explained that he was about to start a computer class designed specifically for PWDs. However, when the time came, he could not start because he did not have the money for bus fare. Although he would be paid traveling allowance, it would not be available until after the first two weeks. A friend promised to
loan him money for bus fare but could not afford to because they had a death in the family. Daniel is awaiting another training opportunity.

**Initial Involvement and Level of Participation**

*Question Two: How did CDA members negotiate their original involvement and level of participation with the organization?*

This question was explored using an informational survey and semi-structured interviews. The areas covered in the survey are: 1) length of membership, 2) volunteer positions held with CDA, 3) participation in the CDA activities, 4) prior involvement with the CDA, and 5) how members learned about the organization. Although the interviews covered similar items as the survey, the interviews allowed the participants to describe how they negotiated their initial involvement and level of participation with the organization.

**Results from Informational Survey**

Of the 55 persons who participated in the survey, there were 28 males and 27 females. They represented the following types of disabilities: blind (22), deaf (2), physically disabled (28), mentally disabled (1), and chronic medical illness (2). Twelve (12) lived in rural parishes and 43 live in urban areas. The following questions were asked to determine how members became involved with the CDA and what kept them connected to the organization. This was based on the rationale that members stayed with the organization because they are receiving some benefit or have some personal connection with the group. This includes being friends with other members.
1) **How long have you been a member of the CDA?**

<table>
<thead>
<tr>
<th>Length of Membership</th>
<th>Number of Persons</th>
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<tbody>
<tr>
<td>Under one year</td>
<td>4</td>
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<tr>
<td>1- 5 Years</td>
<td>11</td>
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<td>6 – 10 Years</td>
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<td>11-15 Years</td>
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<tr>
<td>16 – 20 Years</td>
<td>3</td>
</tr>
<tr>
<td>21 to 25 Years</td>
<td>20</td>
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2) **Have you been part of another disability rights organization?**

Most persons (30) replied “yes” to this question. The following is a list of the groups that members said that they were involved with prior to their involvement with the CDA.

1. Progressive Blind Association (3)
2. Jamaica Council for PWDs (7)
3. Deaf Club (2 persons)
4. Jamaica Society for the Blind (11)
5. Jamaica Paraplegic Olympic Association(2)
6. 3D Self Advocacy (2)
7. National Cultural Group for the Blind (2)
8. Salvation Army School for the Blind(1)
Most of the groups listed are not advocacy groups; the advocacy groups on the list are Progressive Blind Association, which no longer exists, Deaf Clubs, Jamaica Society for the Blind, and 3D Self Advocacy. A comparison of the disability groups reveals that more blind and deaf persons were involved with other disability groups prior to becoming part of the CDA. Although only two deaf persons participated in the survey, they were both involved in an advocacy group prior to becoming involved with the CDA. Based on my observations, deaf persons are more involved with the deaf clubs than with the CDA. For example, when I organized the group interviews, approximately 17 deaf persons attended but only three were members of the CDA.

From examining the data, it appears that blind persons had more options for membership in single disability groups than do persons with other disabilities. Also, persons with physical disabilities have fewer options for group membership. Two interviewees who are physically disabled expressed that, prior to the establishment of the CDA, blind persons were more organized than other disability groups.

From my observations, there is a close bond among blind persons, particularly those who attended the Salvation Army School for the Blind. So, I asked one of my blind informants about it and received the following response,

“Yea man, clan; I would call it a clan. We are brethren. It is very healthy though and we are sensible enough to know when somebody a play the ass, and don’t have any problem to tell somebody him playing the ass...I think it is very healthy. Good and strong, we look out for each other. When it comes to way of life though, the blind live far better and more unified.”
However, blind persons who did not attend the Salvation Army School for the Blind believe blind persons who are not past students from this institution are excluded from leadership in the CDA. This does not occur because the organization discriminates but because board officers have to be nominated and voted in by a majority of members and members tend to vote for their friends.

3) What positions, if any, have you held with CDA?

Members were also asked if they held any positions with the CDA and if so to list them. A total of 28 persons reported that they had not held a position with the CDA; while 21 persons held one or more positions. Seven participants held multiple positions. These positions held include board officer, secretary, treasurer, committee member, DPI representative, and chairperson.

To help determine the level of their involvement with the organization, participants were asked the following questions:

1) Have you participated in any CDA activities?

2) If yes, in what activities have you participated?

A checklist was not used because the researcher did not want participants to be limited to the items on the checklist. Often their first response was they were not involved in any CDA activities. However, when participants said that they could not think of anything, they were prompted with well-known activities such as the monthly rap sessions. However, once they were prompted they remembered other activities that they had not thought of originally. The following is a list of the activities that they participated in:

List of CDA Activities
1. Rap sessions/monthly meetings (27)

2. Seminars and workshops (6)

3. Advocacy activities (3)

4. Annual General Meetings (9)

5. Special events such as beach trips, Christmas program (5)

6. Volunteering (4)

7. Attends all CDA events (3)

8. None (12)

7. **What kind of assistance, if any have you received from the CDA?**

Of the 55 participants, 32 listed the following as things they received from the CDA. Twenty-three (23) persons said they received no assistance from the organization. However, many individual tended to forget that they received any assistance or had different ideas of what should be termed as assistance. When I gave examples of possible types of assistance, they usually remembered that they received something. Also, when they hesitated, I prompted by suggesting that they consider both and tangible and intangible benefits. Then, respondents would think of some intangible ways that the CDA had assisted them. As seen from the list, items such as housing and tax assistance did not come directly from the CDA, but some individuals credited the organization with this because it came as a result of the CDA’s advocacy activities.

**Kinds of Assistance Received**

1. Financial assistant/loan scheme (4)

2. Job training; computer training (7)

3. Food assistance (5)
4. Employment (2)
5. Advocacy benefits such as income tax and housing (3)
6. Study leave (1)
7. Wheelchair (1)
8. Exposure to disability issues; disability awareness (3)
9. Advice, moral support or encouragement (2)
10. Education help for my child (1)
11. Assistance with starting business (1)
12. Received no assistance (23)

7) How did you learn about the CDA?

There are four ways that members learned about the CDA: 1) through a friend or relative, 2) through the JCPD, 3) through their involvement with another disability organization, or 4) through CDA efforts. The majority (30) of those who took part in this survey were referred through a friend or relative. Next greatest (19) learned about the CDA through their involvement with another disability organization such as the Jamaica Society for the Blind or 3D project. Three (3) persons learned about the CDA because of the organization’s outreach and three (3) persons learned about the CDA through the JCPD.

These results indicate changes in the CDA’s recruiting practices. From my interviews several CDA members who became part of the organization in the early years were originally associated with the Jamaica Society for the Blind or had established friendships while at the Mona Rehabilitation Center. Although there was not a vibrant group of physically disabled persons like the blind persons, the “Mona Rehab
experience” allowed persons to bond and develop life-long friendships. Carol explains by describing her relationship with another CDA member which, according to her, was born out of their experiences at the Mona Rehabilitation Center.

“We knew each other from we were children. We would be at the Rehab Center at the same time, so if she had surgery and I went in for surgery she maybe had surgery before me, so I would be there to assist her. So we really, we share our experiences. We grew up together and we always kept in touch so if she had an experience that was negative we would talk about it and we would laugh.”

I found this to be the case with many the physically disabled informants who had polio in the 1950s and 1960s.

“Mona Rehab Center is where my journey with this disability thing began. I stayed there until I was fitted with braces and my little crutches and then I went back home. So over the years what would happen, during the holidays I would go back to Mona Rehab, I stay, and get new crutches and new calipers because you know they do it according to how you grow. I don’t think I live there for a whole year because it didn’t take that long to go through the therapy and get your crutches. I know while I was there I went to school for a short time and then I went back home.”

It was through these experiences that the bonds that remain today were formed.

Some of these individuals still remain in leadership positions in the CDA. These relationships made it possible for the organization to thrive in the early years. This is consistent with disability organizations elsewhere; in that, they tend to be formed out of already socially cohesive groups (Barnatt et al2001).
However, the CDA has members who neither share this “Mona Rehab experience” nor attend the Salvation Army School for the Blind. Many of these individuals are being introduced to the organization through the JCPD with whom the CDA shares a building. The JCPD is the government agency that certifies a person as disabled. This certification is necessary in order for persons to receive any disability benefit. Staffed by several PWDs who are members of the CDA, the JCPD directs PWDs to the CDA for advocacy assistance at which time they are given membership information. Within the last two years, several members have been recruited through the efforts of the field officer. Many of these individuals had no previous knowledge of the CDA or the JCPD.

Results from semi-structured Interviews

Informants were also asked to describe their involvement with the CDA. This aimed to discover how involved people were with the organization, their previous involvement with disability advocacy, and what accounted for their level of involvement. For persons who used to be involved with the CDA but are no longer involved, I also wanted to understand what accounted for the change.

Using the responses of three informants, I will describe how CDA members negotiated their level of participation with the organization. Their ages range from of 23 and 55. Two are visually disabled and three are physically impaired. Their memberships with the organization range from two to twenty-five years. In fact, two of them described themselves as founding members of the organization.

Informant-Phillip
Phillip is physically disabled and has been with the CDA for two years, and has held a position on the board.

Informant-Beverly

Beverly is physically disabled and has been a member of the CDA since it started in 1981. She has held several positions on the board including being elected as the chairperson on more than one occasion.

Informant - Diana

Diana has been a member of the CDA in 1991. She is blind and currently a member of the board and has held several positions on the board. However, Diana was a member of the organization for several years before she decided to undertake a leadership role.

Informants were asked: “How did you become involved with the CDA?

According to Beverly,

“I started out with CDA as a young girl. I think I had left university by that time and then started out in CDA. My perspective having grown up at Mona Rehab was that we should try to function as normally as possible and fit back into society. There was nothing about any movement or anything because you were just to see yourself as normal as possible. Well the IYDP brought a wind of change; because, the whole matter of disability was now highlighted. People began talking about it openly. Well that is where my involvement with CDA began; because although I was kind of involved doing things. I never wanted to
be upfront. But one of the founders kept saying “no man this not for yourself; you
know you doing it for other people so that they you can benefit.” I told him that I
was not an upfront person and I didn’t want to do any interviews on television.
He said yes but you will get accustomed to it. So, I said that this is not just about
me.”

Diana also explained her reason for taking an active role in the organization.

“My serious involvement with CDA, I think started in 1994 when we were having
a regional assembly meeting of DPI. It was Jamaica’s time to host the assembly
and I was part of the committee of the “access;” I think they call it that. I was in
charge of the transportation; getting people from the airport, etc. that kind of
thing and after that, I thought I would cool off a bit. Then I became actively
involved again about 2002 or 2001. It was a new board...and I became the
secretary of that board. My involvement with CDA came at a time when...I was
involved with JSB. I am the kind of person who is always looking for ways to
develop myself. “

Phillip became involved because he wanted to give back to the disability community. He
explains,

“What you find is that the state-run entity (the Council) gives a meager assistance
to person with disabilities. Not that I am not being grateful for the few benefits
that they have created for PWDs but they can do more. But the state had better
governance and better management of public resources. Nonetheless, because of
these meager benefits, I felt obligated to give back to the disabled community so
that was what really encouraged me to become an active member. At the last
Annual General Meeting, an officer of the board was stepping down and not seeking reelection and I saw it as an opportunity to apply what I am learning in school. It is a two-fold benefit both to the organization and me.”

According to these respondents, they were motivated to take on a leadership role in the organization mostly for humanitarian reasons. This tendency to want to help others also stems from the tradition of the charity model to help others who are less fortunate. This is another demonstration of how disabled Jamaicans in their negotiations embrace aspects of this model that they favor and reject others.

International Linkage

Question Three: What is the nature of the linkage between the CDA and Disabled People International (DPI); and, how does this relationship affect the CDA’s policies and procedures?

This nature of the CDA’s relationship with DPI was explored by conducting interviews with four CDA members; three of whom were past and/or current representatives of DPI. All four members have held multiple positions on the CDA board and have been involved with the disability movement at the international level. In addition, I reviewed documents from DPI’s website and the CDA’s archives. The findings will be presented in three sections. First, I will describe the structural relationship between DPI and the CDA. Second, I will describe the dynamics of partnership between Caribbean and North American members of DPI. Finally, I will describe the formation of a new organization by the Caribbean members of DPI.

Key informant Robert:
Robert is a founding member of the CDA and one of the first representatives to the North American and Caribbean Region of DPI. He has been involved with disability advocacy both regionally and internationally. Robert spoke very candidly with much of passion about the movement. After my first meeting with him, he challenged me to consider Jamaica’s contribution to the movement.

*Key Informant Enid:*

Enid has been a member of the CDA since the mid 1980s. She has had multiple roles in the organization including chairperson. Enid was the DPI representative for four years during the 1990s. She was also appointed secretary of the Council.

*Key informant Yvonne:*

Yvonne has been a member of the CDA since its inception. She has also served the organization in various capacities including being the chairperson. At the time of my research, Yvonne was the DPI representative. She has represented the North American and Caribbean region for ten years and also represents the Caribbean on the DPI World Council.

*Key Informant Lavern:*

Lavern is a member of the CDA board. She has been a member of the organization since the 1980s and has held various positions within the organization, including chairperson.

*The Structure of Disabled Peoples International*

DPI is a network of national organizations of PWDs from 135 member countries, most which are from the developing world. DPI is divided into five regions: Africa, Asia/Pacific, Europe, Latin America, and the North America and Caribbean. The North
America and Caribbean region consists of 14 countries, including Canada, the United States, Jamaica and eleven other Caribbean countries. Although DPI is headquartered in Canada, there are offices in each region with the North American and Caribbean regional office located in Antigua and Barbuda. DPI has a world council, consisting of representatives from the five regions that represent the DPI at the United Nations. DPI also has consultative status with the Economic and Social Council of the United Nations. Although each national organization is autonomous, each share the DPI’s goals of 1) “full participation of PWDs in the mainstream of life,” and 2) the development and support of organizations of disability persons across the world. Each national organization designs policies and programs that are relevant to its local situation. The interaction between the local and the international is done through the regional offices.

A Partnership between Developing and Developed Countries

Based on the structure of DPI, each country has equal status. However, in my interviews with Jamaicans who have represented DPI at the regional level, the dynamics of working with the two so-called developed countries (Canada and the United States) in the region has been challenging for both groups.

Although the local organizations are supposed to be autonomous, creating their own local agendas, I was concerned that the developed countries were dominating in these relationships especially since they were the ones with the resources. In semi-structured interviews with CDA members the following are some of the responses I received. However, these responses reveal change over time on the level of influence that DPI has over the local organizations. According to Lavern, describing the level of influence that DPI has had on CDA and other Caribbean organizations,
“Well, it does but not so much influence as it did in the earlier years. When we just started out, we didn’t know much about advocating for ourselves; but, with those people coming down here…the people from Canada, in particular, because the US was never really very involved. Although it’s North America and the Caribbean region, we have always had difficulty identifying an organization in the US to be member of DPI. We had and it did not work; but the Canadians really led the way. They were the ones who would come when we had the regional training sessions; they exposed us to disability issues. They were the ones who opened our eyes. They spoke about sexuality, relationships, just about everything. They were the ones.”

In my discussion with Enid, I asked the following question, “Do you think that the developed countries in DPI tried to impose their values on developing countries in the region?” She explained,

“I think yes, and I think that where the clash came in the 1990s because in the early stages, everybody was setting up organizations and they knew that the resources weren’t there (locally), and because of that even when you did not agree with something is like your funder or benefactor you try to compromise or just live for them because you need their support. So it’s just like a child, after you start growing up and having your own views about things. Yes, we appreciate what was done for us. We support most or a fair amount of the ideals and so on. But now thinking of things on these lines, I think that DPI had a problem in letting go or slacking up the hold that they had. They felt threatened. That is my opinion based on the history and also based on the experience that I
had coming in. They felt threatened by the fact that disabled persons in the
Caribbean, though they want you to take charge of your own life, it’s like being
catch between a rock and a hard place. They wanted you to be independent.
They wanted you to take control of your own life. They wanted all of this; but,
they didn’t want you to become totally independent of them. Here it is,
organizations were now deciding that we don’t want things this way. No, you
can’t dictate to us and so on and they became...the animosity started to set in.”

This reflects the historic dependency relationship that has existed between the
Caribbean and developed countries, such as the United States, and Canada. As activists
in the Caribbean found in working with these countries, the tendency is for these
countries to assume that they know what is best for Caribbean and other developing
countries. However, because of the economic imbalance, developing countries such as
the Caribbean often give up their autonomy for the benefits that these countries offer.
Although Jamaica and the other Caribbean countries understood the dynamics of this
relationship, their choice to remain within the established framework was a strategic one.

While giving up of their autonomy is definitely a cause for concern, it was a
conscious and, arguably, a prudent choice because it saved them from possible reprisals,
allowing them to establish a vibrant Caribbean movement. Nevertheless, this action
should be taken into account when looking at the strategies and programs that these
organizations implemented during the early years. If local realities were not taken into
account, some of these strategies and programs would have been irrelevant to its local
needs.
One of my concerns was how much of a voice the Caribbean had in the regional council considering that Canada and the United States were part of the same region. The responses revealed that initially the Caribbean did not have a strong voice in DPI. However, that has changed. According to Yvonne, remembering her first attendance at regional training in the 1990s.

“I attended a meeting in Dominica and a lot of Canadians were there, and Americans as well. It was a two-week training program with seminars and workshops. Persons from the Eastern Caribbean and the smaller islands were sort of selling their souls to these persons from the Canada and the US. They were not in agreement with some of the things that they were saying but at the same time they felt that they were the super powers; so, they couldn’t oppose what they were saying. Although in the evenings, they would sit down in their rooms and say that they didn’t like that or whatever. I was a new representative; so, I listened at first but then it got to me and I realized that when we sat in the conference room you could have your hand up for eternity, they would not recognize you. It was just the Americans and the Canadians who had they say.

So, one morning, I was trying to say something and they would just by pass me. So, I sat with my hand up and they would still bypass me; so, I got up and I stood on my feet and they said, ok Yvonne. Then, I said that I am going to talk now; and they said [someone else] was on the program. But, I said I was there before her. As a matter of fact, I should have been on the program from last week; and I just started talking, and people started cheering. But I was upset with them though; they should have done this a long time ago. This was the sort of autonomy that
they were giving these people. So right there and then I spoke and other persons felt more confident to share things and we went away with a good meeting, a fruitful meeting. Then those people from that group remembered me and when they come to our meetings here in Jamaica or to other places in the Caribbean they ask for me. You respect people but you want people to respect you as well and that was not there. The attitude was, “I am here and I am speaking down to you and you listen to me, it was that sort of situation that we had.”

The Formation of a New Caribbean Group

In 1998, the Caribbean countries in DPI formed a separate organization, Disabled Peoples Organization of the Caribbean (DPOC) which was based in Jamaica. The formation of this organization resulted in further animosity between the Caribbean and DPI. Lavern describes

“When they realized that DPOC was being established and that it was not going to be a sub-group of DPI, they became antagonistic toward the Caribbean. When they realized they were not going to be dictating, they started opposing the setting up of the organization. They opposed to extent that when I was on teleconferences with them and DPOC was on the agenda, they refused to discuss it. They discussed everything and said that we can put this to the next teleconference. And not only that, but we were written very strong letters. The chairman even asked to me, how dare you set up an organization without the permission of DPI and we had to get permission before we set up DPI. So, I asked, how come you didn’t say that to SAFORD (the subgroup for Southern African countries) and they felt that I should not have responded in that way on
the call. Only Mexico and Costa Rica was kind of in my corner and this guy from Ireland. They felt that if SAFORD did not have to get permission to set up, they didn’t see the reason why the Caribbean had to get permission. That was my view and these three countries shared it. As a matter of fact, after a while DPOC was no longer an issue on DPI’s agenda. Then we realized that if you were going to do DPOC, we would have to do it on our own. What we were saying to them was ok we would not be a sub group but we would want to collaborate with DPI but they were averse to doing that. They never said it in so many words but they never responded to some of the things that we sent to them but started laying pressure on us. They didn’t give us (that is the DPI regional office) any money for two years because DPOC was being set up by DPI’s Council in the region.

We also began to get some problems with the North American faction of the North American (Canada and US) and Caribbean region. For example, they stopped sending us information. They would change presidents and not tell us and then eventually they would write a letter to the DPI headquarters to say that they are not hearing anything from the region and that they didn’t think that the region was treating them fairly. We would get a lot of “rude” letters from the headquarters with the attached letter from Canadian organization. As a matter of fact, one our arguments were that USA never applied for membership to the region but they were supposed to be members. That became an issue and they had to apply. Then they said that they didn’t need the Caribbean; the Caribbean needed them. That was big. How could this little Third World, underdeveloped region want to dictate to us? So, they didn’t used to come to our meetings.
Canada would come but when Canada came, they wouldn’t stay where we stayed.
They would want to stay at the big hotels like Pegasus then they would want us (region) to pay for it.”

Although she was not involved on the international level until after the formation of DPOC, I also asked Yvonne about her perspective on the formation of DPOC. The following was her response,

“DPOC was formed because they wanted to break away from the US and Canada not in a destructive way but the connection to the US and Canada was to our disadvantage. Sometimes with funders, if you are linked to those two developed countries, they will not recognize you as a developing country; because if you are linked with these countries, then you should be OK. Also, the Canadians had sort of dominated things and they had an executive director there who was not for the Caribbean. Because of these things, not just the attitude but also the connection with the US and Canada and the deprivation that we were feeling because we were connected to these two high powered countries, we decided that we would form another organization but not breakaway from DPI. The national organizations in each country were still members of DPI but they were now members of DPOC.

So, if we made representation to the Caribbean Development Bank, it would be a Caribbean Organization not a North American and Caribbean Organization. So that was one of the main reasons why, to my understanding that they broke.

**Strategies Used By CDA**

*Question Four: What strategies are employed to mobilize PWDs in Jamaica to participate in advocacy activities?*
This section describes the various strategies that the CDA employs to mobilize PWDs to participate in advocacy. CDA exists for the purpose of advocating on the behalf of PWDs and to ensure equal access to the whole range of opportunities offered by the society (CDA 2006). Although its primary purpose is advocacy, the association has gradually expanded its services to include several non-advocacy activities such as public education, skills training, and a limited number of social welfare programs, some of which have been discontinued. The CDA’s choice of programs is largely in response to the needs of its members and the availability of funds. Based on data drawn from semi-structured interviews with the CDA members, staff, and document review, the following are some of the activities that the CDA used over the years.

**Advocacy Activities**

In order to ensure that PWDs have equal access to all the opportunities that are available to the society, the CDA mobilizes and empowers its members to participate in advocacy activities. In keeping with its motto “Nothing about us without us,” The CDA promotes the participation of PWDs in all matters concerning their welfare and development. The organization’s main advocacy activity is lobbying government to pass legislation. To date there have been several accomplishments, which were mentioned previously. The CDA also seeks to gain representation on local boards and committees.

While the organization has been fairly successful in mobilizing individuals in Kingston it has not experienced the same level of involvement in the rural parishes. To engage rural residents, the CDA has used various strategies, including the establishment of the Rural Development Program in 1994. The main aim of this program was to
increase the membership and participation by establishment of a CDA chapter in each parish.

Prior to the starting this program, the CDA had two affiliate chapters, Western Disabilities Association (WDA) and Eastern Disabilities Association (EDA). However, funding from CUSO, a Canadian development organization, made it possible for the CDA to expand its outreach and established groups in the St. Elizabeth parish and one in the St. Thomas parish. Funding not only allowed the CDA to start the two new groups but also to strengthen the existing chapters. This was facilitated through the employment of a field officer; but when funding ran out, the CDA was no longer able to employ a field officer and the program ended. Currently, WDA and EDA are still operating but the chapters in the two other parish chapters no longer exist.

Although the Rural Development Program is no longer functional, the CDA reaches out to rural residents. According to the CDA staff and board, the organization has not given up on this effort but does not have money to devote specifically to it. So, instead of focusing specifically on funding for a rural outreach, the CDA incorporate rural communities in all of its projects. For example, in 2006, the CDA received funding to conduct training seminars on disaster preparedness; these were done throughout the island. The CDA divided the country into four zones eastern: western, northern, and southern, and held four seminars. Seminars were held in all four regions, which made it easier for persons to attend these seminars than if they were held in Kingston.

Two years ago, as part of a funded program, the CDA hired a field officer to conduct a disability census as well as an outreach to rural areas. However, this proved to be a formidable task resulting in an incomplete census because the field officer became
extensively involved in doing the job of a social worker. Although the field officer has been successful in signing up several new members, another CDA chapter has not been established. As the field officer explains,

“It is difficult to convince people that they can lead themselves and also to some to accept their disability. One of the challenge is to get people to come together, for example, in Clarendon, that is a very huge parish but it is difficult to get persons to really come to a meeting because of all sorts of problems such as transportation, lunch money and all that. We have to fix a budget to meet all those needs and that is difficult.”

The stigma associated with disability in some communities prevents persons with disability from participating in collective action. As Hahn (1985:310) suggests, it is often difficult to get people to organize around an “aspect of their identity if they consider it to be negatively stigmatized.” Furthermore, because someone has a disability does not mean that they want to take part in collective action with other PWDs (Scotch 1988).

In March 2006, with the help of the field officer, the CDA scheduled a meeting with some PWDs in the parish of Clarendon. This was one of many attempts to establish a CDA chapter in this parish. Although approximately forty persons were in attendance, The CDA was unable to identify someone who was willing to lead a chapter.

As part of its advocacy activities CDA attempts to have a representative on all community boards that deal with issues relevant to the PWDs such as the JUTC. Recently, a the CDA member sat on the board of the Friendly City 2007 that is responsible for planning World Cup Cricket. Having a person with a disability on this board ensures that steps will be taken to make facilities accessible to PWDs.
Public Education

Another aspect of advocacy is that of sensitizing the public to disability related issues through presentations by CDA members and staff. These presentation are conducted both in the rural and urban communities. These are designed for the public official and the public in general. According the CDA chairperson,

“We plan these programs based on the collective experiences of our members and the things that we have problems with out there. For example, a person in a wheelchair comes and has to park way down at the end, will have difficulty. But, people don’t think. So our training programs are really based on the experiences that we have in the buses where some of the seats are reserved for PWDs and people will go in and sit down and a disabled person will come in and they just refuse to get up. So things like that as you go along the experiences that we have had collectively. For example, you think that a blind person is going to be walking on the sidewalk and you might park your vehicle on the sidewalk. Now you trying to put your car out of the road and you put yourself on to the sidewalk. But a blind person, who normally uses that sidewalk, will not know that you have parked your car there, and they will walk headlong into it. Things like that you would want to sensitize the public to. And another thing that you want to do to, you want them to understand too that we function normally given the opportunity, because a lot of times people don’t employ us because they think that if we employ a blind person it going to be a problem. They are not going to be able to do this or going to be able to do that or if we take this wheelchair person then they have to
put in ramp. They see all the barriers and they don't think that the person will be able to perform by making a little alteration to the work environment.”

*Raps Sessions*

These are monthly business meetings held for CDA members. This is also used as an opportunity for advocacy. For example, each month guest speakers and presenters from various agencies that provide services to PWDs are invited to the rap session. At these sessions, CDA members have the opportunity to interact with agency representatives by asking questions and getting answers to issues that they might have with a particular agency. During 2006, representatives from the JUTC, National Insurance Scheme (NIS), and HEART Trust, a vocational training and certification agency that prepares persons for employment were three of the groups who attended the rap sessions.

*DEEDS Industries*

As mentioned previously Diversified Economic Enterprises for Disabled Self-help (DEEDS) Industries, Limited was established by the CDA and provided employment for approximately 70 persons, most of whom were PWDs. DEEDS was established 1) to demonstrate the potential of PWDs to work alongside those without disabilities in an open employment situation; 2) to provide employment and income for PWDs; and 3) to provide income for the CDA.

CDA members talk about DEEDS, some with pride, some disappointment, and some with anger. They are proud that this successful business was a model for PWDs
employment. However, many are disappointed because they believed that it was not managed properly. For example, although there were problems with the manager who misappropriated funds, some believe that the DEEDS board did not take the appropriate steps to acquire the property that the company was renting. As a result, when the facilities were sold DEEDS was unable to find a new place for relocation. Some former employees are angry because they saw DEEDS as their only opportunity for employment and that was taken away from them. The CDA is committed to reestablishing DEEDS or a similar company that will provide employment to disabled individuals.

Job Placement and Training

With about 50 percent of its members unemployed, the CDA is trying to assist with job placements and training opportunities. Currently it has an arrangement with a local telecommunications company to hire as many qualified PWDs that CDA sends to them. However, the organization is having a difficult time finding enough qualified applicants to submit to Digicel. The CDA director expresses concern that so many members do not have the minimum qualifications for employment, which are a high school diploma as well as a passing grade on three Caribbean Examination Council (CXC) or GCE O Level subjects. These are minimum requirements to obtain most entry level positions in the private or public sector.

In collaboration with agencies such as HEART Trust and National Youth Service, the CDA offers computer classes and other skills training opportunities for its members. However, these are offered on a small scale. During my tenure with the CDA, I helped to prepare a grant proposal to acquire funds that would help to provide CDA members with CXC examination preparation classes. However, these funds were not awarded.
Food Distribution

The distribution of grocery items is the CDA’s main social welfare program. However, this has caused some controversy because while some members see it as meeting a need, others see it as distracting the organization from fully focusing on its advocacy role. Food distribution provides several challenges for the CDA, such as the pick up, storage, and distribution of items. The CDA receives several items of groceries from Food for the Poor, a charitable organization in Kingston. However, the CDA is responsible to pick up the items from the warehouse but it does not own vehicle; so the CDA has to hire a truck to pick up the products. Next, food items are usually in 40 pound bags and need to be stored but the CDA does not have adequate storage for these products. As a result, they are stored in the CDA office which has very limited office space.

The packaging and distribution of the food is tedious at times unless volunteers come in to help. If there is no volunteer help then it falls on the office staff. In my interviews with board members, I asked what they thought about discontinuing food distribution and everyone agrees that there is a need and that the CDA should continue. Even staff who do most of the work agree that food distribution should continue because it is the only option that many members have for getting their groceries.

Advocacy versus Social Services

Some CDA members disagree with the organization’s involvement in directly addressing social welfare needs of its members. Although this was not a part of my original set of questions, this is one of the issues I discovered during participation observation. As mentioned earlier, some members believe that the organization should
focus on advocacy and allow other agencies to address the social welfare needs. The arguments against food distribution are based on the following reasons: 1) The CDA does not have the capacity in manpower or financial resource to undertake this responsibility; 2) There are other agencies who are better equipped to address these needs; and 3) If the CDA should use advocacy to make government more responsive to the social service of PWDs. On the other hand, some members believe that the CDA has an obligation to address the social welfare of its members because other agencies would not be attentive to needs of PWDs. In my interview with two CDA board members, I asked their opinion on the organization involvement in social welfare and got the following responses:

Albert is visually impaired and an active board member. He is the one person that you can expect to see at the office during food distribution time. He is very attentive to PWDs who comes into the office for assistance.

Lavern is physically disabled and an active member of the board. She is a key person in the organization and has been part of the CDA’s leadership for over twenty years.

Evadney is physically disabled; she considers herself a founding member of the CDA. She is not currently on the board but has held several board positions in the past. During my interview with Albert, I asked him what he thought about the CDA’s involvement in the social welfare and he responded,

“I think that we need to assist persons who really can’t afford it. You do have members who to look forward these food supplies, so I think we should be giving it. Not all members agree even on the board, because the last meeting we had, I fought, fought strongly for it to keep up so it’s me why it is here. I don’t think this
is affecting advocacy because we are just giving to people. The only thing it does that I can agree with is does mess the place up to an extent, and probable to a large extent, let me not be biased; but, I think about it, would you prefer to have it clean inside the office and a hundred of your members are out there and can't find something to eat for a week? Those are of the things I considered. I consider needs before prestige.”

I also asked what he thought about the idea that CDA should focus on advocating and let agencies with these resources do the job of distributing food.

“No they would not want to do that. No agency wants a large number of disabled persons coming into their business just to collect food supplies. They will not want to have their workers attending to them and neglecting their official duties. That is what they would say and we deal with them since we understand them.”

I also asked Lavern if she thought that participation in social welfare detracts the CDA from the missions of advocacy. She stated,

“The main role is advocacy, but because of the needs of our members we do have a social welfare part of it as well. Well I think we have maintained a fairly good balance in that ...we are constrained by the lack of resources. To really do welfare you have to have the things to give. And the only reason why we have been able to give is because we have that good link with Food for the Poor. Without Food for the Poor, we would not be providing food for people and things like that. If we had somebody who needed help with something and we would call on somebody out in the public to donate and contribute it. But, I think because we don’t have the resources to go into welfare but then again in terms of how we
manage the very limited resources that we have... like because our resources are so limited there so many other things that we could be doing in terms of advocacy, you know but because there is so much I would love to see in the organization. First of all, the building, well if we had more space we really could expand our services. We would need a storage facility because even now we have to be limiting the amount of things that we accept from Food for the Poor because it makes the office so untidy when you have to all of that stuff stored there.”

According to Lavern, to meet the social welfare needs of its constituents, the CDA always tried to balance it social welfare with advocacy. For example, she explained, “In the early days, when we were working on the national disability policy issue there were the things that they were interested in, [people would say] don’t tell me about [advocacy], I need a job. Now I think that we have moved somewhat beyond those days where people are now beginning to recognize it is a rights issue. So now, you find that more persons are interested in the development of the national disabilities act. So there is a change. There is a link between the two because if you see that those basic needs that they are rights, you know, the rights to housing, to everything and if we put the necessary policies in place, they will be addressed, where you will have access to more than what you have right now.”

Another issue that emerged is the belief that there are a greater number of persons from the lower social classes who are becoming disabled. So, I asked Lavern, if she noticed changes in this area. Her response was, “There is. Because now you find a lot of these violence people who are now becoming disabled so it’s a different thing. I could almost say that we need to
look at changing face of disability in Jamaica. I look and see a taxi going down the road and somewhere I see a wheelchair, you know stuck somewhere there peeping out. A little community and you see a wheelchair there.”

Evadney also talked about the differences in the SES of PWDs in the CDA.

“Today now, the people who are becoming disabled, disability it is a bread and butter issue. It is about what they can get because what the people who are now disabled are from ok to put it succinctly, disability and poverty go hand in hand. Alright so you are going to find well then that the people who are coming into the organization now definitely is about what they can get. If CDA is having a function or planning something we will have to ensure that there is sufficient food because once you say food is there everybody will come because there is not enough money, because of the poverty thing you can’t think about inviting them to a function and hoping that they will find their own transportation to come. Its going to be difficult they are going to need assistance. They need jobs, so for them it’s a bread and butter issue. It puts a lot a pressure on the organization and you really have to be committed to move this thing. To move this whole disability thing, you have to be committed. There are individuals who have genuine needs but the needs are basically bread and butter.”

The idea of focusing on advocacy without addressing social welfare may be ideal for disability rights organizations in the United States and other developed countries. However, in Jamaica and other developing countries where there is not a well established social welfare system, it is impossible to ignore the primary needs of a large number of
PWDs. While advocacy accomplishments are important, PWDs who are unemployed, for example, do not care that there is an income tax exemption or that there is five percent housing allocation because it is usually not beneficial to them.

Over the CDA’s 25-year history, it has used various strategies to mobilize PWDs. Programs such as the revolving loan scheme, and the women, men, and youth interest groups are mentioned by some members as something that they think that the CDA should restart.
Chapter Seven

Conclusions and Recommendations

This study is about disability rights advocacy in Jamaica. Using the CDA as an ethnographic case, it seeks to answer the following questions: (1) how is disability constructed within the context of Jamaican culture; (2) how does CDA members negotiate their initial involvement and level of participation; (3) what is the nature of the linkage between the CDA and Disabled People International; and 4) what strategies the CDA uses to mobilize PWDs for advocacy.

Conclusion on the Construction of Disability

The medical, charity, and social models combined with Creole cultural beliefs contribute to the construction of disability within the context of Jamaican society. Both the charity and medical models viewed the individual’s impairment as a hindrance to full integration into society. Adopted in rehabilitative settings, the medical model has influenced the approach to rehabilitation, resulting in the quest for cures and use of corrective procedures. The charity model, on the other hand, which perceived persons with impairments as needy, helpless and incapable of directing their own lives, has also influenced societal treatment of these individuals.

There is evidence of the belief that PWDs are abnormal and incapable of conducting normal activities or having normal desires such as playing sports, having a child, desiring to be attractive, or having sexual relations. Because these actions are not associated with PWDs, these persons are expected to be dependent and taken care of by the society. As a result, PWDs are finding that society underestimates their ability to
“manage,” and in so doing take away their independence. For example, able-bodied persons are usually ready to rush to the aid of disabled individuals, even at tasks that the disabled person can accomplish easily. This is also seen in the tendency of some to believe that blind persons should not be out in public without a guide.

Although more persistent in rural areas, the Creole belief that disability is the result of supernatural causes such as obeah (witchcraft), duppies (evil spirits), or retribution from God continue to be part of the Jamaican construction of disability. While it is uncertain the extent to which these beliefs are held, they are widely known. For example, in the Clarendon group that consisted mostly non-CDA members, participants with disabilities expressed the belief that disability was the result of chastisement by God. This belief was also held by some individuals in Portland which were mostly members of the Eastern Disabilities Association, an affiliate group of the CDA. In both groups, most people were aware of or had experiences with these beliefs, but few expressed agreement with them.

In Kingston, where two group interviews were conducted, beliefs of supernatural causes of disability were not held by participants. Nevertheless, individuals were aware also aware of their existence and some had personal experiences with them. However, they clearly expressed that these beliefs belonged to the “dark ages” or that it only existed among persons living in the rural areas. What this study is not able to measure is how many persons hold these beliefs but because of education and exposure have learned the politically correct way to talk about disability.

In both the Kingston and rural groups, persons were not concerned with the cause of disability; instead, they were concerned with equality and social acceptance. For
example, they were concerned that society considered PWDs as abnormal, underestimated them, and treated them differently from the rest of society.

The social model, which was intended to change the societal framework for the treatment of PWDs, has not replaced these earlier models. Instead, individuals negotiate between these models as they try to understand the phenomenon of disability. For example, people use Creole cultural beliefs to explain the causes of disability while seeking out medical cures. The CDA and the international disability movement promote the social model of disability which contradicts the earlier models as well as local beliefs about disability.

Conclusions on Initial Involvement and Level of Participation

The CDA’s members were asked about their initial involvement and their level of participation through an informational survey and semi-structured interviews. The results indicated that they learned about the organization in one of four ways: 1) through a friend or relative; 2) through the JCPD; 3) through their involvement with another disability organization; or 4) through direct recruitment by the CDA. A majority (32 persons) of survey participants were referred to the CDA through a friend or relative. This demonstrates the connection between members of the organization, which is not surprising, considering that the CDA was formed out of already existing groups where members had developed prior friendships.

Several persons have decided to join the organization after registering with the JCPD. This number is growing because the CDA is located on the same premises as the JCPD and PWDs are usually directed to the CDA by JCPD employees when they are going to register with that agency. While many of the persons who join CDA can hardly
afford the membership fee of JA$100, several are employed professionals and few are affluent. However, some members of the CDA believe that there are individuals from the upper classes with disabilities; but they do not need the CDA and when they do use the CDA, it is only to receive benefits, but once the benefit is received, they show no further interest in the organization.

There are varying levels of participation among survey participants. Participation is measured by attendance at the CDA events, serving on a committee, volunteering at the organization, or being a member of the board. Although board membership is not considered greater involvement, persons who volunteer to help the organization were viewed as more involved than persons who only attended social events. The CDA has many critics among its membership, however, the work of the organization is carried out by a limited number of persons usually, the same ones.

However, there are several limitations to involvement. Because the CDA is located in Kingston, most of the events take place in Kingston which makes it difficult for persons who live outside the corporate area to attend. Even within the Corporate Area, persons using wheelchairs have difficulty getting around because public transportation is not fully accessible for wheelchair users and often requires additional cost. As one board director explains, it is difficult to find persons who can come and volunteer without the organization having to provide them with bus fare or lunch money. One of the leaders in Portland also explains that she used to have high attendance at monthly meetings but she knew that the main reason why many people came was because she provided a hot meal at every meeting. As a result the leadership of affiliate groups express that the leadership is often a financial burden on the leaders.
Conclusions on the CDA’s International Linkage

The CDA is structurally linked to DPI by being part of the North American and Caribbean region. This connection started in 1981, when the CDA was one of forty national organizations who combined to form DPI. This meant that the association’s representatives participated in crafting the original DPI constitution. Jamaica’s role in the movement is influenced by its historical relationship with the United States and Canada as a developing country in the Caribbean.

During the early years of the CDA’s existence, the organization received considerable assistance in the form of training and development from DPI through the Canadian national organization. In addition, the CDA shares membership in the North America and Caribbean region, with the United States, Canada and 13 other Caribbean countries. Having two North American countries as part of the region created challenges for the CDA and other Caribbean organizations. Firstly, because efforts to acquire funding for the region have been hindered because of the connection with “two high powered” countries. However, the Caribbean countries were instrumental in forming an alternate regional organization, Disabled Peoples Organizations of the Caribbean (DPOC). This action had serious consequences for the region as DPI did not agree with the formation of DPOC and withheld funding from the region for an extended period.

Another challenge with this partnership was the tendency of Canada and the United States, who led most of the early regional activities, to dominate with no input from the Caribbean countries. Again, the CDA was instrumental in leading the other Caribbean countries to resist this dominance which in the long run resulted in better collaborations between the Caribbean countries and DPI.
Conclusions on CDA’s and Strategies

The CDA exists for the purpose of advocating on behalf of PWDs in Jamaica to ensure that they have equal access to the same opportunities that are available to the rest of society. Although the organization’s primary focus is advocacy, over the years, it has expanded its services to incorporate public education and social welfare programs. Currently, the CDA’s welfare program of the distribution of food supplies is believed to meet the needs of many PWDs. Some members believe that the CDA should focus solely on advocacy; and not become “mired in social welfare” because the CDA does not have the resources to participate in social welfare. Rather, this task should be left up to other agencies that are better equipped for that purpose.

With approximately 50 percent unemployment among its members, the CDA tries to assist with training and job placement. In addition to the limited number of jobs available, many the PWDs do not have the minimum qualifications to acquire these jobs. Through collaboration with HEART Trust and National Youth Service, the CDA has made efforts to offer vocational training on a small scale. Efforts to establish classes to help PWDs improve their education standing are hindered by the lack of funding. However, the CDA has plans to restart the DEEDs industries in the near future, a successful business enterprise once operated by the organization.

Limitations of Study

The two most prominent limitations to this study are time and financial constraints. Although I spent several months in Jamaica, and collected data in four parishes, I was still not able to visit all the affiliate groups. I was able to meet with the groups in Kingston and Portland. However, I was not able to meet with the Western
Disabilities Association located in the parish of St Ann. There are no data collected from these members. Although I scheduled a meeting in September it was cancelled.

The cost of research is a major determinant of what gets studied and are included. The lack of funding prevented me from including more deaf persons in the study. For example, the cost of sign language interpretation by a certified interpreter from the Jamaica Association for the Deaf (JAD) plus administrative cost and transportation for the interpreter was not affordable. The cost was escalated by the requirement of the JAD is if the interpreter is needed for thirty minutes or more then two interpreters must be used. Although there are other local interpreters at a lower rate, the quality of interpretation may be compromised.

**Recommendations for the Agency**

I believe that the findings of this research will be useful to the CDA and the JCPD. Since the focus of the study is on the CDA’s strategies, the organization awaits recommendations on how to be more effective in reaching the broader disabled population of Jamaica. As the implementing agency for the national policy for PWDs, the JCPD will need to collaborate with the CDA in order for some of these recommendations to be implemented. Some of these recommendations originated from suggestions that I received from PWDs during my experience in the field.

My first recommendation is for stronger collaboration between the CDA and the JCPD. This would involve requiring the JCPD to keep better records of the PWDs’ population of in Jamaica, which will help to facilitate outreach to rural clients. The establishment of a database of PWDs across the island is critical to assessing the needs of this population. It was surprising to me during my visit to the JCPD’s May Pen
office that there was a very limited record of the number of disabled persons in the parish of Clarendon. Furthermore, the field officer informed me and the CDA field officer that the list of PWDs was destroyed during Hurricane Ivan. However, two years is ample time to recreate the list or to start a new one. Although the field officers may not have access to computers at field locations, this information could be sent to the main office in Kingston where the data can stored as the agency is equipped with the computers and the latest software.

The CDA’s rural outreach could be enhanced by better collaboration with JCPD. Since the lack of funding prevents the CDA from having a full time field worker, the organization could display its brochures inside the office of the National Insurance Scheme and JCPD locations throughout the island. This would give rural residents the same options as residents that in Kingston have when they visit JCPD and NIS.

My second recommendation is that the CDA to establish a membership database with accurate records. From my observations and experiences with archival data, the CDA has written records of members and event participants. For example, every activity that the organization conducts, there is a sign-in sheet where participants give their names, type of disability and their contact information. This information could be centralized and continually updated.

**Recommendations for Anthropological Study**

Since this study only allowed for limited inclusion of deaf persons, I am recommending a future that would focus on the role of deaf persons in the CDA to understand how well their needs are met in the context of a cross-disability group. From talking with persons with other impairments, there is definitely a lack of understanding
about the deaf and their needs. In fact, this is the only group of PWDs that uses language that the other members do not understand, which makes it difficult for them to communicate with persons with other disabilities.

From my observations of the deaf at the CDA rap sessions, especially when a pertinent discussion is taking place, they are not fully included in the discussion. Although this is not intentional, communication barriers make it difficult for them to compete with persons who are speaking, as they usually dominate the conversation. For example, hearing persons tend to dominate conversation and talk out of turn while deaf persons have to wait until they are given permission to speak. However, this could be corrected, if the moderator is aware that deaf persons are not being given a fair chance of participating. It would also be interesting to discover from deaf persons their perceptions of the CDA, and to know if they experience a sense of belonging that some CDA members experience.

Since communicating with deaf persons presents challenges, for this research, it would be helpful to pursue electronic means of communications, such as a live chat room. This would allow the researcher to communicate with informants without an interpreter, which might reduce the cost while offering confidentiality.

Another group for a future study in Jamaica is persons who are mentally or cognitively impaired. This group was excluded from this study. Although this group is included in the organization’s membership, these persons do not represent themselves on the board. Instead, they are often represented by a parent or guardian. However, research indicates that these individuals can participate in research and that they have opinions on the issues that affect their lives (Angrosino 1992; 1998). It would be
interesting to obtain the perspectives of these persons about the social exclusion they experience and adding their stories to the body of literature on disability because their experiences are often excluded. I believe that the findings of these research projects could be beneficial to decision makers as they create policies, implement and fund programs and services for PWDs in Jamaica and other developing countries.

In conclusion, this study sheds light on the understanding of the various challenges the societies around the world encountered when developing countries adopt and attempts to implement disability legislations that originate from international bodies such as the UN. By focusing on the efforts of a disability rights organization and the experiences of its members, my research reveals the realities of the local environment within which, local authorities, disability rights organizations, and PWDs must function. As the findings of this research reveals that organizations often has to adjust their agendas to address their local realities.
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Appendices
Appendix 1

Informed Consent for Focus Group Participants

Social/Behavioral Sciences
University of South Florida

Information for People Who Take Part in Research Studies

The following information is being presented to help you decide whether you want to take part in a minimal risk research study. Please read carefully. If you do not understand anything, ask the Person in Charge of the Study.

Title of Study: A Study on Disability Rights Advocacy in Jamaica

Person in Charge of the Study: Joan Tucker, M.A.

Study Location(s): This study is based in Jamaica, West Indies.

General Information about the Research Study

The purpose of this research study is to learn about disability in Jamaica and the self-organization of persons with disabilities as they advocate for full inclusion. Once the study is completed, I will analyze the information, prepare a report, which will be made available to the Combined Disabilities Association and other organizations that represent persons with disabilities.

Plan of Study

As part of the study, we are asking that you agree to talk with us about your experiences as a person living with an impairment in Jamaica. If you choose to participate in the study, you will be asked to take part in a focus group that will last approximately sixty to ninety minutes. The focus group will be audio-taped.

Payment for Participation

You will not be paid for your participation in this study. However, you will receive a $20 phone card in appreciation for your time and effort, which will be given at the end of the focus group session.

Benefits of Being a Part of this Research Study

There are no direct benefits for participating in this study. However, your involvement will help us understand the experiences of persons with disabilities as they seek to be fully included in Jamaican society.

Risks of Being a Part of this Research Study

We do not anticipate any risks if you take part in this study.

Volunteering to Be Part of this Research Study

Your decision to participate in this research study is voluntary, and you are free to withdraw at any time. Your decision to participate or not to participate will in no way affect any services that you or your family receive from the Combined Disabilities Association now or in the future.

Confidentiality of Your Records

Your privacy and research records will be kept confidential to the extent of the law. Authorized research personnel, and the University of South Florida Institutional Review Board, its staff, other individuals acting on behalf of USF, may inspect the records from this research project. By law, anyone who looks at these records must keep them confidential. The results of this study may be published. However, the data obtained from you will be combined with those from others in the publication. The published results will not include your name or any other information that would personally identify you in any way.

Limits to confidentiality: You will be cautioned to keep the comments discussed in the focus group confidential. Please do not share your comments with others outside of the focus group sessions.

IRB Approval
FWA 00001669
IRB Number: 104235
From 3/19/2006
Questions and Contacts

- If you have any questions about this research study, you may contact Joan Tucker at (870) 876-8578 in Jamaica.
- If you have questions about your rights as a person who is taking part in a research study, you may contact the Division of Research Compliance of the University of South Florida at 1-813-974-5936 (United States).

Adult Consent

By signing this form, I agree that:

- I have fully read and had the information about the research project and the informed consent fully explained to me.
- I have had a chance to ask questions of the person in charge of the study and I am okay with the answers.
- I know that I am being asked to take part in research, I understand the risks and benefits, and I freely give consent to take part in this study as described on this form, under the conditions indicated in it.
- I have been given a signed copy of this informed consent form to keep.

__________________________  __________________________
Signature of Person Taking Part in the Study          Date

__________________________  __________________________
Printed Name of Person Taking Part in Study          Date

Statement of Person Obtaining Informed Consent:
I certify that I have carefully explained to the person taking part in the study what he or she can expect. To the best of my knowledge, the person who agrees to this interview can give written consent because he or she:

- Understands what the study is about
- Understands what needs to be done
- Understands what the potential benefits might be
- Is able to hear and understand when the form is being read to him or her
- Does not have any problems that could make it hard to understand what it means to take part in this study.
- Is not taking drugs that make it hard to understand what is being explained.

__________________________  __________________________
Signature of Person Obtaining Consent          Date

__________________________  __________________________
Printed Name of Person Obtaining Consent          Date

APPROVED

USF INSTITUTIONAL
REVIEW PROTOCOL (IRB)
Appendix 2

Informed Consent for Interviews

Informed Consent for Interview Participants
Social Behavior Sciences
University of South Florida

Information for People Who Take Part in Research Studies

The following information is being provided to help you decide whether you want to take part in a minimal risk research study. Please read carefully and if there is anything that you do not understand ask the person in charge of the study.

Title of Study: A Study on Disability Rights Advocacy in Jamaica
Person in Charge of the Study: Joan Tucker, M.A.
Study Location: This study is based in Jamaica, West Indies

General Information about the Research Study

Researchers at the University of South Florida are conducting a research study about disability rights advocacy in Jamaica. The purpose of this research study is to learn more about the self-organized advocacy of persons with disabilities in Jamaica as they advocate for human rights in Jamaican society. To do this, we need the help of people who agree to take part in a research study.

Plan of Study

As part of the study, you are being asked to agree to take part in a study about your experiences as a person living with an impairment in Jamaica as well as your involvement with the Combined Disabilities Association. If you choose to participate in the study, you will be asked to take part in an interview that will last approximately one hour by telephone. If you agree, the interview will be audio-taped.

Payment for Participation

You will not be paid for your participation in this study. However, all the time and effort you spend will be appreciated for your time and effort.

Benefits of Being a Part of this Research Study

There are no direct benefits for participating in this study. However, your involvement will improve the understanding of the experiences of persons with disabilities as they advocate for human rights in Jamaican society.

Risks of Being a Part of this Research Study

There are no known risks to anyone who takes part in this study. However, if you have difficulty with a question, you may skip it and come back to it later. If necessary, you may choose to stop the interview and continue at a later time.

Volunteering to Be a Part of this Research Study

Your decision to participate in this research study is voluntary and you are free to withdraw at any time. Your decision to participate or not to participate will in no way affect any services that you or your family receives from the Combined Disabilities Association now or in the future.

Confidentiality of Your Records

Your privacy and research records will be kept confidential. Authorized research personnel and the University of South Florida Institutional Review Board, its staff, and other individuals acting on behalf of USF may inspect the records from this research project. By law, anyone who looks at these records must keep
Appendix 2 Continued

Informed Consent for Interview Participants
Social/Behavioral Sciences
University of South Florida

Information for People Who Take Part in Research Studies

The following information is being presented to help you decide whether you want to take part in a minimal risk research study. Please read carefully and if there is something that you do not understand, ask the person in charge of the study.

Title of Study: A Study on Disability Rights Advocacy in Jamaica
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Researchers at the University of South Florida are conducting a research study about disability rights advocacy in Jamaica. The purpose of this research study is to learn more about the self-organization of persons with disabilities in Jamaica as they advocate for full inclusion in Jamaican society. To do this we need the help of people who agree to take part in a research study.

Plan of Study
As part of the study, you are being asked to agree to talk with us about your experiences as a person living with an impairment in Jamaica as well as your involvement with the Combined Disabilities Association. If you choose to participate in the study, you will be asked to take part in an interview that will last approximately sixty to ninety minutes. If you agree, the interview will be audiotaped.

Payment for Participation
You will not be paid for your participation in this study. However, at the end of your involvement you will receive a $50 phone card in appreciation for your time and effort.

Benefits of Being a Part of this Research Study
There are no direct benefits for participating in this study. However, your involvement will increase the understanding of the experiences of persons with disabilities as they advocate for full participation in Jamaican society.

Risks of Being a Part of this Research Study
There are no known risks to anyone who takes part in this study. However, if you have difficulty with a question, you may skip it and/or come back to it later. If necessary, you may choose to stop the interview and/or conduct it at another time.

Volunteering to Be Part of this Research Study
Your decision to participate in this research study is voluntary and you are free to withdraw at any time. Your decision to participate or not to participate will in no way affect any services that you or your family receives from the Combined Disabilities Association now or in the future.

Confidentiality of Your Records
Your privacy and research records will be kept confidential. Authorized research personnel, and the University of South Florida Institutional Review Board, its staff, and other individuals acting on behalf of USF, may inspect the records from this research project. By law, anyone who looks at those records must keep
Appendix 2 Continued

Consent for Audio-taping

I, __________________________, agree to be audio taped as part of the research study entitled *A Study on Disability Rights Advocacy*. I understand that the researcher(s) in this study will audiotape me in order to make sure that the transcription is accurate. I have been informed that the transcription of the audiotape will not be seen by anyone other than the study staff. I also understand that choose not to be audiotaped, I can still take part in the study.

_____________________________                      ______________
Signature of Participant                  Date

_____________________________                      ______________
Signature of Investigator                 Date

I do not give my consent to be audiotaped.

_____________________________                      ______________
Signature of Participant                  Date

_____________________________                      ______________
Signature of Investigator                 Date

APPROVED

USF INSTITUTIONAL REVIEW BOARD

Page 3 of 3
Appendix 3

Support Letter from CDA

COMBINED DISABILITIES ASSOCIATION LTD
(A NON-PROFIT GROUP OF DISABLED PERSONS)
18 NAPON ROAD, KINGSTON 5, JAMAICA
Telephone: (0876) 923-1300
Email: info@jamaica-cda.com

December 15, 2006

Division of Research Compliance
University of South Florida
University Professional Center
3503 East Fletcher Avenue
Suite 511
Tampa, Florida 33612
U.S.A.

Dear Sirs:

Re: Organisational Strategies and International Networks: Disability Rights Advocacy in Jamaica

This is to confirm that the Combined Disabilities Association has agreed to allow Mrs. Jean Tucker to undertake the above research among members of our Association. She will be accommodated at our office at the above address and given the necessary tools and information for the successful completion of this research project.

Mrs. Tucker will also be facilitated in contacting and gathering information from other agencies with whom we network.

We welcome Mrs. Tucker’s research on disability, as studies in this area are sadly lacking in Jamaica. For this reason, we have been encouraging more students in our own country to undertake this type of study.

Yours truly,

[Signature]
Gloria Coffie
Co-ordinator
Appendix 4

Interview Guide for CDA Board Members


Personal Information

1. Tell me about how you acquired your disability
2. Tell me about your initial involvement with the Combined Disabilities Association
3. What is your role within the organization?

The Disability Rights Movement

4. Give me an idea of what it was like when PWDs started organizing in Jamaica
5. Tell me about any resistance received from existing local disability organization.
6. Which local organizations supported the local disability rights movement during the early years?
7. What role did PWDs in Jamaica play in the formation of the international disability movement?
8. Did the Jamaica movement receive support from the US disability rights movement?

Local Attitude toward Disability

9. What has been your experience with local beliefs about disability such as:
   a. It is sent from God as punishment
   b. It is sent from God as a gift
   c. Caused by evil spirits
   d. What other beliefs have heard about
10. How do these beliefs influence CDA’s plans and strategies?
11. Does the CDA have plans to influence current beliefs and attitudes about disability?
Appendix 4 Continued

**The Organization**

12. What is the primary need of persons with disabilities Jamaica?
13. How does the CDA propose to reach the general population of PWDs?
14. What efforts has the CDA made to reach PWDs in rural areas?
15. How successful are these efforts?
16. What efforts has the CDA made to collaborate with other disability groups in Jamaica?
17. What plans does CDA have to increase the organization’s membership?
18. What are the efforts or plans, the CDA has to involve non-disabled persons involved with the organization?

**Funding**

19. How is the organization funded?
20. Does the CDA receive any funding from international sources?
21. What plans does the CDA have to increase funding?
Appendix 5

Guide for CDA General Members

Person experience with Disability

1. Tell me about how you acquired your disability

2. What is it like living with your disability in Jamaica?
   a. Treatment by the general public
   b. Treatment by institutions (school, employment, church, medical facilities, etc).
   c. Relationships/friendships

Initial involvement and level of participation

3. How did you become involved with the Combined Disabilities Association?

4. Why did you choose to become a part of this organization (CDA)?

5. How well do you know the other members of the organization?

6. What is your role within the organization?
   a. What positions have you held?
   b. Do you volunteer to help with events
   c. Do you encourage other disabled people to join the organization?

7. Do you believe that you have been given enough opportunity to participate in the leadership of the organization?

8. How are regular members encouraged to become involved in the leadership of the organization?
Appendix 6

Focus Groups Questions

I started out by sharing an incident that I observed on the bus because I thought that it depicted local attitudes toward persons with disabilities. This was used as a springboard for the discussion.

1) Based on your experiences/observations what are some of the things that Jamaicans say/think about disability?
   Probe: How do people explain disability i.e. causes?

2) What do you think about these ideas and opinions?
   a. Probe: Are they negative/positive?

3) Where do think that these ideas originate?
   Probe: What is influencing these ideas?

4) What are your ideas about disability?
   a. Probe: If different from the general opinion, why do they share this view?

5) How do the various opinions about disability affect the way that people with disabilities are treated in Jamaica?

6) What should be done, if anything, about these ideas and beliefs?
   Probe: Should these ideas be changed or allowed to continue?
   Probe: How could we accomplish this?

7) What have you done to influence the way people think about persons with disabilities?
About the Author

Joan Tucker is originally from Kingston, Jamaica and migrated to United States in 1984. She holds a Bachelor’s and Master of Arts degrees in sociology from the University of South Florida. Joan is interested in advocating for the rights of persons with disabilities, specifically among minority populations. She has been an active member and current chair of the Hillsborough County Chapter of the Federation of Families for Children’s Mental Health and has participated in advocating for and supporting families of children with serious emotional disturbances.

During her enrollment in the Ph.D. program in Applied Anthropology at the University of South Florida, Joan did her internship with the Combined Disabilities Association in Kingston, Jamaica.