1-1-2009

The responses of Bamenda disability organizations to HIV and AIDS: A multiple case study

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ABSTRACT

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by

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MSPH, Walden University, 2007
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B.Sc., University of Toronto, 1986
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Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
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ABSTRACT

In Cameroon, many disabled people (an estimated 10-20% of the population) have inadequate access to education and health care, and disabled people's organizations (DPOs) are advocating for social change. Yet, there is a scarcity of information regarding how African DPOs address HIV and AIDS. The purpose of this study was to assess how DPOs in Cameroon have responded to AIDS in the disabled population and to identify strategies to enable DPOs to manage AIDS issues. This study was guided by the complex adaptive systems theory as the theoretical framework. The research questions focused on what DPOs have done to develop their organizational capacities to address AIDS issues, and on the contextual factors that influence these organizational capacities. To answer the research questions, a qualitative, multiple case study was conducted. A purposeful sample of 25 people, primarily executive members of four community-based nongovernmental DPOs and key informants with experience in this field, participated in interviews and focus groups. Information was gathered from documents and participant observation. Data were coded using *a priori* and emergent codes and iteratively analyzed into themes. Evident themes were that capacities in these groups were limited by marginalization and poverty, a lack of connection between DPOs and the AIDS community, limited health education, and inadequate understandings of the complexity of AIDS. DPOs desired participation in AIDS-related efforts and continued to explore potential opportunities. These results could be used to enhance social change by improving AIDS practices and research programs, increasing organizational capacity and social inclusion of DPOs, and the development of policy at organizational and governmental levels.

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ACKNOWLEDGMENTS

First, I thank Dr. Jeanne Connors for her assistance and encouragement throughout this dissertation process. Dr. Connors encouraged me to carry out a study that I was passionate about, and she remained supportive through the various challenges of completing the dissertation. I would also like to express my gratitude to my dissertation committee: Dr. Hadi Danawi, who has shown interest in my work since we first met several years ago, and Dr. Chester Jones, who provided encouragement at many stages of the journey.

Ngang Emmanuel agreed to be my research assistant when I realized that the study would be much better if I had the right kind of help. Emmanuel, without your astute and careful assistance, the study would have taken me much longer to complete. We learned a lot from each other. Thank you for stepping in at the right time. It was thanks to Dr. Jude Fokwang that I met Ngang Emmanuel; this introduction was just one of Jude's contributions to this study.

I was away from Cameroon for many years. During that time, my mother, Dr. Elizabeth Cockburn, kept me in touch with my second home and up to date with Cameroonian friends, issues and developments. She inspired me not to let go of my dream to some day return and be a part of the community that she, too, loves so much. It was an honor and a pleasure to be able to work on this study with her encouragement and love.

In Cameroon, there are so many colleagues and friends who have gone out of their way to make this study possible and I can only name a few. From our first meeting, Mr. Peter Mue has shared my excitement for disability and rehabilitation work that many others find mundane. Peter encouraged and helped me to complete this study. Dr. Pius Tih, Mr. Ezekiel Benuh, and many others at the Cameroon Baptist Convention Health Board provided ongoing information, support and assistance. Thank you.

I am extremely grateful for the steadfast friendship of Takusi Daniel Watcha, and his willingness to share his unique insights into issues that are difficult for me to grasp.

To Andrea and Gavin – thanks for being with me on this journey, for showing me the work that still needs to be done. You inspire and encourage me. Much of this work is in your honor, and stems from the love that you share with me. I am a very fortunate mother indeed.

And my husband, Keith: You had patience beyond belief, understanding even when you did not agree, and provided unshakable stability. Your love and humor were always ready, and you supported me through all the hours and days and months it took to complete this program of study. I am forever in your debt.

In spite of the many challenges that arose from the commitment to carry out this study, it has been a tremendous pleasure to have this opportunity to work with and learn from all of you.

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CHAPTER 1: INTRODUCTION TO THE STUDY

Introduction

As the Secretariat of the African Decade (2006) has reported, conceptual and practical connections among disability, rehabilitation, the human immunodeficiency virus (HIV), and acquired immunodeficiency syndrome (AIDS) are gradually being made in Africa. However, very little research has been conducted about the impact of HIV and AIDS on people with disabilities or with regard to African disability groups (Albert, Dube, Hossain, & Hurst, 2005; Groce, Trasi, & Yousafzai, 2006). Current estimates are that at least 10% of the global population is living with some form of disability (United Nations, 2006). Additional details will be discussed in the literature review in Chapter 2. Disability groups and disabled people's organizations (DPOs) have formed over the past several decades in many parts of the world to offer support to members with disabilities and to combat the stigma, social discrimination, and exclusion that people with disabilities experience (Enns, n.d.). Collaboration between DPOs and other groups could prove successful in improving the inclusion of disability in AIDS efforts.

Nature of the Study

The study took place in the North West Province (NWP) of Cameroon. This location was chosen because of the need in the area. It is the province with the highest HIV prevalence in the country, has a large number of people with disabilities, and two of the leading rehabilitation centers in the country. In addition, I have an ongoing and committed working relationship with a number of individual and organizational stakeholders in the area. These organizations expressed interest in collaborative research and identified this topic as a pressing need. Further details of the health and social systems of the province are in the literature review in Chapter 2, and implications of this context on the study are in Chapter 3.

The Republic of Cameroon is a country located on the African continent and is relatively stable politically. On November 12, 2008, President Paul Biya declared that the country's provinces would immediately become known as regions. This study was conducted before the decree was enacted; therefore, the terms *province* and *NWP*, rather than *region* and *NWR*, are used.

The NWP is a picturesque hilly area also known as the Grassfields because of the vegetation. There are a number of forested areas. The NWP has a mix of urban and rural areas, little industrial activity, and relatively few tourists. The capital city of the province, Bamenda, is a busy commercial centre with a population of around 315,000 people in 2001 (L'Institut National de la Statistique du Cameroun, 2006). An abundance of crops grows throughout the province, and many families rely on farming to survive. Health and social services are provided by a combination of public, private, and faith-based organizations; overall, there are inadequate services for people with disabilities offered through these systems (Fongwa, 2002; Hashemi, 2006). Some details are in the following sections, and a more detailed picture of the context is provided in Chapter 2, the review of the literature.

Problem Statement

This section provides background information to suggest why Cameroonian DPOs have limited capacity to deal with HIV and AIDS issues. It provides a brief review of the literature in the areas of disability and rehabilitation, the formation of disability groups as a response to social stigma and exclusion, and an overview of the HIV and AIDS situation in the province. (The terms *HIV* and *AIDS* are now being used separately to show the distinction between the virus and AIDS, therefore that convention is used in this study.) What emerges is a picture of how several factors combine to create an extremely difficult situation: Disability groups face barriers such as stigma, significant poverty, and lack of leadership education, which affect their organizational capacities.

Disability

In the African context, decreased health outcomes and the sequelae of infectious illnesses often result in impairment and long-term disability. It is estimated that between 10 to 20% of the populations of low-income countries, including those in Africa, live with at least one impairment or disability, and that rates are higher amongst groups with low education (UN, 2006). Although accurate estimates can be difficult to obtain, UNESCO suggests that over 90% of disabled children do not attend school in poor countries such as Cameroon (UNESCO, n.d.), further increasing the risk for negative health outcomes as improved education has been linked with positive health outcomes (Woolf, Johnson, Phillips, & Philipsen, 2007). In addition, “about 75% - 80% of disabled people in the African Region are in rural areas, where services for prevention and rehabilitation are either limited or unavailable” (WHO/AFRO, n.d., p. 2). People with disabilities are considered to be the “poorest of the poor” often relying on the generosity of others as they are excluded from employment (Bonnell, 2004).

No broad epidemiological studies on aspects of disability appear to have been conducted in the NWP of Cameroon (Mue, 2006). Mue, with several years of experience in the field, suggested that the global estimates of disability are reflected in this area: The population of the province is approximately 2 million (PTG North West, 2006), placing the probable number of people with disabilities at 200,000 to 400,000 (10 to 20% of the population), most are very poor. The full number of disability groups and DPOs is not known, as there has not been an effective coordinating body or public record of these types of groups.

Although there are laws that provide some rights to persons with disabilities, including access to public institutions, medical treatment, and education, these are not enforced (Hashemi, 2006; U.S. Bureau of Democracy, Human Rights, and Labor, 2006, 2007). According to the laws, the government is obliged to bear part of the educational expense of persons with disabilities, to employ them where possible, and to provide them with public assistance when necessary; however, these obligations are often not known by government representatives and are not followed (Hashemi, 2006; US Bureau of Democracy, 2006, 2007). The U.S. Bureau of Democracy, Human Rights, and Labor (2007) stated:

> There were few facilities for persons with disabilities and little public assistance; lack of facilities and care for persons with mental disabilities particularly was acute. Society largely tended to treat those with disabilities as outcasts, and many felt that providing assistance was the responsibility of churches or foreign NGOs. The law does not mandate special access provisions to private buildings and facilities for persons with disabilities. (Section on Persons with Disabilities)

Rehabilitation

Despite the large population of people with disabilities, the health system in the North West Province has several weaknesses, and generally provides few rehabilitation services (Fongwa, 2002; Hashemi, 2006). There are few published reports of rehabilitation initiatives in the NWP. However, from visits and discussions in the area, I am aware that there are several established disability groups and a few rehabilitation programs that are actively involved in trying to ameliorate the impacts of disability. Rehabilitation programs run by the Cameroon Baptist Convention Health Board include a community-based rehabilitation program and physiotherapy departments at the Mbingo and Banso Baptist Hospitals. Rehabilitation programs are offered at the Catholic Njinikom Hospital, operated by the Tertiary Sisters of St. Francis, and at St. Joseph's Children and Adults Home (commonly known as SAJOCAH), a rehabilitation centre run by the Sisters of St. Joseph in Bafut. One orthopedic surgeon works at the Mbingo Baptist Hospital, and the Njinikom Hospital regularly has teams of orthopedic surgeons visit from Europe. Currently one physiotherapist works at the Bamenda Provincial Hospital, none at other publicly funded hospitals in the province. Fewer than five physiotherapists are working in private practices. There are no resident occupational therapists, speech language therapists, or audiologists in the province. Occasionally there are visiting therapists and other rehabilitation specialists from Europe, North America or other parts of Africa. At least one local private school has a small, non-accredited physiotherapy training program.

Social Exclusion

Stigma, discrimination, and social exclusion take many forms and continue to face people with disabilities, including people living with HIV and AIDS, in African societies (Limen, 2006; Somma & Bond, 2006). Social exclusion includes being prevented from joining in community activities; not being included in social conversations; and not being allowed to participate in education, faith, or work activities. Stigma and discrimination are important for public health workers to consider, because they are social processes that perpetuate inequities and oppression. Because of the difficulties in conceptualizing and measuring stigma and discrimination, interventions and change efforts can be difficult to evaluate (Somma & Bond, 2006; Van Brakel, 2006).

Life in the NWP is challenging for all of its residents because of the social, geographic, economic and political environments (Central Intelligence Agency, 2006). In this context, women and men living with disabilities experience added social exclusion, which magnifies the barriers they face (Hashemi, 2006; Limen, 2006; Mue, 2006). Many people with disabilities have difficulty maintaining active and satisfying engagement in daily community activities. Barriers include poor roads, inaccessible buildings, traditional beliefs about causes of disability (e.g., impairments may be attributed to unhappy ancestors or to “witchcraft”), lack of health and rehabilitation services, lack of income supports, political corruption requiring additional fees to carry out business, disregard of disability policies, and exclusion from workplaces (CIA; Hashemi; Limen; Mue). These challenges make organizing disability groups even more difficult than the already difficult endeavor of community organizing for those in the general population. Nevertheless, a few groups of people with disabilities are forming and developing in the area (personal communication, S. Nyincho, July 25, 2006).

Disability Groups

DPOs and other disability groups have emerged in many parts of the world in response to the stigma, social discrimination, and exclusion that people with disabilities experience (Enns, n.d.). Community-based disability groups require nurturance and leadership to grow and to develop adequate capacity to carry out their mandates (Postma, 1998). In a low-income area such as Bamenda, groups appear to face many difficulties.

One of the first forms of a group or association for people with disabilities probably emerged in the province with the introduction of a centre for the treatment of people with leprosy almost 60 years ago at Mbingo (Maynard, 2004). However, the most significant increase in the DPOs and support groups has occurred since national policies and laws were changed in the late 1980s and 1990s. These changes responded to structural adjustment programs allowing citizens to freely associate and to form nongovernmental organizations (NGOs) and common interest groups (CIGs) (Sauerborn, Bodart & Essomba, 1995; Essomba, Bryant & Bodart, 1993). In the NWP there are now several groups addressing disability issues in some way. The history of how these organizations have developed, the number and types of groups that are actually in existence, and their mandates has not been documented. The Coordinating Unit for Associations of Persons with Disabilities is a fledging umbrella group that is receiving little community support and is selective in its membership (personal communication, Samuel Nyincho, July 25, 2006; personal communication, Shirin Kiani, June 19, 2007). As it develops, more of information may become available.

DPOs receive minimal governmental support, with most of them obtaining resources for running their operations from members and from donations from community members and external international nongovernmental organizations (INGOs). Some individual groups and the Coordinating Unit have made limited efforts to address HIV, but community members are not aware of these activities nor was there a documented record (personal communication, S. Nyincho, August 10, 2007).

DPOs deal with issues of marginalization and powerlessness. Organizations dealing with disability issues have to decide whether their efforts should be in bringing their concerns to mainstream organizations with the goal of integration, or in the development of parallel organizations focusing on specific disabilities. Disability specific activities can increase awareness and support but are outside of mainstream activity. Ideally, both efforts would be possible: disability issues would become part of all social and development organizations, and disability organizations would also have resources to focus on concerns specific to the needs of their members. However, especially in contexts with very limited resources, this parallel development is often not possible. Women with disabilities have an additional decision – whether their efforts and very limited time and resources should be focused on creating disabled women's organizations to create a positive and supportive space that may not be found in disability groups led by men, or to join in broader groups where they may have to constantly fight for recognition and risk continued marginalization.

HIV and AIDS

HIV and AIDS rates continue to rise in Cameroon, and in the NWP specifically. Of the 10 provinces in Cameroon, the prevalence of HIV and AIDS is the highest in the NWP. It is officially estimated to be about 9% overall and is significantly higher in women, at 12%, and is over 25% for female sex workers (Measure DHS, 2004; PTG North West, 2006). The Provincial Technical Group (PTG) of the Ministry of Public Health and private health groups are actively engaged in several strategies to stem this growing epidemic (PTG North West, 2006). The PTG (2006) estimated that at the end of 2006 there were almost 89,000 persons living with HIV in the province, and about 50,000 orphans, many of whom have lost both of their parents to AIDS.

A significant body of literature has developed addressing the importance and mechanisms of community empowerment initiatives in response to the AIDS epidemic. For example, some evidence indicates that participation in community groups can contribute to improved HIV and AIDS outcomes (Gregson, Terceira, Mushati, Nyamukapa, & Campbell, 2004; Latkin and Knowlton, 2005). However, people with disabilities are often not included in AIDS initiatives or groups. Therefore, AIDS educators and service providers have been encouraged to include DPOs as valued members of the team from the beginning of the planning process (Groce et al., 2006). Based on the World Bank study (Groce, 2004), and other studies, Groce et al. (2006) have identified the pressing need for research exploring the leadership roles that disability advocacy organizations could play around HIV and AIDS issues, as well as health related matters more generally.

The information in the following paragraph is based on information gained from several conversations and general work in the area over the past few years, but has not been well documented in academic, governmental, or nongovernmental reports. Despite the growing problem of HIV and AIDS in the NWP (Measure DHS, 2004), and the apparently large number of people with disabilities, program development and research which links the two issues have been slow to appear. This situation appears to be gradually changing. Connections and programs are emerging, and are occasionally supported through governmental programs or through international development initiatives as health care and social service providers recognize the need to address the wide range of situations that are developing. Disability support groups, as well as AIDS support groups are forming and growing, and it would be beneficial for social change and sustainability efforts to recognize the positive actions that are underway so that these can be strengthened. The links between DPOs and AIDS groups that are beginning to emerge could be documented and analyzed so that the community and decision makers could learn from successes. Groce and colleagues note the need for resources for these groups, which are often run with very little funding, and make the case that if these kinds of organizations are asked to participate in AIDS efforts, funding to help support their contributions of time and energy should be seriously considered (Groce et al., 2006). Although there do not appear to be any studies documenting activities or resources used by disability groups in this area, the funding that disability groups in the NWP are receiving for their contributions to HIV and AIDS outreach, education, and support efforts was estimated to be inadequate.

Purpose of the Study

The capacity of disability groups in Africa to address HIV and AIDS issues is neither well resourced nor understood. This brief description of the background, and overview of the literature, indicates that this is true for Africa generally, and the NWP specifically. Disability groups appear to be struggling to organize themselves to respond to the AIDS epidemic with limited funding, little education or mentoring about organizational development and leadership, and few resources that are specific to the issues with which they are dealing. However, as community leaders and organizers, these groups need to be contributors to efforts to stem and deal with the AIDS epidemic. Therefore, there is a need for research into the current capacities of disability groups to address HIV- and AIDS-related issues, as well as to identify what can be done, particularly from a public health perspective, to build their capacity to deal with this growing issue.

The purpose of the study was to assess the organizational capacity of community-based disability groups in sub-Saharan Africa (SSA) to deal with the AIDS epidemic. This was done by constructing a multiple case study that explored, conceptually and practically, how community-based DPOs in Cameroon have responded to AIDS issues in the past, what has been effective and less successful in these responses, and identifying outstanding needs and recommendations for further development. The study took place in the city of Bamenda, the capital of the NWP of Cameroon. In recognition that men’s and women’s experiences and needs can be diverse, and that women are often marginalized in community groups, the study also analyzed the situation from the perspective of gender as part of the data analysis.

Specific Research Questions

The study addressed the following research questions:

1. What have disability groups in NWP done (and by extension, what has been missing or prevented) to develop their organizational capacities to address HIV and AIDS issues? What contextual factors have influenced organizational capacity?
2. What could disability groups in NWP do to develop their organizational capacities to address HIV and AIDS issues?
3. From the perspective of DPOs, what could AIDS service organizations do to support the development of capacity within disability organizations to address HIV and AIDS issues?

Theoretical Framework: Complex Adaptive Systems

This study used the case study method to allow for the development of a detailed description of organizational capacity applicable to this context. Complexity theory, specifically the complex adaptive systems (CAS) theoretical perspective (Begun, Zimmerman, & Dooley, 2003; Brown, 2006; Holden, 2005; Kernick, 2005; Olney, 2005; Rowe & Hogarth, 2005; Stackman, Henderson, & Bloch, 2006; Trochim et al., 2006) was employed to assess, explore, and explain how the capacities of disability groups have been influenced by the emergence of HIV and AIDS in their communities and to explore the links between these influences and organizational actions and outcomes.

Understandings of the relationships between individual factors, organizational factors, and social factors became evident through the study. The study developed recommendations for disability groups and other stakeholders.

Key features of the complex adaptive systems approach, which is also known as complexity science, are (a) connectivity and relationships, (b) feedback and communication, (c) diversity and self-ordering within organizational systems, and (d) a recognition that although history is relevant, it cannot actually lead to prediction regarding organizational outcomes. This study used this theory in several ways. The focus of the study was on the system of disability organizations in the city of Bamenda in the NWP. The study intention was to examine a minimum of three established disability organizations within this system to allow for diversity of perspective as well as to identify similarities. Further details about sample selection are in Chapter 3. Each group could be considered a complex system in its own right, but the focus of this multiple case study included attention to the broader situation in the Bamenda area, as one loosely conceptualized system.

In keeping with complex adaptive systems theory, relationships were a key focus of the study. Relationships are seen as forming an entangled web involving many agents and forces, both internal and external to the system under study (Olney, 2005). The concept of an entangled web of relationships corresponds well to what was already known about the complexity of communities and disability groups in the NWP. The investigation of disability groups focused on the organizational relationships within each group, between the groups, and between the systems outside of them.

Complex adaptive systems theory recognizes that there is constant change, adaptation, and evolution of the system in an unpredictable, nonlinear manner. The shifting relationships between the parts of the system may lead to unusual reactions throughout the system. Large and seemingly well-planned initiatives may yield little impact, while small events are sometimes seen to create big impacts (Olney, 2005, p. S59). Attention was paid to a range of types of elements, including events which might have been seen initially to be of lesser impact, but which, over time, became more significant. Participants were asked to reflect on how the group had changed and adapted over time, particularly as HIV and AIDS become more prominent in the community.

This study intended to explore and document emerging patterns and ways in which the grassroots community-based disability groups organized to respond to HIV and AIDS issues. The theoretical perspective of complex adaptive systems was well suited to this goal, as it recognized that complex systems display patterns of behavior that reflect the ability of the system to organize itself using “self-ordering rules” (Kernick, 2005) through a bottom-up process. These rules are not always well planned or predetermined. The theory posits that the rules guiding the changes in systems “emerge through a complicated system of relationships, influences, and feedback loops inside and outside the system” (Olney, 2005, p.S59).

Feedback loops are crucial for complex adaptive systems. Olney (2005) stated that feedback loops “carry information, material, and energy among agents in the system. If feedback loops are well designed, they facilitate change and adaptation of the system” (p. S59). The study looked for instances of how information and energy was shared within each disability group and within the system as a whole, and how these loops supported or inhibited adaptation of the organizations.

The outcomes of a complex adaptive system cannot be predicted, because new patterns emerge from the complex activities of the system. Therefore, timelines for organizational activities must be flexible; a range of unexpected developments can influence plans negatively or positively. In research on systems, therefore, it is appropriate to ask participants to reflect on previous and current goals and timelines in their organization, and specifically to identify how expected and unexpected events have influenced the group.

According to complex adaptive systems theory, it is important to explore the boundaries of the system, because that is where significant communication and adjustment takes place. Boundaries are seen as permeable and are key parts of the system, deserving of attention in a study of the evolving system. Therefore, attention was given to how each group delineated itself, how it communicated with other groups and with the broader community, and how it saw itself in the social context. In addition, this perspective assumes that patterns of behaviors in the complex system can be observed and named. Attention was paid in the study to identifying and making visible *attractors* and patterns of behavior that impact on responses to HIV and AIDS issues. Olney (2005) stated:

> A paradox of complex adaptive systems is that, while they can be dynamic and changeable, they also can demonstrate systemwide patterns of behavior, generated by variables known as attractors, which will be repeated at many levels of the system and can be difficult to alter. Attractors may be written organizational priorities, seasonal events like

> year-end fiscal budgets, or more erratic variables like the day-to-day needs of the clients served by a CBO [community based organization]. (p. S59)

Finally, although in research on a complex adapting system the focus must be on one system (such as an individual, a community-based organization, or a country), this theoretical perspective recognizes that patterns of behavior may repeat themselves at different levels of a system and across systems. Olney stated:

> In a complex adaptive system, different attractors stimulate similar responses and those responses will be observed at different levels and parts of the system. These patterns are known as *fractals* [Jackson, 2003]. While behavior is never exactly the same, similarities will occur across parts of the system, across systems, and across time. (Olney, 2005, p. S59)

Attention to different disability groups as part of a broader system reflected this concept of fractals and informed the analysis.

Definitions of Terms

Several interwoven concepts link disability issues and the experience of living with HIV and AIDS. The first set of linked concepts centres on changing notions of *disability*. Views of what constitutes a disability are changing; disability is now seen to be the result of social constructions such as attitudes and discriminatory behavior, in addition to the biomedical understanding of disability as being located within the individual and caused solely by impairments to the body. To discuss issues of impairment, disability, activity, and social participation, this study used the World Health Organization (WHO) International Classification of Functioning, Disability and Health (ICF) (2002a) for definitions of terms related to impairment and disability:

Body functions are physiological functions of body systems (including psychological functions).

Body structures are anatomical parts of the body such as organs, limbs and their components.

Impairments are problems in body function or structure such as a significant deviation or loss.

Activity is the execution of a task or action by an individual.

Participation is involvement in a life situation.

Activity limitations are difficulties an individual may have in executing activities.

Participation restrictions are problems an individual may experience in involvement in life situations.

Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives. (WHO, 2002b)

What is notable in this set of definitions is that disability is not included as a defined concept. The ICF presents an understanding that disability can be created through body impairments as well as through activity limitations and participation restrictions at the social level.

Using the WHO framework (WHO, 2002b), HIV and AIDS can be considered a disability; therefore models, responses, interventions, and evaluations familiar to the disability and rehabilitation fields may make useful contributions to HIV and AIDS work (Bell, 2005; Butler, 1994; Hwang & Nochajski, 2003; Neuve, 1995; Worthington et al., 2005). Applications of the ICF framework to HIV and AIDS may assist with improved understandings of the experiences of living with AIDS.

Disability groups and organizations for and of people with disabilities

Disability groups are organizations and associations of people who share an interest in disability issues. What constitutes a disability group, and the roles of those without disabilities in these groups, has been the focus of much discussion in disability communities around the world. These groups may include people with disabilities, service providers, family members, and others who are supportive of the collective goals (McColl & Boyce, 2003). Disabled people's organizations, commonly referred to as DPOs, are controlled by a majority (51%) of people with disabilities at the board and membership levels, and usually have a strong social justice perspective (Enns, n.d.). For example, Disabled Peoples' International, commonly known as DPI, defines an "organization of disabled persons" as a group in which a majority of the members and the members of the governing body are persons with disabilities (DPI, 1993).

Organizational Capacity

Organizational capacity is a focused term that refers to the ability of local community organizations, groups, and associations to take action and to create appropriate solutions to the issues and problems arising in their communities, including the support of those who are disadvantaged or marginalized (Ncube, 2005; Postma, 1998). It incorporates quantity, quality, and efficiency dimensions as well as "value-based, life-centric dimensions" (Postma, 1998, p. 58). The complexity of organization capacity was reflected in a report done by Ncube (2005) with a group of DPOs in

Mozambique. This group felt that organizational capacity develops over a period of time, and includes the ability to conduct needs assessments and to garner support from a variety of partners.

> …the DPOs were clear that the internal institutional capacity (based on its access to needed human, material and financial resources) has to be linked to the use to which the organisation puts such resources in the service of the members…So, the strength of an organisation has to be seen to relate to its ability to address the needs of its constituency – the members. (Ncube, 2005, Section 4, ¶ 3)

Postma provides a metaphorical definition of capacity, which fits well with the complex adaptive system perspective that was used in this study:

> Like the river, growth in organizational capacity is not a straight or 'as the crow flies' path. Capacity happens in fits and starts. A river meanders and winds with the lie of the land and the contours of the topography. Organizational capacity happening at its best, may be two steps forward, one step back, perhaps not at all incrementally or in any sequential fashion, and perhaps at a timeframe that begs patience. (Postma, 1998, p. 59)

Organizational capacity becomes visible through what a disability association does in response to the AIDS crisis, such as the development of health promotion educational programs or an AIDS support group, and how it participates in community activities. Developing a better understanding of the strengths and limitations of organizational capacity within disability organizations can improve community capacity building efforts and strengthen disability and AIDS related program and policy initiatives.

An organization's capacity to participate in community activities is salient in this discussion, and reflects the notion of community capacity. Community capacity, which is distinct from organizational capacity, includes the community's ability to allow the participation of people with disabilities and DPOs in the ongoing activities of the community. Goodman et al. (1998) proposed that the concept of community capacity is complex and multidimensional, and includes social participation, leadership, social and inter-organizational networks, a shared sense of community and community values. Depending on the community's capacity, DPOs may participate in broader social or community groups (e.g., business associations, service clubs), community associations that have a particular focus on a specific disease or disability (e.g., association of epilepsy groups, or an association of people who are blind), or address broader pan-disability issues (e.g., national disability associations, Disabled Peoples International, Handicap International).

Assumptions, Limitations, and Scope

This study focused on DPOs in the Bamenda area of the NWP of Cameroon. It primarily used qualitative methods that aimed to obtain detailed information in order to develop a picture of how these groups have responded to the AIDS situation. Contextual factors were considered. The study was not intended to be a comprehensive examination of complex situations related to health and other systems. For example, detailed analyses of how the social, economic, and political systems influence disability, rehabilitation and AIDS issues were not fully researched because these were beyond the scope of the study. Secrecy or reluctance to share information with outsiders, particularly related to health issues and to membership in associations, is also highly valued by some members of these communities (Maynard, 2004) and may have affected the information gathered in this study. One assumption, therefore, is that a beneficial understanding of the pertinent issues could be developed from engaging in this type of research process, despite not leading to a full understanding of all possible factors.

Other assumptions were made to carry out the study. The concerns expressed by several health care providers, social service providers, and community members living with disabilities or AIDS, will continue over the next many years, and therefore were worthy of focused attention. Although there were some communication challenges, these were not sufficient to negate the findings of the study because steps were taken to minimize the negative impact of these difficulties. Communication challenges are discussed in Chapter 3, Research Method.

Weaknesses of the study are also evident. The lack of participation of potential key informants (i.e., if an invited informant did not agree to participate, there was no other way to obtain their perspective). There were difficulties or delays in obtaining information from organizations, newspapers and other publications that were not readily available. Many of the participants have had very limited exposure to research projects of any kind, and they may have had hidden assumptions and understandings. The study was limited to the city of Bamenda, and therefore groups and activities that took place in other parts of the province were not included. As a researcher who is not resident in Bamenda, there may have been statements, issues or details that I did not adequately comprehend or understand. Issues related to my role as a non-resident researcher are further explored in Chapter 3, Research Method

Significance of the Study

The study has the potential to contribute to better understandings of disability, HIV, and AIDS issues from a social systems perspective in sub-Saharan Africa by addressing how disability and rehabilitation groups can have a stronger impact on the AIDS pandemic. It can provide direction for community workers who want to improve services for people with disabilities, and provide recommendations for policy development at organizational and governmental levels. Publications arising from the study will contribute to bridging the gaps in the literature about how disability groups are responding to the AIDS pandemic. Most importantly, by sharing the stories and struggles of how disability organizations are working to create new answers to the questions about dealing with HIV and AIDS, this study validates the dignity, worth, and efforts of people living with disabilities and with HIV and AIDS.

Summary

This chapter has highlighted the need for a study examining how disability organizations in the NWP of Cameroon were addressing HIV and AIDS issues from theoretical and practical perspectives. The literature indicates that there has not been a similar study in this area and this literature is described in more detail in Chapter 2. This introduction to the study provided an overview of how the study evolved. The purpose of the study was to assess the organizational capacity of community-based disability organizations in the NWP. To ground the study theoretically, complex adaptive systems theory was used. Evolving definitions and understandings of disability, DPOs, and organizational capacity were explored in relation to the study.

The methodology is described in more detail in Chapter 3. The results of the study are presented in Chapter 4. The study resulted in the identification and description of four established DPOs in Bamenda, along with a detailed picture of the historical, social, and political contexts in which they operate. Five themes emerged from the analysis of the information gathered. These findings are discussed in Chapter 5. DPOs were found to have limited organizational capacity to respond to AIDS, despite their desire to do more. They have not been included in mainstream AIDS initiatives, and there was very little accurate information available for organizations to use with their members. Finally, the implications for social change practice and research, and conclusions of the study, are outlined at the end of Chapter 5.

CHAPTER 2: LITERATURE REVIEW

Introduction

Chapter 1 of this paper addressed the background and rationale for the study. Chapter 2 provides a more in-depth review of the literature to situate the research in the broader scholarly discourse, and Chapter 3 provides a description of the methodology that was used.

The review of the literature in this chapter addresses six related areas. The first section covers the Cameroonian context generally and provides information about the geographic, historical, political, social, and economic contexts in which the study took place.

The second section addresses disability and rehabilitation issues, with a focus on what is known about these issues in the NWP, Cameroon, and similar contexts in Africa. Terminology and models of disability, epidemiology, policy, and service provision related to disabilities are discussed.

The third section briefly explores HIV and AIDS issues, particularly in Cameroon and in sub-Saharan Africa. As the literature addressing HIV and AIDS is now quite extensive, this section focuses on perspectives of social issues, disability, and rehabilitation in the context of AIDS.

The fourth section reviews concepts of organizational capacity within community-based organizations, and organizational capacity related to community issues, social capital, and organizational development. The particular focus of this section is on what is known about community-based organizations in the Bamenda area and the NWP, including a discussion of gender issues. This section assisted in identifying potential themes and perceptions that the study could explore in relation to organization capacity.

The fifth section combines the previous four areas to explore concepts of organizational capacity within community-based organizations as they relate to disability or HIV and AIDS issues. The review of the literature reflected the recognition that organizational capacity needs to be developed on HIV, AIDS, disability, and rehabilitation within community-based groups.

The final section reviews literature on theoretical and methodological issues related to the conduct of cross-cultural, community-based case study research, with African and disability communities. Recommendations from key resources were identified. Complex adaptive systems theory is the theoretical framework that grounded the study and is addressed in this section.

Each section reviews the literature on the topic, including a discussion of the similarities and differences of the points of view or research outcomes, and ends with a summary of the implications for the study.

Problem statement and study questions

It is now recognized that stemming the AIDS epidemic in Africa will require attention to the complex social factors that sustain transmission, as well as to the biomedical understandings of the illness (Duffy, 2002; Campbell, Williams, & Gilgen, 2002). The lack of capacity of disability organizations to respond to HIV and AIDS issues appears to be a potentially significant factor which does not appear to be well understood in discussions of the epidemic. As described in Chapter 1, there is a need for more research into how disability organizations have responded to the AIDS epidemic in

Africa, and in particular, in the NWP of Cameroon. The purpose of this study was to construct a case study about the organizational capacity of community-based disability groups in the city of Bamenda, Cameroon to deal with the AIDS epidemic. The research explored, conceptually and practically, how community-based disability organizations have responded to HIV and AIDS issues in the past, what has been effective and less successful in these responses. It identified outstanding needs and recommendations for further development. In recognition that men and women's experiences and needs can be diverse, and that women are often marginalized in community groups, the study included a gender lens, i.e. an examination of the issues from the perspective of gender (Van Koughnett, Day, & Watson, 2007), as part of the data collection and analysis.

As mentioned previously, the study questions are:

1. What have disability groups in NWP done to develop their organizational capacities to address HIV and AIDS issues (and by extension, what has been missing or prevented)? What are the contextual factors which have influenced organizational capacity?
2. What could disability groups in NWP do to develop their organizational capacities to address HIV and AIDS issues?
3. From the perspective of DPOs, what could AIDS service organizations do to support the development of capacity within DPOs to address HIV and AIDS issues?

Search Strategy

This review of the literature comes from several sources. A systematic review of the literature on disability, rehabilitation, and Cameroon was started several years ago

(So, 2005). This part of the literature review was conducted by searching several databases for a number of key terms related to disability and rehabilitation in Cameroon, including Source, Pubmed, CINAHL, Medline, Embase, Healthstar, and Africa Studies. The CIRRIE (online collection of international disability and rehabilitation literature), Google Scholar internet search engine, and websites of major organizations such as the WHO and United Nations (UN) were used. This strategy resulted in the identification of over 100 potential abstracts and the subsequent selection of approximately 40 articles that specifically addressed disability or rehabilitation in the NWP or Cameroon in a meaningful way. These 40 articles appear to represent the extent of peer-reviewed published research addressing any aspect of disability or rehabilitation in this geographic area; the small number of published studies clearly illustrates the need for further research.

I also used the results of a recent scoping review on disability and rehabilitation conducted by O'Brien and Wilkins (O'Brien & Wilkins, 2007). The goal of their study was to advance research and clinical practice in rehabilitation in the context of HIV. Their specific objectives were to (a) identify research priorities related to HIV and rehabilitation that will advance policy and practice, and (b) identify guiding principles that should be used for the development of best practice guidelines for rehabilitation in the context of HIV. To address these questions, they conducted a comprehensive review of the global HIV, AIDS and rehabilitation literature and initially identified over 4500 abstracts that addressed AIDS, disability and rehabilitation in some way. To reduce this to a manageable number, they focused on the Medline database, as it provided a good overview of the field, and that reduced the number to 1260 abstracts. They then developed rules on how to select articles that addressed their research questions. They excluded drug rehabilitation, developing countries, pharmaceuticals (including complementary and alternative medicines), which resulted in 615 articles for detailed review. From these 615 articles, they identified 147 that were the best to answer their questions. O'Brien shared the reference list of these 147 articles, as well as the full list of 1260 articles from Medline.

To address the research questions for this study, I selected all articles on O'Brien and Wilkins' short list which were from 2003 – 2007 (i.e., the most recent 5-year period) and also selected several articles from a search of their full Medline list (of 1260 articles) which included "Africa", "Nigeria" or "Ghana" (these two countries have cultural similarities to Cameroon) because "developing countries" had been excluded from their short list. There were no articles in the Medline list with the word "Cameroon" in the citation. This process resulted in a list of 107 articles selected from their review which addressed issues of disability, rehabilitation and AIDS.

In addition, the reference lists of many articles identified from the above two search strategies were reviewed for relevant articles. The tables of contents of several specific journals (e.g., Disability and Rehabilitation, Social Science and Medicine, The American Journal of Public Health, Development in Practice) were searched for relevant articles and for the key words Cameroon and disability. Google Scholar, Amazon.com, and the University of Toronto library were searched for relevant books and other resources. Cameroon news was regularly reviewed through the website www.Bamenda.org for articles pertaining to disability issues, which publishes current news items relating to Bamenda, and this yielded several background articles from the popular press about the province and the issues under consideration.

Several electronic databases (Medline, CINAHL, Academic Search Premier, Google Scholar) were searched for studies particularly relating to the theoretical perspectives about organizational capacity, complexity theory, complex adaptive systems, participation, social organizations and similar concepts in public health or disability studies. Finally, the proceedings of recent conferences (2006 Bamenda conference on Disability and Rehabilitation, 2006 American Public Health Conference, June 2007 North American conference on the International Classification of Functioning) were reviewed for key contributions.

This process resulted in a total list of approximately 500 articles, reports and presentations that have relevance to the current study, with many of the papers addressing African or Cameroonian contexts. The most pertinent from the full list were selected for inclusion for this review.

The Cameroonian Context

The socio-political context of the North West Province of Cameroon

The country now known as The Republic of Cameroon (Cameroun in French, commonly shortened to Cameroon) received independence in two stages, during 1960 and 1961 (Fanso, 1999). Cameroon remains a diverse mid-African country of about 17 million people and over 240 linguistic groups at the juncture of West and Central Africa. The NWP is one of two Anglophone provinces in the country and the other eight provinces are Francophone. The vestiges of the British (and other) colonization efforts are still apparent in its social, religion, educational, and health systems (Fanso; Ndi, 2005). Cameroon is often referred to as “Africa in miniature” because of its cultural, religious and geographic diversity. Lessons learned here have the potential to be informative for other parts of Africa.

The capital city of the NWP, Bamenda, has a vibrant cultural history and is known for its economic activity (Acho-Chi, 1998; Awambeng, 1991). The province is part of the area known as the Grassfields, which despite individual differences in various villages, towns and cultural groups, shares dominant cultural features of the Bamileke, Bamum and Tikar groups (Mbuagbaw, Brain & Palmer, 1987). It is a hilly area, known for its red clay soil and moderate climate. Anthropologists and other social scientists have studied the Grassfields for decades (e.g., Fowler & Zeitlyn, 1999; Kaberry, 1952; Maynard, 2004) resulting in a rich collection of work about the historical and cultural roots of the area.

The initial period of optimism in the years after independence were tempered with the reality of political repression (BBC News, 2008; US Bureau of Democracy, Human Rights, and Labor, 2007). There was a lack of academic freedom to carry out research, explore new learning, and contribute to developing new systems in the country, including little opportunity for health or disability studies. Mbock and colleagues (2004) examine the historical disconnections between policy and research uptake in the country, illustrating that it is not solely in the areas of health or disability policy that connections were, and continue to be, missing.

In the first decades of the new country, any research examining social issues could be charged with “subversion” and subjected to intellectual censorship (Mbock, 2004, p. 38). Historically, therefore, the concept of citizens or scholars who attempted to engage in research that would have an applied utility, including policy analysis, could be considered to be in direct conflict with the ruling government's goals. In that climate, researchers could either address public health and social issues and potential solutions, or present politically acceptable options, but probably not do both. Although the research context may be changing, the central government continues to set policy for the local and provincial jurisdictions, and the tendency for bifurcation between policy and research remains: "the policy-research interface operates in Cameroon in a climate of mutual indifference that is not devoid of suspicion" (Mbock, et al., p. 41). It is important to note that although the difficulties in linking health research and health policy are always unique to particular contexts and the idiosyncrasies of the Cameroonian context should be acknowledged, challenges exist in many countries (Hanney, Gonzalez-Block, Buxton & Kogan, 2003).

The political, social, and economic contexts have significant impacts on social organizations. Generally, Cameroonians work in civil services jobs or small businesses. The official minimum wage is approximately $50 USD (23,500 CFA francs) per month (approximately $600 per year), which does not adequately cover the cost of living for an average worker and his or her family. The average annual income per person is approximately $800 USD (440,000 CFA francs) (US Bureau of Democracy, Human Rights, and Labor, March 6, 2007). At least 40% of the population live in poverty and unemployment rates are high (Republic of Cameroon, 2006). Official estimates are that 50% of people with disabilities live in poverty (Republic of Cameroon, 2003, p. 16), but anecdotal reports suggest that the actual experience may be higher.

In many African contexts, divisions between individual and group identities are perceived to be indistinct; personal identity is closely tied to social participation and the collective worldview of the extended family and communities of which one is a part (Maynard, 2004). Being part of the community is the starting point for a sense of identity, rather than a factor that can be considered separately or following a consideration of an individual sense of identity (Nyamnjoh, 2005; Van Niekerk, Lorenzo, & Mdlokolo, 2006). Cameroon society is also characterized by the strong sense of community and associational life with extended family systems, which have been well studied (Chilver, 1964; Endelely, 2001; Fonchingong & Fongong, 2002; Fonchingong, 2005; Goheen, 1996; Kaberry, 1952; Maynard, 2004). These studies illustrate that, as in other parts of the world, family and community life have been influenced by struggles between ethnic groups over land use and tenure, changes in economic and political relationships, and gender roles. Reading these detailed historical descriptions provides contextual information for examinations of the current situation and provides background about what is influencing current social participation and social change trends, including national and local community development.

The picture that emerges is that loyalties and obligations to the family, village, school, political party, and religious group are often extremely strong. Therefore, an organization’s ability to develop and contribute to a sense of the collective, or community, is crucial to building identity. Meetings and gatherings allow members to come together, for celebration, support and condolence. Especially when they are cohesive and well led, these meetings can strengthen and reinforce the sense of identity and belonging.

Social identity can be harnessed to create improvements in public health. For example, Latkin and Knowlton (2005) state:

> Promoting a group identity based on collective social identity may be one way to promote behaviour change. Social identity theory suggests that when individuals identify with a group, the collective group concept becomes part of their self-concepts … In this process, a redefinition of self emerges and the individuals' behaviours tend to become congruent with the group's goals and actions. (p S105).

However, these strong allegiances, often relatively invisible, can create tensions when people from different groups try to work together. Although not well studied in the NWP, this dynamic process would presumably apply to disability groups and organizations also. The literature on factors influencing organizational development is discussed in the section below on social organizations and community development.

The public perception in Cameroon is that officials are open to bribes in most situations. Transparency International reports that an average household pays over $200 USD each year in bribes, or more than 20% of the average person's annual income (US Bureau of Democracy, Human Rights and Labor, 2006). Corruption is also evident in journalism and news reporting (Ndangam, 2006) resulting in significant cynicism regarding information received through newspapers and television.

The NWP is known to be the home of political opposition in the country (Gros, 1995), and current debates about the autonomy of the Southern Cameroons, which includes both NWP and the South West Province, continue (Ndi, 2005; BBC News, 2008). Anecdotal reports are that some opposition activists in the province have become disabled (amputations, head injuries) because of retaliation for their political engagement, but receive little assistance or compensation for their injuries.

History of health and disability in Cameroon

Public and private health, education and social services systems in the province are present, but are inadequate to meet the needs of the population generally, or the needs of people with disabilities. This section provides some history about these systems, to assist with understanding the current context and situation. Ndumbe and colleagues identify four major periods in the history of Cameroonian health service systems (Ndumbe, Daniels, & Bryant, n.d.). These are the colonial period, the post-independence or experimental period, the post-Alma Ata or primary health care period, and the current period of reorientation of primary health care. The current reform period in Cameron began in 1998, with formal launching in September 2001 of the document entitled *The Health Sector Strategy*

Since 1972, legislation in Cameroon is developed and passed at the national level; there is little provision for provincial legislation or policy development. In 1983, *Décret 83/013 du 21 juillet 1983 relative a la protection des personnes handicapées* (*Decree 83/103 of July 1983 Regarding the Protection of Handicapped Persons*) was passed, recognizing the needs of people with disabilities. This legislation was introduced but not implemented until 1990, with the passing of Loi (Law) 90/1516 (Hashemi, 2006). Many health and social service providers are not familiar with the legislation or with the rights and obligations that it addresses (Hashemi, 2006). Pouagam (2000) wrote a book to inform people about their rights under this law, but it is not easily obtainable and most people with disabilities are not aware of it. In one of the few public critiques of disability issues in Cameroon, Fankam writes about how this legislation is still not effective, as it has not been implemented in any significant way (Fankam, 2003). Periodically, newspapers run stories about the challenges of people with disabilities. For example, in anticipation of the July 2007 national elections, a newspaper article reported on the inaccessibility of voting stations for people with disabilities (Manyong, 2007).

In addition to national public policy, it is important to recognize the impact that international policy programs have on the health, disability and social services systems and programs. The Structural Adjustment program (SAP) that the International Monetary Fund imposed on Cameroon in the mid 1990's led to a sudden devaluing of health workers salaries by over 50%, with resultant damage to the motivation and professional functioning of the workers, as well as deterioration of the health systems (Israr, Razum, Ndiforchu, & Martiny, 2000).

The Bamako Initiative

One model of health care provision widely implemented in Africa is known as the Bamako Initiative; this model has had a significant impact in Cameroon, including on rehabilitation services. The African Ministers of Health, including Cameroon, adopted the Bamako initiative in 1987 as a strategy to promote primary health care (Awasom, personal communication, November 2005; Godin, 1998). This initiative placed more responsibility on local communities to identify problems and manage their health-care services and resources. A key element of the Bamako initiative was the change to cost-recovery policy, which mandated that the immediate providers and users of public health services would be responsible for recovery of those costs. The Cameroon Ministry of Public Health changed its primary health care system in 1989 to the new primary health care system, which was not formally adopted as "reorientation" until April 1990. This new system included several features with a cornerstone being that there would be one health care center, as the basic unit of care, in each health district.

Included in this change was the provision that village health workers were no longer able to prescribe drugs (Godin, 1998). Each village was intended to have a health committee with representations from the local village as well as the local health center. Local health center staff were used and supplies are provided through the provincial capital (Godin). Based on his research, Godin advocates community-based and community directed treatment programs to ensure program sustainability.

Currently no public health insurance program is in place in NWP or nationally, however a recent forum brought together government officials, including the Minister of Health, to discuss possibilities (Cameroon Ministry of Health, 2006). Some private health insurance appears to be available but few details are accessible in the published literature. The literature appears to be silent on the impact of the Bamako Initiative and primary health care reform on people with disabilities and disability policy in Cameroon. Disability and rehabilitation are not mentioned in most reports of the health system (e.g., Fongwa, 2002).

Monitoring and measuring change in this context

Health information systems and data collection face significant challenges in this area and little information is actually available. Few epidemiologic studies have been done in NWP regarding disability (So, 2005), although some studies have been carried out examining some of the causes, such as epilepsy (e.g., Zoli et al., 2003). Without baseline information or agreed on indicators, it is difficult to assess the situation or to measure change at either individual levels or from the perspective of organizational and systems.

Implications for the research

This review of the geographic and political context reveals that there are high levels of poverty and corruption, and low levels of service provision. The disability and rehabilitation "systems" are located within broader systems that are not adequate for providing basic levels of care and rehabilitation for the public. Very little systems research has been conducted examining how disability issues are being addressed in the current context, indicating that there may be significant challenges in obtaining a detailed, contextualized picture. It is possible that the government might not have been supportive of this study if it provided a direct critique of their policies. However, the provincial representatives of the Ministry of Health, the Ministry of Social Affairs, and, the Ministry of Women's Empowerment and the Family showed interest in the past, and encouraged research in the field of disability, rehabilitation, and AIDS. It is important to acknowledge that the relevant ministries or service providers might not acknowledge or adopt recommendations resulting from the study.

Disability and Rehabilitation

Conceptualizing "disability"

The concept of *disability* is contested and complicated but the word itself continues to provide a linguistic tool to assist our understanding of health and daily functioning (Pledger, 2003; WHO, 2002a). Within the heterogeneous group of people with disabilities, several specific groups can be identified, although it is recognized that these subgroups are not always considered discreet categories. In addition, social, economic and other environmental factors need to be considered in conceptualizing disability (WHO, 2002). The physical location of home or homelessness, gender and sexual identity, substance availability and abuse, poverty, distribution of wealth, and education levels are examples of related issues that have significant impacts on how individuals, families and communities experience living with disability.

In recognition of this complexity, internationally, concepts of disability are undergoing change to reflect a social model of disability which embraces inclusive, functional, and human rights perspectives rather the charity and medical models which have been prevalent in many societies in the past (Albert, 2006; Manderson, 2004; WHO, 2002). The United Nations named 2000 to 2009 The African Decade of Disabled People (ADDP) (UN, 2004). The decade aims to promote "full participation, equality and empowerment of people with disabilities in Africa" (UN, ¶ 3). During this African Decade of Disabled People, advocacy groups across the continent and internationally are working to improve knowledge about, and the lives of, Africans with disabilities (Pan African Federation of the Disabled, 2005). January 2007 marked a historical moment in the world with the adoption of the International Convention on Disability at the United Nations in New York (UN, 2007). Cameroon was a participating country in these discussions. The WHO, in constructing and promoting the ICF, aims to recognize the range of biomedical issues (body structures and functions) as well as the social, environmental and personal factors, that limit activity and participation (WHO, 2002).

Despite these efforts and many others, Albert (2006) reports that

> relatively very little of practical value has yet been achieved either to bring disabled people into the mainstream of the development process or to improve their lives. Furthermore, although many aid organisations have adopted the

> human-rights language and slogans of the disability movement, with few exceptions, their attitudes and actions remain rooted in a medical understanding of disability and its concomitant top-down, charity-like, 'professionals-know-best' approach to disabled people themselves (p. 1).

The attitude that people with disabilities should be seen as being objects of charity rather than being full social citizens also remain prevalent in the NWP. There appears to be relatively little public discourse on disability issues, including regarding social models of disability. Very little literature is published about disability in the area, as indicated by a study which examined disability policy (Hashemi, 2006) and which a systemic review revealed (So, 2005). Generally those who live with disabilities or are at risk for developing them are divided into four groups: people with physical and mobility disabilities, people with mental or cognitive disabilities (e.g., developmental delay, epilepsy), people with hearing impairments, and people who are blind or have low vision (Mbakwa, 2006).

Estimating the impact of disability

It is estimated that between 10 and 20 % of the populations of low-income countries live with at least one disability, and that rates are higher amongst groups with low education (UN, 2006). Although accurate estimates can be difficult to obtain, UNESCO suggests that up to 90% of disabled children do not attend school. In addition, approximately 75% to 80% of disabled people in the African Region are in rural areas, where there are limited or no services for prevention and rehabilitation (WHO, n.d.).

It appears that very few epidemiological studies on disability have been conducted in the NWP (Mue, 2006; So, 2005). Personal communication and anecdotal reports suggest that the global estimates are also reflected in this area (Mue). The population of the province is approximately 1.7 to 2 million persons, placing the estimated number of people with disabilities at 170,000 to 340,000.

Conceptualizing rehabilitation as part of community based initiatives

There are inadequate services regarding rehabilitation services for people with disabilities in Cameroon and in the NWP. The government of Cameroon has pledged to improve this situation (Republic of Cameroon, 2003; Republic of Cameroon, 2006). Rehabilitation is clearly seen as part of the promotion of social inclusion. For example, the government, through its 2003 plans to reduce poverty in the Poverty Reduction Strategy Paper (PRSP), writes about social reintegration:

> Steps will be taken to develop effective reception facilities, promote rehabilitation, and improve the provision of social services for socioeconomic integration. To this end, the following will be carried out:
>
> (i) the restoration of training institutions for the disabled;
> (ii) the diversification of effective rehabilitation facilities depending on the type of disability;
> (iii) the promotion of community action networks and alternative services for the disabled; and
> (iv) the development of social integration services for the socioeconomic integration of the handicapped.
> (Cameroon Poverty Reduction Strategy Paper 2003, p. 84).

In the 2006 Progress Report on the implementation of the PRSP to December 2005, there appears to be only one mention of people with disabilities. The government reports that poverty can be seen in many areas, including:

> increased insecurity and the precariousness of life, notably the falling moral standards and sexual exploitation of minors as well as abuses of all kinds (prostitution, procuring, drug addiction, etc.); urban violence, (armed robbery, witchcraft, fighting, rape, burglary, etc.); the increase in the number of street children and mental patients. Moreover, disabled and aged people lack specialized areas and equipment. (Republic of Cameroon, 2006, p. 61).

External views of the situation mirror these perceptions of how under resourced the situation is. For example, the US Bureau of Democracy, Human Rights, and Labor Reports from 2005 and 2006 contain sections regarding people with disabilities that are very similar; and it is notable that there is only a slight change in wording in these two reports (indicated with italics):

> *2005:* The law provides certain rights to persons with disabilities, including access to public institutions, medical treatment, and education, and the government was obliged to bear part of the educational expense of persons with disabilities, to employ them where possible, and to provide them with public assistance when necessary; *however, the government rarely honored these obligations* [italics added]. There were few facilities for persons with disabilities and little public assistance; lack of facilities and care for persons with mental disabilities particularly was acute. Society largely tended to treat those with disabilities as outcasts, and many felt that providing assistance was the responsibility of churches or foreign NGOs. The law does not mandate special access provisions to private buildings and facilities for persons with disabilities.
>
> *2006*: The law provides certain rights to persons with disabilities, including access to public institutions, medical treatment, and education, and the government was obliged to bear part of the educational expense of persons with disabilities, to employ them where possible, and to provide them with public assistance when necessary. *On August 2, the Minister of Secondary Education and the Minister of Social Affairs signed an order that made access to public secondary education free for persons with disabilities and children born of poor parents with disabilities.* [italics added]. There were few facilities for persons with disabilities and little public assistance; lack of facilities and care for persons with mental disabilities was particularly acute. Society largely tended to treat those with disabilities as outcasts, and many felt that providing assistance was the responsibility of churches or foreign NGOs. The law does not mandate special access provisions to private buildings and facilities for persons with disabilities.

Implications of this study

Disability organizations in Bamenda are operating in a social and political context that is characterized by high needs (many thousands of people needing service and support, few resources are available) and limited support by governments for disability and rehabilitation services. The study includes information about this context to allow for an understanding of how DPOs have responded to the AIDS situation.

HIV and AIDS

The UN estimated that between 21,600,000 and 27,400,000 people were living with HIV and AIDS in sub-Sahara Africa in 2005 (UNAIDS/WHO, 2005). Cameroon, despite its relatively small population of 17 million overall, had approximately 510,000 persons living with HIV or AIDS, which placed it at number 16 in the countries of the world with respect to prevalence of HIV and AIDS (Central Intelligence Agency, 2006; Kaiser Family Foundation, 2006).

Epidemiological aspects of treatment of AIDS

Antiretroviral therapies (ARTs) are increasing available in SSA but are still not reaching everyone who needs them (Joint United Nations Program on Aids, 2006, Chap. 7). In Cameroon, until recently, estimates were that less than 30% of those who need ARTs were actually receiving them (Joint United Nations Program on Aids, 2006, Chap. 7). However, in early 2007, the National Minister of Health announced that ARTs would be free for all who need them in the country (Njechu, 2007), and within a few weeks of this announcement, changes were evident (Kaiser Daily HIV/AIDS Report, 2007; personal communication, D. Bambo, May 30, 2007). Although the treatment is now more readily available, there are still several other costs that an individual has to pay out of pocket, including consultation fees, transportation to get to a clinic or hospital, and other medications. There do not appear to be any specific provisions made for people with impairments or disabilities to cover these costs.

In addition, HIV affects not just the person with the virus but also parents, children and the extended family. In Cameroon, as in other African countries, many of those who are HIV positive are parents, possibly passing on the virus to their children. Some initiatives are occurring in the NWP province to support HIV positive parents and to prevent transmission in new births (CBC HB PMTCT Program, 2006; Tih, n.d.; Tih, 2006). The parents may not be able to work because of illness, the children may not be able to attend school because they must work to pay bills (there is no free publicly funded health care in Cameroon) or be home to take care of ill family members. Very few studies have explored these issues with an epidemiological perspective, or from the perspective of disability.

The New Awareness: HIV, AIDS, disability and rehabilitation

This review has explored issues of disability and rehabilitation, and of HIV and AIDS, in the context of the NWP of Cameroon. Disability has been discussed as a generic construct to provide an overview of the issues. This next section addresses the emerging awareness that several factors influence the relationships between disabilities, HIV, and AIDS. Following this discussion is an examination of the literature that analyzes the concept of disability with respect to HIV and AIDS issues by looking at three aspects of body structures and body functions: psychiatric disabilities and mental health issues; physical disabilities; sensory, and cognitive disabilities. This type of analysis is leading to new understandings of the relationships between issues, service provision and of researching and understanding the AIDS situation, and of the need for more work to allow effective responses to develop.

Social and environmental factors affecting HIV transmission and progression in people with disabilities

There are a number of factors affecting HIV transmission and progression particularly with respect to disability issues. Despite the high numbers of people affected by HIV and disability, the field of public health still has to do considerable bridging work in order to ensure that people with disabilities are included as target populations in HIV and AIDS initiatives, and that the impact and ramifications of HIV and AIDS are understood from disability, functional, and rehabilitation perspectives. For example, a search of the American Public Health Association 2006 conference for HIV and disability yields no papers that have both words in the title. The 2006 Toronto International AIDS Conference had few sessions that directly addressed disability issues; the primary session on the topic was scheduled at 7 a.m., not exactly a prime time to get attendees, especially those who may need extra time to cope with disabling conditions and environments (Canadian Working Group on HIV and Rehabilitation, August 17, 2006). Relatively little attention has been given to issues of disabilities and AIDS from either individual or social perspectives. This lack of attention has led to a dearth of evidence about the social and environmental aspects of the situation, and the need for much more research and information (Secretariat of the African Decade, 2006).

What is well known is that the impact of HIV and AIDS in sub-Saharan Africa has been devastating. People living with AIDS report that their health related quality of life is severely compromised, with significant limitations in mobility and usual activities affecting many people, as well as pain and discomfort (Hughes, p. 375). One of the social factors impacting this group is the relative lack of conceptual and theoretical attention given to how communities respond to these issues from a functional or rehabilitative perspective (i.e., a lack of systems focus), and how a disability and rehabilitation orientation could contribute to improving the situation for people with AIDS (Crothers, 2005; Worthington, Myers, O'Brien, Nixon, Cockerill, 2005). There appears to have been relatively little work done to explore how community organizations and institutions such as rehabilitation centers, hospitals and health clinics, and governmental programs can work together to create social change initiatives to improve the availability of disability and rehabilitation services. For example, there are very few home care programs for people living with AIDS. One such study was conducted by Mumba (2004) to examine how home care for people living with HIV or people with disabilities (PWD) could assist recipients to maintain personal dignity and stay as well as possible, especially in situations where family members are not available or willing to do so. Mumba’s study revealed that individuals often felt that formal providers were much more supportive than family members were.

Research reflects the priorities of the broader society, and this lack of attention to issues of daily life may reflect the stigma and discrimination commonly directed at both AIDS and disability in SSA. Stigma, discrimination and social exclusion are common experiences for both people living with HIV and AIDS, and people with disabilities in many parts of the world. People with disabilities in sub-Saharan Africa are often socially excluded (Alade, 2004; Sweeney, 2004), and this is also the situation for people with disabilities in Cameroon (US Bureau of Democracy, Human Rights, and Labor, 2006). Theories and models of social exclusion and discrimination can assist with developing current and variable understanding of why some members of society actively exclude others (e.g., Link & Phelan, 2001). This information can lead to strategies that are more effective to create positive social change in the direction of a more inclusive society. Moving from a charity model to a human rights or social inclusion model will require shifting not only the attitudes of people with disabilities, but also their families and communities. Evidence is growing that stigma and discrimination can be reduced through the provision of appropriate AIDS programs, and that other barriers to access and interventions may actually be more prevalent than stigma in some circumstances (Castro & Farmer, 2005; Tih, n.d.).

In low-income communities, there are a number of concerns that affect peoples' experiences of disability and of AIDS, especially women's experiences. Poverty and disability, poverty and AIDS: clearly thousands who experience disability and AIDS in SSA also experience poverty, as there may be no, or limited social and financial support systems, employment or other means of income. Poverty influences every aspect of life and health. For example, there is evidence that poverty increases people's risk for engaging in high risk sexual behavior (e.g., multiple partners, lack of condom use) especially young people who have limited sources of income (Rwenge, 2003) but these links have not been studied amongst disabled populations in the NWP. In addition, social factors cause the experiences of disability and AIDS to affect women differently than men.

Public education, AIDS, and people with disabilities

People with disabilities are often not targeted in public health or other educational campaigns about AIDS and therefore do not have access to relevant information (Burrows, 2005; Groce, 2004; Secretariat of the African Decade, 2006). The largest study to date to support this assertion was conducted by Groce at Yale University with support from the World Bank, which collected information from respondents around the world (Groce, 2004). Yousafzai, Dlamini, Groce, & Wirz (2004) conducted focus groups with youth with disabilities (n=32) and those without (n=56) to see if the two groups had differing levels of awareness and knowledge. They did find that those with disabilities were much more limited in their exposure to information and were more misinformed. It appears that people with disabilities have less knowledge about AIDS than the general population (Groce, Yousafzai, & Van Der Maas, 2006; Groce, Yousafzai, Dlamini, & Zalud, & Wirz, 2006).

It is well known that there are differences between living with a disability in urban and rural areas (Allotey, Reidpath, Kouame, & Cummins, 2003) but these differences have not been explored from the perspective of the links between disability, HIV, and AIDS, or with respect to public health education. People with disabilities in rural areas may be even more vulnerable to HIV as they may have lower literacy levels, and less access to information (Burrows, 2005). There are many questions about how the experience of social participation, inclusion, and exclusion may differ depending on the rural or urban context.

Individual factors affecting HIV transmission and progression in people with disabilities

Understandings of disability from a social perspective, as provided above, are important to understand the experience of living with disability or HIV. The next section of the review explores the concept of disability with respect to AIDS issues by looking at three aspects of body structures and body functions: mental health issues and psychiatric disabilities, physical disabilities, and sensory and cognitive disabilities.

Mental Health issues, psychiatric disability and AIDS

Many areas of sub-Saharan Africa do not have well developed mental health and psychiatric services, and few mental health services for those who are also living with HIV or AIDS. A study by Bolton, Wilk and Ndogoni (2004) explored the prevalence of major depression in the general population in rural Uganda, an area affected by HIV. The authors found that 21% of the population could be considered depressed, a rate higher than countries less affected by AIDS, and almost as high as HIV affected groups. However, based on anecdotal reports, they had expected to find higher levels of depression in this area than they did. They speculate that because their findings are similar to rates observed before the AIDS epidemic, the high rate of depression may be related to poverty or other local conditions. They also found that many people were very limited in their everyday activities. The authors do not make recommendations for intervention. However, their findings suggest that interventions should not be focused primarily on AIDS or on relieving the depression through medical treatment, but on the intersections of these issues with the broader social context.

People with existing disabilities and disorders, including mental health disorders, may be at increased risk for contracting HIV, and disability may negatively affect the progression of the illness. For example, Olley and colleagues have explored mental health issues in persons with HIV. In some reports, they discuss the predictors of depression (Olley, 2003; Olley, Seedat, & Stein, 2004; Olley, Seedat, Nei, & Stein, 2004), and the impact of post-traumatic stress disorder (PTSD) (Olley et al., 2005). These studies indicate that PTSD is higher in people who are newly diagnosed with HIV, and suggest that being diagnosed with HIV may be experienced as a traumatic event leading to PTSD.

They also suggest that that there may be links to experiences of other traumatic events in the HIV population. As discussed in other sections of this review, women with disabilities are vulnerable to many types of traumatic events and abuse, including rape. For example, some people believe that women with disabilities are virgins, and that having sex with a virgin can cure AIDS (Groce, 2003; Groce & Trasi, 2004).

NWP has few formal services for persons with significant mental illness and so individuals are primarily cared for by their families as reported by a priest with extensive local community experience and a psychiatric nurse who works in the province (Father Brian Byrne, personal communication, February 14, 2005; E. Gola, personal communication, September 19, 2007) or by traditional healers (Ngassa, 2003). Very little is documented about what this care entails. Some medicine is available in pharmacies and in the local market (van der Geest, 1991) and is poorly regulated or monitored (E. Gola, personal communication, September 19, 2007). It is important that programs addressing disability and AIDS consider mental health promotion as well as mental illnesses and psychiatric disabilities (Worthington et al., 2005). Mental health issues, psychiatric disability, and the relationship with HIV and AIDS is complex and incorporates several significant factors and questions; research addressing these issues and relationships needs to allow for complexity.

Physical health issues, physical disability and AIDS

The impact of physical disability needs to be considered in examinations of community based AIDS programs (Worthington et al., 2005). A recent South African qualitative study suggests that physically disabled young people have limited knowledge about HIV and AIDS (Wazakili, Mpofu, & Devlieger, 2006). The authors report that these youth need love, acceptance, job security and stable family life, and that these needs were more important than practicing ‘safe sex’. They call on the developers of AIDS programs to conduct research to understand better the realities of those they are trying to reach to understand the lived experiences and decision-making processes. AIDS education should also include an empowerment focus or specific information relevant for people with physical or mobility issues. For example, persons using orthotics may need additional assistance on how to use condoms (Burrows, 2005).

For people living with AIDS, the syndrome may manifest as physical disability and impaired functioning. For example, one study examined physical disabilities experienced by PWA receiving home based care in Zambia (Mumba, 2004). Using the ICF framework, the author concluded that upper and lower limb impairment, and mild to moderate difficulty in the area activity limitations and participation restriction were common in the this group. The most affected area for these people was in daily activities, including household chores, performing previous roles, and carrying out a job. The participants in this study reported receiving more support from health professionals than from family members. Other research studies have addressed these issues, for example in the area of quality of life and fatigue, but to inform localized responses further work needs to be done as very few have taken place in sub-Saharan Africa or been published (Groce, 2004).

Neurological and sensory issues and disabilities in the context of AIDS

As with other disabilities, people who have vision or hearing impairments may not be reached by AIDS public health education initiatives (Groce, 2004; Secretariat of the African Decade, 2006). For example, Thune (2003) describes a Knowledge, Attitudes and Practices survey conducted in Ethiopia with 205 deaf people. Results indicated that there were considerable levels of misinformation about transmission and living with the virus. As a result, a national training program was developed.

Neurological and sensory impairments are common in AIDS. Many PWA have neuropathies, with central or peripheral nervous system involvement resulting in loss of physical impairments and function loss such as apraxia and weakness (Hwang & Nochajski, 2003). Cognitive losses are also a manifestation of AIDS and require assessment, intervention and support to ensure that the person is able to maintain optimal functional levels. Therefore, these issues also need to be included in public health initiatives.

Implications for the current study

There are complex and challenging relationships to explore in understanding disability, HIV infection, and AIDS from different vantage points, including social and biomedical models. There are diverse issues and key factors for different groups; therefore, this study considered how organizations addressed this complexity when looking at the HIV and AIDS needs of various disability populations.

Organizational Capacity in Community-Based Initiatives

The previous sections have focused on perspectives of disability and AIDS using a social model, but from an individual perspective. This section now explores what is known about participation in social groups and organizations, broadly speaking, to provide context about disability organizations, as well as specifically about the Cameroonian context. The review provides background information about social groups and associations, and then focuses on understandings of the relationships between social groups and health, disability and AIDS issues.

Social groups, associations and organizations

People are social beings and social groups form for many reasons. Discussions of participation and social inclusion are connected to theories about the benefits of such involvement. About 20 years ago, Putnam published a study that focused on how involvement in civic society has changed over the years in the USA. He made the case that people needed “social capital” as well as financial capital for a satisfying life, and that greater levels of civic engagement and associational activity likely led to governments that were more democratic and effective.

Since then the concept of social capital has spawned many studies, including those which examine social capital in the lives of people living with AIDS (Campbell, Williams, & Gilgen, 2002), and with disability (Buckland, 1998 as cited by Van Niekerk, Lorenzo, & Mdlokolo, 2006). The study by Campbell and colleagues used a simple measure of social capital as voluntary membership in community organizations and did not explore the nature of the membership. Findings were mixed. Membership in an organization did not always lead to better health outcomes. They concluded that social capital is a complex phenomenon that needs assessment that is more sensitive. Fonchingong (2005) also used the concept of social capital to explore associational life in NWP, and found that it may be a useful concept for research in this context.

There have been several critiques and rebuttals to Putnam’s thesis. I will explore Koelble (2003) response here, chosen for its relevance to the development and post-colonial context of Cameroon. Koeble (2003) states that human cooperation can take different forms and is too complex to be distilled down into simplistic notions of how relationships affect health and democracy, as theories of social capital attempt to do. He believes that it is only through detailed and rigorous ethnographic work that a researcher can come to actually understand the particularities of a given community in a post-colonial context, and how the cultural practices of that community impact its health. Unlike Putnam's somewhat static notions of how social capital and democracy are connected, Koeble proposes that understandings must be fluid, adaptable, and encompassing of local, national and global contexts. His concern is that analyses such as that conducted by Putnam will lead to significant gaps in understanding; he calls for researchers to examine power relationships between civil society, political and economic structures in order to understand the impact on local individual and community health issues.

The second key theorist to be recognized for addressing social exclusion and social capital is Amartya Sen, an economist-philosopher who received a Nobel Prize for his work related to social justice perspectives of economic theory. His perspective is that economic and social lives are intimately connected, and most notably for purposes of this review, are related to experiences of poverty, social inclusion and exclusion, and therefore, to community health issues. Sen provides an understanding of poverty and social exclusion as "capability deprivation - that is, poverty seen as the lack of the capability to live a minimally decent life" (Sen, 2000). Focusing on poverty from this capability perspective, rather than on income or other measures that are often used is an idea that has been attractive to many in the disability field (Mitra, 2006; Terzi, 2005). There continues to be an active global discourse exploring his ideas (for example, see special theme issues of the *Journal of Social Economics* (June 2007) and *Feminist Economics* (2003).

Pertinent to the current study, critiques of the concept of social exclusion are emerging from empirical studies in Africa. For example, du Toit (2007) illustrates how it can be social inclusion that contributes to poverty and other significant problems. He states:

> More to the point, poverty results not from people's exclusion from that market but from the ways they are included. This is true not only in Ceres [the area in which his study was focused] but in much of present-day South Africa. There is a close link between inequality and poverty on the one hand, and, on the other, the historical processes of dispossession that have worked to render people dependent on the labour market in the first place … It is tempting to argue, from this perspective, that what poor people dependent on insecure and poorly paid jobs may require is not more integration, but less — strategies and resources that may help them become more independent of systems and networks in which they have little power (p 1002-1003).

It is also important to recognize the work of Martha Nussbaum, who has responded to and expanded Sen's theorizing about the capability approach. She stated that there was a need for the approach to be more specific, both conceptually and practically. She advocated for recognition of the many capabilities that are inherent in Sen's approach, and proposed ten central Human Capabilities (Nussbaum, 2003). These capabilities include several that relate to being able to participate in social groups, most notably affiliation. Nussbaum proposed that affiliation is "Being able to live with and toward others, to recognize and show concern for other human beings, to engage in various forms of social interaction; to be able to imagine the situation of another"(p. 41). Nussbaum states this capability means that society has to protect freedom of political speech, freedom of assembly, and the institutions that allow for affiliation. The second part of this capability is creating spaces for the social bases of self-respect and non-humiliation; that people are treated as dignified beings whose worth is equal to that of others. For this capability to be realized provisions of nondiscrimination based on race, sex, sexual orientation, and other characteristics are required.

There are relatively few papers addressing the concepts of disability, inclusion, and capability approaches with respect to the society and culture of the NWP. Njoh (2002) provides a brief history of formal community development initiatives in Cameroon, from colonial times through the development of the Department of Community Development in 1959 to the current situation in which the department is part of the Ministry of Agriculture and sets out policies for local projects. By examining a specific water project, he identified the significant contributions made by local residents, as well as several barriers they encountered. These barriers included paternalism, selective participation, and inter-group conflicts.

Acho-Chi (1998) stated, “There is a strong tradition of mutual assistance in the Cameroon grassfields” (p. 367); he found that local planning and participation was evident and could improve the quality of social welfare of local communities. He especially called on development planners to include those who will be affected by proposed changes ensuring that they be actively involved in selecting and managing community development initiatives. However, the cost of these allegiances also need to be recognized: loyalties to family, ethnic group, religious and political affiliations can foster competition and conflict within group membership, resulting in negative impact on the development of community structures and organizational capacity.

Establishing a group that supports PWD or persons living with HIV or AIDS requires significant vision and effort. Membership and participation mean that an individual has an affiliation with an organized group of people who share a characteristic, such as disability or HIV status, and that the individual has a "sense of being a member" of the group. The capacity of the organization has to be built gradually to allow leadership to develop and members to participate in meaningful ways. Key problems and issues have to be identified and collective action undertaken, to create change and to identify the shared values and goals on which the group is based. In the NWP, the establishment and operation of disability groups and AIDS support groups are often encouraged through faith-based initiatives and NGOs as there are few governmental supports. There are a few successful local groups that can be used as examples.

In summary, in the NWP, there are several nuanced aspects and challenges to address with respect to conceptualizing and operationalizing participation in community organizations, including the types of organizations, the types of participation and memberships, and the relationships of community organizing with health, illness and disability issues.

Participation and Involvement in Disability and Development

People with disabilities want to and are able to participate in the everyday activities of community life, including social groups and gainful employment (Alade, 2004); it is often social barriers, which prevent participation in civic life, rather than impairments in body structures, or functions (Mitra, 2006; WHO, 2002; Nussbaum, 2006; Sen, 2000).

Expectations for participation in community development programs place uneven demands on people. Those who are able to negotiate the social and physical contexts more easily (i.e., they have access to mobility, money, social support, education) may not understand the increased costs that PWD experience in attempting to engage in social participation. People with disabilities are often living in extreme poverty, and attending a meeting may require addition costs for transportation or support (e.g., someone who is blind or deaf may have to pay two taxi fares to allow a support person to attend) and the cost may mean missing a meal. Therefore, although a program may want to have community participation, it should carefully consider issues of equity and participation to prevent additional burdens for community members whose lives are already very difficult (Christens & Speer, 2006). There can be many reasons why people may not be able to, may choose not to, or may be excluded from participating in social organizations. Community leaders and organizers have to be careful and sensitive regarding what is expected within a project, and how people are supported to participate, especially if they are dealing with several impairments or challenges. Possible strategies could include ensuring that transportation costs are covered, that food and childcare are provided, and that venues are accessible and that specific issues (e.g., communication with those who are blind or deaf; accessible toilet facilities) are anticipated. For example, Van Niekerk, Lorenzo, & Mdlokolo (2006) report on the use of participatory action research in the development of a partnership project to support income generation for people with disabilities in a periurban area of Cape Town, South Africa. They found that Buckland's discussion of the links between economic and social capital and forms of participation to be useful in planning their project. Buckland believed it necessary to make a distinction between participation as contribution, where the emphasis is placed on obtaining results and on building economic and physical capital, and participation as empowerment, where the emphasis is on the process of community members' involvement and the development of social capital and sustainability (Buckland, as cited in Van Niekerk, Lorenzo, & Mdlokolo, 2006)

Programs such as the one suggested by Van Niekerk, Lorenzo and Mdlokolo (2006) might provide models for other centers who want to improve community and public health services and outcomes. Anecdotal reports are that such a program may be increasingly necessary in the urban areas of the NWP as more people live with disabilities, HIV, and AIDS. The community based rehabilitation model, which has been well established in the area for more than two decades, supports the development of disability groups. The CBR workers can assist in bringing members together and in developing organizational capacity, although this work is challenging to carry out with the minimal budgets and groups skills available to the CBR workers (WHO & SHIA, 2002). Disability groups can help people develop friendships and social connections, improve communication skills, initiate economic development programs, and take on advocacy roles in their communities (WHO, CBR Voices Part 2, 2002).

Some disability organizations choose to focus on attempting to change or influence policy development through advocacy work. McColl and Boyce (2003) examined the development of disability advocacy organizations in Canada to construct a descriptive framework that could be used to explore the workings of these organizations. They identified three ideological factors (purpose, tactics and view of disability) and two practical factors (membership and resources) which can be used to direct information gathering about disability organizations. Several key points from this study are worthy of mention: that groups may shift over time along a continuum of collaboration to confrontation; that views of disability are reflected in expectations of participation within the workings of the organization, and that views of participation in the organization may in turn reflect views of participation of people with disabilities in society more broadly (e.g., charity vs. human rights perspectives); the significant impact access to resources has on the productivity of a group and the real and theoretical connections to the poverty that people with disabilities often experience in their lives; and significantly the role of the state in shaping and co-opting DPO's goals through an array of possible actions. Organizational culture and expectations can also have significant impact on attempts at building partnerships and collaborations (Van Niekerk, Lorenzo, & Mdlokolo, 2006). These dimensions may be useful in understanding disability organizations in the NWP.

The next sections explore additional dimensions that need to be considered. These are issues of gender and sexuality, first from the perspective of women, then of men, then from the perspective of sexuality and homosexuality.

Women's issues in social life and community organizations

As in other parts of the world, in Cameroon women, including those with disabilities, are not a homogenous group; they have many and fluid identities (Kiani, 2007). They are daughters, mothers, wives, workers, neighbors, and members of social groups, amongst other roles and identities (Kiani). Health and social issues influence these identities. Several authors, including Duffy (2002), Groce and Transi (2004), and Quinn and Degener (2002), highlighted the importance of examining issues of violence, poverty, chronic noncommunicable diseases, and mental illnesses in the lives of Africa women, as these risk factors can significantly impact other health problems such as AIDS. In the discourse of international development, there has been a shift to mainstream gender in recognition that women's issues must be attended to for progress to occur (Duffy, 2002).

Alade (2004) reported on a community vocational training program for people with disabilities, where twice as many male as female participants were enrolled. There were a smaller number of women in the program, and the author suggests that it might have been due to cultural factors: "…females with disabilities are routinely married off to men old enough to be their grandfather as second, third or fourth wives in polygamous settings" (p. 146). Women with disabilities are vulnerable to sexual violence, cannot always insist on safer sex in violent situations or in other situations, and therefore may have higher incidence of HIV (Burrows, 2005; Limen, 2006; Yousafzai, Dlamini, Groce, & Wirz, 2004). Charowa (2005) reported that a study of sexual violence and women found that out of the 87.4 % of disabled women who had been sexually abused, 52.4 % tested HIV positive, and suggested that a similar situation was present in Namibia and Botswana. Hendrietta Bogopane, South African Parliamentarian, articulates an additional reality:

> It's the rumour that having sex with a virgin cures your HIV; and because disabled women are regarded as asexual, then, automatically, they are virgins - because nobody is expected to be having sex with them. Yes, the rumour is very strong and it puts disabled women at much higher risk. (Rowland, 2002, ¶ 22)

Others (Groce & Trasi, 2004) have also documented this concern; dispelling these kinds of myths should be part of community-based health education and training.

Cameroonian women face significant obstacles in fully participating in civic and daily life. Fonchingong conducted several studies about social organizations and women's groups, examining factors that influence involvement in community life (Fonchingong, 1999; Fonchingong, 2005). His work, along with others such as Endeley (2001), linked concepts of gender, community, and social capital to the NWP situation to present a picture of how women's opportunities to engage in civic life are heavily influenced by cultural norms. As Endeley (2001) reported "women, regardless of marital status, face serious difficulties in empowering themselves politically and socially, as a result of the negative portrayal of women in their cultural context" (p. 38). Issues related to women's experiences, gender relationships, and social groups also influence disability groups. Disability groups may replicate the dominant patterns of men making the decisions, and women facing social barriers and playing marginal roles. Bonnel, in discussing awareness of disability issues globally, emphasizes the importance of addressing women's roles in disability groups, reminding organizers that unless these patterns are noticed, women's contributions are not included:

> Special attention needs to be given to two social groups who are particularly neglected, namely disabled children and disabled women.…Women, who are disabled, bear a double burden and because of that are more than ever the target of exclusion, stigma and violence. However, disabled women remain invisible in all the gender action plans included in Poverty Reduction Strategy Plans. (Bonnel, 2004, p. vii)

Disability, HIV, and AIDS affect women and men's roles in community organizations differently, along the continuum from clinical manifestation through societal role. However, few studies appear to have examined these issues in detail. In sub-Saharan Africa, women now surpass men in prevalence of HIV infection (Joint

Program, 2005). Females with disabilities suffer the double stigma of gender and disability, and with addition of HIV, discrimination becomes threefold. When a child in a family has a disability, it is a female issue because the care often falls to the mother; if a spouse or parent has a disability, it is often a female issue as women are expected, and often want to, take on the role of caregiver. Despite the prevalence of HIV infection among women with disabilities, access to voluntary counseling and testing facilities and centers is often limited. Anecdotal reports indicate that these are also issues in NWP, although it appears that no studies or reports are available to provide specific details.

Men's issues in social life and community organizations

In the NWP, there are strong cultural perceptions about male roles which can be very prescriptive (Maynard, 2004; National Centre on Fathers and Families, n.d.) and limiting as personal communications with several men and women from the province have demonstrated. Disability activists (e.g., Nyincho, 2006; Bih, 2006) are challenging the general perception that men with disabilities should not or cannot become husbands or fathers. Although AIDS education has to be done sensitively, it does present an opportunity to discuss issues such as patriarchal privilege in marriage, the role of fathers in sexual education of children, and the broadening male social roles.

Other gender and sexuality issues

Community groups can also be influenced by other factors; the practice of exclusionary actions also manifests in other gender and sexuality related issues. For example, homosexuality is not legal in Cameroon (Amnesty International, 2006; Behind the Mask, n.d.), and there are few public discussions about homosexuality or transgender issues apart from negative religious statements and occasions when people are arrested on legal charges. Many health and social service professionals do not want to discuss homosexuality, stating that it does not exist outside of larger cities, and many believe that homosexuality is not an issue in the NWP. Several people have stated that there are no homosexuals in the NWP, which appears to be a reflection of the lack of public acceptance and discourse rather than a reflection of reality. Others have indicated that historically, there was a place for homosexual men in the inner houses of the *fons* (chiefs), but I have not yet found any of this literature. In some parts of Africa, research indicates that gays and lesbians believe they are not vulnerable to AIDS, as it is perceived as an illness that affects only heterosexuals because almost all of the public education is targeted to heterosexual populations (Epprecht, 2007). This may also be the case in Cameroon. Virtually no information is available about transgender people in Cameroon. Therefore, public health educators have to consider carefully how to discuss information that would be appropriate for gay men, lesbians, and transgender people.

Implications for current research

The study reported on here needs to be seen as one piece of work in a much larger tapestry, one which has local, national, regional and global connections. Even though this study was centered on the local context, it was situated within national and global stories of how the world is dealing with disability and AIDS. The roles of the government and state also have significant impact in shaping and potentially co-opting DPO’s goals through an array of possible actions. This review of studies and authors who have explored related issues reveals that any given situation (and therefore, studies of that situation) should not been seen as static. A study can only represent one interpretation of a moment in time, and must pay attention to how a group has shifted over time along a continuum of collaboration to confrontation with other groups and with the state.

This review also shows that a case study must draw from several fields to construct an understanding of the situation, and that this research can, and should, be collaboratively done with people who are living the situation. Views of disability are reflected in expectations of participation within the workings of any given organization, and these views of participation and disability in the organization may in turn reflect views of participation of people with disabilities in society more broadly (e.g., charity vs. human rights perspectives). This review highlights the need to include the impact of poverty on the workings and productivity of each group for its relationship with health and illness issues, and for the real and theoretical connections to the poverty that people with disabilities often experience in their lives.

The Need for Strong Organizational Responses: Transformative Practices and Research

There is a growing understanding of the African situation with respect to AIDS and disability, which includes recognition and a shift to a human rights orientation to research. There are indications that disability communities, rehabilitation programs, and health services are not as well prepared to deal with HIV and AIDS issues as they could be (Groce & Girois, 2007). Many people in this context believe that people with disabilities are the deserving objects of charity and that considerations of rehabilitation and work are not necessary (Alade, 2004). Perhaps this is one reason why there appears to be a significant shortage of relevant and effective interventions for people experiencing both disability and AIDS in sub-Saharan Africa generally (Secretariat of the African Decade, 2006), and in Cameroon particularly (personal communication, Dr. M. Mayer, July 2006). These are large and daunting challenges, but change and improvement are possible.

In light of all of these factors in the Cameroon context, initiatives to improve the lives of people living with disabilities or HIV and their families, and which aim to improve health outcomes, must therefore explore and develop programs which address the complex intersections of health, gender, ability, income and access to resources through community organizations and social inclusion. To provide background information about possible organizational development and linkages, this section briefly explores the literature that reports on the challenges and the optimism that transformative practices are possible.

The large INGO, Handicap International, has developed and provided disability programs in several parts of the world for many years, including in public health organizations, and is increasingly finding that HIV and AIDS issues need to be addressed in these programs (Thune, 2003). Recently, they initiated a new campaign to increase awareness and resource information and to reduce the vulnerability of disabled people to the impact of HIV and AIDS. People with disabilities will be actively included in developing and promoting HIV and AIDS policies, programs, information and services (Secretariat of the African Decade, 2006). Ncube (2005) conducted a study on capacity building in Mozambican disability organizations, and their relationships with Northern funders. He identified several factors that led to more successful outcomes including shared experiences, control of the local organization by local people rather than strong control by outsiders and transparent operations.

The development of educational and resource materials have been recognized as key interventions in HIV, AIDS and disability work (Burrows, 2005; Groce et al., 2006; Neuve, 1995; Thune, 2003). These materials can include written, audio and video resources that give practical, basic information about conditions and situations, legislation, policy and rehabilitation strategies, community organizing, and a variety of other topics, and can be targeted at DPOs or for service and public health providers. At the 2007 meeting of the Africa Campaign on Disability and Rehabilitation in Cape Town, Groce and Girois (2007) summarized several resources that are either currently or soon to be available, including a *Resource Manual for Disability and HIV/AIDS Training* (DPSA), *Manual for getting AIDS information to adolescents with disability* (Rehabilitation International); *Guidelines for including Disability in National AIDS Programs* (Groce/WHO/ILO), *What you need to know about HIV/AIDS: a guide for people with disabilities*, *Disabled people's Organizations and the AIDS Epidemic: What DPOs can do to lead the fight against HIV/AIDS for persons with disabilities.* Groce and colleagues (2006) also suggest that AIDS programmers can conceptualize programs as being at one of three levels with respect to addressing the needs of people with disabilities:

Type I: Inclusion as Part of General HIV/AIDS Outreach with No Adaptations

Type II: Minor Adaptations to General Programs that Foster Inclusion

Type III: Disability Specific Programming

The recognition that this work is important, yet quite difficult, is vital. HIV and AIDS and disability present a double strain, and service providers and educators are challenged to develop responses and programs that take these considerable demands into account. Without minimizing the importance of including PWD in AIDS education and outreach as promoted by Groce et al. (2006) and ensuring that PWA are not excluded from disability communities, as described in the previous section, it is important to not add additional demands on people who are already struggling to survive.

Individually, living with a disability and living with AIDS can each present very difficult issues to deal with, and together, they can be extremely taxing, further limiting an individual or family's ability to participate in community interventions. Significant poverty is a reality for many of these people and organizational responses need to recognize these substantial daily challenges.

At the January 2007 Strategic Planning session of the Africa Campaign on Disability and HIV & AIDS in Cape Town, Groce and Girois (2007) summarized the outstanding research needs in this field. They identified that much more needs to be understood about sub-groups of disabled persons, if and how training is effective with different stakeholder groups (consumers, families, service providers, administrators and governments), how HIV affects persons with preexisting disability, and how best to construct, implement and evaluate programs. In addition, they identified needs in the area of consistency in language and attention to privacy issues in social contexts that place high value on collective life.

The members of the disability and rehabilitation communities need to be involved in whatever process is developed to improve the disability system to ensure that their needs are being met and the priority of the projects that are taken on. Ndumbe and colleagues (n.d.) outline four possible types of reform that have relevance in this context: (a) improving dialogue structures and increasing funding mechanisms to support citizen involvement, (b) the creation of a new structure to promote dialogue in districts and provinces, (c) changing the culture of the government so that citizen and community involvement is seen as an integral part of the policy making process, and (d) promoting associational networks and supporting capacity building in voluntary organizations to further develop civil society. Elements of each of these reforms should be included in any proposed model for a disability system: funding and opportunity for civic engagement needs to be provided to people with disabilities, dialogue between different levels and types of providers needs to occur, changing the receptiveness of the government to citizen input, and establishing and supporting professional and self-help associations needs to open up. Community mobilization, for example through local njangi groups, has been used to promote health behaviors (Babalola et al., 2001), and could be used to shift community attitudes towards disability. The importance of local groups with administrative oversight at a broader level, ongoing training and professional development of the staff, as well as outside donor agency financial support are important factors for sustainability in this context, and it is crucial that more research be conducted to understand the similarities and differences between Northern and Southern contexts (Alade, 2004; Eliason, 1999; Ncube, 2005). As a representative from Cameroon said at a previous meeting of the group that was considering the International Convention on Disability: "There is an enormous gap between developed and developing countries…So some provisions must be open in nature, allowing developing countries to support such provisions as well" (DPI, 2006, ¶ 12).

It is important to emphasize that change must occur gradually, and that this study represents one part of a longer-term vision, one that will take many years to achieve. The ongoing analysis should address questions such as: How do the services available in NWP compare to other provinces and to other African and low-income countries? In this province, known to the government as a seat of political resistance (Gros, 1995), is the significant lack of disability and rehabilitation related programs, research or policy in the province a reflection of general lack of services and programs nationally, or a more targeted response by the central government? How have the few successful programs managed to grow and develop? These are also key questions that need to be answered to truly understand the current situation.

In addition, efforts must be sustained to prevent disabling illnesses and injuries. The significant changes that have occurred in the past several decades in other parts of the world with respect to disability prevention, health promotion, disability, and rehabilitation issues remind us that change is possible, and that people with disabilities can be included in communities when there is a convergence of political and social will. Disability and rehabilitation systems should gain more prominence as the NWP continues to develop and grow. A systematic examination of how people with disabilities or HIV and AIDS are actively contributing and engaging in processes of social change in their communities can contribute significantly to these longer term social change efforts.

Implications for current study

Several studies illustrate that disability organizations need skilled community leadership (McColl & Bryce, 2003; Van Niekerk, Lorenzo, & Mdlokolo, 2006), and so exploring notions of leadership is a relevant area for further study. The studies are also of the view that participation can be seen as empowerment, and are emphatic that this process takes time. Therefore, the current study attempted to consider how organizations have perceived the relationships between time, participation and empowerment. The importance of enough time for the development of relationships and understandings of the issues also has implications for the study itself. Although the study took place over a relatively short period (several weeks), it occurred within the framework of a longer term initiative.

Theoretical Perspectives

Embarking on public health, community health, and community based research requires studies to be grounded in a theoretical perspective or perspectives that are appropriate to the nature of the problem, the questions being asked, the goals of the research endeavour, the logistical requirements of the field, and the orientation of the researcher(s) involved. There are a number of theoretical perspectives that could be used in this study; the complex adaptive systems approach was chosen as being most appropriate.

Complex Adaptive Systems Theory

This study used the case study method to allow for the development of a detailed description of disability organizations and organizational capacity, specifically applied to the context of how these organizations responded to the AIDS situation in Bamenda. The theoretical perspective used had to be able to assess the fluid and complex natures of the organizations and their responses. Therefore, the study used the complex adaptive systems theoretical perspective, which originated from other fields (Begun, Zimmerman, & Dooley, 2003; Brown, 2006; Holden, 2005; Olney, 2005; Rowe & Hogarth, 2005; Kernick, 2002; Stackman, Henderson, & Bloch, 2006; Trochim et al., 2006) and is gradually being applied to public health (Leishow & Milstein, 2006). This theory was used to explore and explain how the capacities of disability groups have been influenced by the emergence of HIV and AIDS in their communities, what links between these influences and organizational actions and outcomes emerged, and to identify the relationships between individual factors, organizational factors, and social factors. Complex adaptive systems theory is compatible with ecological models of health, which may be more familiar to some public health practitioners (Trochim et al., 2006).

Public health is gradually embracing systems theories such as complex adaptive systems theory. For example, the American Journal of Public Health devoted a 2006 issue to deepening understandings of systems approaches. In that issue, Trochim and colleagues (2006) point out that much of the public health arena is composed of various types of very complex systems (for example, emergency response systems, and the field of health and tobacco); therefore complex adaptive systems theory has significant theoretical potential in the field. Key features of the complex adaptive systems approach, also known as complexity science, are (a) connectivity and relationships, (b) feedback and communication, (c) diversity and self-ordering within organizational systems and (d) a recognition that although history is relevant, it cannot actually lead to prediction regarding organizational outcomes.

In keeping with complex adaptive systems theory, relationships were a key focus of the study. Relationships are seen as forming an entangled web involving many agents and forces, both internal and external to the system under study (Olney, 2005), which corresponds well to what is already known about the complexity of communities and disability groups in the NWP. The investigation of disability groups focused on the organizational relationships with each group, and to some extent, between the groups and systems outside of it.

Complex adaptive systems theory recognizes that there is constant change, adaptation, and evolution of the system in an unpredictable, nonlinear manner, and leads to both large and small effects (Olney, 2005). Therefore, in studies such as this one, documentation needed to be made of a wide range of elements, including events which might have initially been seen to be of lesser impact, but which over time became more significant. Participants were asked to reflect on how groups have changed and adapted over time, particularly as HIV and AIDS have become more prominent in the community.

This study was intended to explore and document emerging patterns and ways in which the grassroots community-based disability groups organized themselves to respond to HIV and AIDS issues. The theoretical perspective of complex adaptive systems was well suited to this goal, as it recognized that systems display patterns of behavior that reflect the ability of the system to organize itself using *self-ordering rules* (Kernick, 2002) through a bottom up process. Complex systems are not controlled centrally, rather they are self-organizing (Trochim et al., 2006); this is a concept which, in the Cameroon context, may not be in alignment with attempts to create and enforce centralized government policy perspectives and therefore warranted further exploration. A system's organizational rules emerge over time, as the system goes through a complicated process that includes relationships, influences, and feedback loops internally and externally. Managers and others cannot predict or force change in a system but can try to influence it through awareness of how the system operates (Olney, 2005).

Feedback loops are crucial for complex adaptive systems. Olney (2005) states that feedback loops “carry information, material, and energy among agents in the system. If feedback loops are well designed, they facilitate change and adaptation of the system” (p. S59). Research should look for instances of how information and energy is shared within components, and within the system as a whole, and how these loops support or inhibit adaptation of the organization.

The outcomes of a complex adaptive system cannot be predicted because new patterns emerge from the complex activities of the system. Therefore, timelines for organizational activities must be flexible; there can be a range of unexpected developments that influence plans negatively or positively. Study participants can be asked to reflect on previous and current goals and timelines in their organization, and specifically to identify how expected and unexpected events have influenced the group’s responses to HIV and AIDS.

According to complex adaptive systems theory, it is important to explore the boundaries of the system, as that is where significant communication and adjustment takes place. Boundaries are permeable and are key parts of the system, deserving of attention in a study of the evolving system. Attention should therefore be paid to how each group delineates itself, how it communicates with other groups and with the broader community, and how it sees itself in the social context. In addition, the complex adaptive systems perspective assumes that patterns of behaviors in the complex system can be observed and named. A paradox of complex adaptive systems is that, while they can be dynamic and changeable, they also can demonstrate systemwide patterns of behavior, generated by variables known as attractors, which will be repeated at many levels of the system and can be difficult to alter. Attractors may be written organizational priorities, seasonal events like year-end fiscal budgets, or more erratic variables like the day-to-day needs of the clients served by a community-based organization (CBO) (Olney, 2005, p. S59). In a complex adaptive system, different attractors stimulate similar responses and those responses will be observed at different levels and parts of the system. These patterns are known as fractals [Jackson, 2003, as cited by Olney, 2005]. Although behavior is never exactly the same, similarities will occur across parts of the system, across systems, and across time (Olney, 2005, p. S59). For example in a study such as this one, attention should be given to identifying and making visible attractors and patterns of behavior that impact on responses to HIV and AIDS issues.

Finally, although in research on a complex adapting system there needs to be a focus of attention on one system (such as an individual, a community based organization, or a country), this theoretical perspective recognizes that patterns of behavior may repeat themselves at different levels of a system and across systems, and that the boundaries, set for a particular study or project, are arbitrary. To make any study manageable, limits need to be identified at cellular, organism, individual, community, national or international levels. Reflecting the concept of fractals, different disability groups were seen as part of a broader system in the analysis.

Trochim and colleagues (2006) point out that common misconceptions of systems theory are that it does not include reductionism or positivism (it does) and that it is not scientifically rigorous (it is) (Trochim et al.). They also report a concept-mapping study, which resulted in eight key *rules* and 100 statements, which they suggest could be used as a framework for understanding the challenges facing public health systems, and subsequently posted a website to allow ongoing learning and discussion about systems theory in public health (www.greaterthanthesum.com). The system is recognized as being more than its parts, and therefore, simply understanding the component parts will not be enough to show how the whole system works. Therefore, research using this approach has to find ways and methods to address and include the complexity of the relationships between the components with each other and with the system, and of the total system to construct a fuller picture.

Review of Relevant Methodologies

This section provides an overview of the need for community-based research when conducting research related to disability issues or AIDS issues, provides a consideration of several possible methodologies that could have been used, and ends with a rationale for the use the case study approach.

The need for community-based research

In the fields of disability studies and of AIDS practice and research, there have been strong calls for collaborative, community-based approaches to research that include a gender analysis (Albert, 2006; Duffy, 2002; Ulin, Robinson, & Tolley, 2005). To be credible in the current environment, research seeking to understand disability organizations need to involve PWD and DPOs in most, if not all, stages of the research process. For example, one of the key recommendations arising from the large Knowledge and Research Programme on Disability and Health Care Technology in Britain, reflects much of the other literature that has been discussed in this review of the literature: that international development programs addressing disability and AIDS issues need to discard charity and expert models in favor of a broader perspectives of capacity and empowerment:

> …programmes should adopt a social model understanding of and a human rights approach to disability. Greater priority should be given to encouraging and funding those projects which clearly have the active involvement of disabled people and their organisations, and can demonstrate, through their presentation of research methodology and project monitoring and evaluation, their capacity to deliver high quality and sustainable action-research. (Albert, McBride, Seddon, et. al. (2002) as cited by Albert, 2006, p. 2)

Public health, rehabilitation and social science researchers also promote this perspective (Bishop, 2005; Minkler & Wallerstein, 2003; Trentham & Cockburn, 2004). It is therefore necessary for studies to use community-based approaches such as community-based participatory research, which include people with disabilities and disability organizations in meaningful ways in the research process whenever possible. Not doing so weakens the credibility of the research and risks presenting results that are not useful, applicable, or accurate for the situation. In the current study, community involvement and participation was addressed using an advisory group, by asking people directly involved and affected by disability issues to participate, and by locating the study in a specific community context. Engagement of the community is further discussed in Chapter 3, Methodology.

Possible methodologies

Because this was an exploratory study with a relatively small population (disability organizations), qualitative or mixed methods approaches were more appropriate than primarily quantitative methods. A quantitative study, such as a survey using a standardized or preexisting questionnaire would most likely miss crucial information or not have sufficient participants to reach statistical significance.

There are many possible approaches to qualitative inquiry, using a variety of methods including phenomenology, grounded theory, ethnography, and case study (Creswell, 1998). Phenomenology focuses on the meaning that a particular phenomena has for an individual or group of individuals. It typically uses interviews, perhaps scaffolded with other information. This approach was not the best choice for this study as the research problem and questions were not particularly focused on meaning or uncovering individual understandings, and the primary use of interviews would not provide a broad enough collection of information to understand the responses of disability organizations.

Grounded theory aims to generate a substantive theory or model, primarily using interviews, although other forms of information such as documents can also used (Creswell, 1998). Grounded theory uses a systematic process of open and axial coding, and usually results in the development of a visual model of the categories that emerge from the examination (Creswell). Although this could be a possible approach for this type of study, the development of a model was not the key objective of the study. Because of its rigor and process, grounded theory is also less accessible to community members, and could potentially be difficult to explain to people in DPOs in Bamenda as an approach to research.

Ethnographic approaches focus on the behaviors and culture of a group of people (Creswell, 1998). It requires long periods in the field, and places the researcher to some extent, as the interpreter of the cultural experience of those under study. This could be a design that would be useful to address the current research problem and questions, but logistically was not feasible, as it would have required an extended stay in the field, which I was not able to do.

Case Study Research

The process of focusing a study on a particular person, program or organization is referred to as case study research. Case studies of various kinds are common in health care and public health research. The summation or written report of the findings in this tradition can also be referred to a case study (Stake, 1995). Stake made the distinction that not everything is a case, as cases are specific, have limits, are bounded by certain parameters, and can be considered a complex and functioning entity (Stake, 1995, p. 2.) He also distinguished intrinsic from instrumental case studies. Intrinsic cases are those that are examined primarily for what they tell us about their specific characteristics, such as a client who is particularly challenging or a specific agency that has a unique location or position in the landscape of its community. Instrumental case studies are those that allow for some general understanding of a problem or situation; by looking at a particular case, ideas can be generated which might apply to other cases. Instrumental in this context refers to the fact that the study of the case is instrumental to understanding other cases, such as other organizations or other programs (Stake, p. 3). Collective or multiple case study is the term used when more than one case is considered within one study.

Stake (1995) stated that case study research is not sampling research, as the researcher’s first obligation is to understand thoroughly the particular case or cases under consideration. Although he did provide some guidance on sampling process, and encouraged researchers to consider carefully sampling issues when they have that option, he also stated that when there are choices, much of the selection process does come from the researcher's understanding of the goals of the study, the issues under consideration and the availability of cases. According to Stake, the primary criteria used in selecting cases are to maximize what can be learned and to choose cases that are relatively accessible and open to inquiry to allow the learning to occur. Stake encourages the researcher to gather as much information as possible without disturbing the ordinary activity of the case, while recognizing that there are times when the researcher does affect the workings of the case. Case study is not intended as a method to test out interventions.

Case study approaches attempt to capture the multiple realities that emerge from the various actors, they are approaches that accept that there can be diverse and even contradictory interpretations of what is happening. This kind of approach is needed for exploratory research in an area with several difficult issues, such as was the situation in the NWP. Creswell (1998) stated that he tends to use unusual cases in multiple case studies, using maximum variation as a sampling strategy to gather divergent perspectives. Theory can be used to plan and inform the research design, and can also be brought in as the perspectives on the case takes shape (Creswell, 1998).

Case study research uses several data sources such as interviews, participant observation, and document review to allow for as complete a picture as possible, and emphasizes triangulation and member checking as key aspects of the research process (Creswell, 1998; Stake, 1995). The researcher collects, organizes, analyses, interprets and reports on the case, which requires significant time and attention for data organization and reflection on what is being learned. Details of how this method was implemented in the study are described in Chapter 3.

Blending Case study with community based research

Case study was an appropriate method for this study as it allowed for the collection and use of data and information from several sources, and was completed in an appropriate time. In contrast to research approaches which rely solely on interviews, it allowed data to be collected from several sources including key documents and photographs. For example, in this study, there were relevant organizational materials and newspaper articles that were used, and not including them would have weakened the richness of the study. In contrast to ethnography, it did not require prolonged immersion in the field. For example, Stake suggested that the data collection for many case studies can be conducted within a period of several days or a few weeks (although the writing up may take longer).

It is important that the process and the results of community-based public health research be relevant to the people who are living with the problems under consideration. Case studies are compatible with community-based research as the process can be transparent, and in addition to academic papers and presentations, the products can take the form of narratives or stories, which are more accessible, and therefore useable, by the members of the community who are interested and who have contributed to the research.

Summary

This review of the literature has summarized key issues with respect to the fields of disability, rehabilitation and community organizations. The concept of disability continues to evolve as new models and understandings increasingly take into account social and contextual factors. The review of the literature indicated that there are very few research studies or services available locally to address disability and rehabilitation issues, including those of DPOs.

Case study methods have been used in many health and other research studies. This review provided an overview of complex adaptive systems theory as a theoretical foundation for case study research and indicated the appropriateness of this theory to case study research in Cameroon. Although few previous studies have used this combination for research in the Cameroon context, there were indications from other studies that it was a complex environment, and that this would therefore be a fruitful approach to use.

The next chapter shows how the information obtained from the review of the literature was used to structure, plan, and analyze the study. Following complex adaptive systems theory and case study methods, the study collected information about a range of information regarding understandings of impairments, and of organizational capacities to deal with disabilities, HIV, and AIDS within the context of the province. Chapters 4 and 5 then present the results and discussion of this approach. The discussion in Chapter 5 relates the results of the study to the literature above.

CHAPTER 3: RESEARCH METHOD

Introduction

Chapter 1 provided an overview of the study and situated it in context. Chapter 2 reviewed the literature to explain how this study meets a need and has the potential to add to the scholarly discourse. This chapter now describes the research design in detail, including information about how the case study approach was an appropriate form of inquiry to use to address the problem, the research questions, select the participants, collect data, and to plan for analysis.

The purpose of this case study research was to assess the organizational capacity of community-based disability groups in Bamenda, Cameroon to deal with the AIDS epidemic. The research explored, conceptually and practically, how community-based disability organizations have responded to AIDS issues in the past, what has been effective and less successful in these responses, and outstanding needs and recommendations for further development. In recognition of the fact that men's and women's experiences and needs can be diverse, and that women are often marginalized in community groups, the study included a gender lens as part of the data collection and analysis (Diaz-Granados, & Stewart, 2007; Van Koughnett, Day, & Watson, S., 2007).

The findings may increase understandings of how DPOs and AIDS support and service organizations, as well as other groups and individuals, can be involved in community health initiatives for HIV and disability prevention. In addition, the study has provided recommendations for future research.

The main research question is: How are community-based disability organizations responding to the AIDS pandemic in Bamenda? Additional questions include: How have disability groups in NWP developed their organizational capacities to address HIV and AIDS issues (and by extension, what has been missing or prevented)? What contextual factors influenced organizational capacity? How could disability groups in NWP develop their organizational capacities to address HIV and AIDS issues? From the perspective of DPOs, what could AIDS service organizations do to support the development of capacity within disability organizations to address HIV and AIDS issues?

Research Design

The choice of research methodology was selected to fit with the purpose and questions of the study. Because this was an exploratory study, and a detailed picture of a complex situation was desired, qualitative research was used. The use of several forms of qualitative data collection allowed for deep and rich information about perceptions of the organizational capacity of disability groups to respond to the AIDS pandemic. In Chapter 2, I provided a theoretical literature review and description of why case study approach was appropriate for the current research problem and study. In the next section, I describe how this research design was carried out.

Case Study

The multiple case study approach allowed for the use of several (primarily qualitative) information sources. The case study approach encouraged detailed and in-depth collection of information from a number of sources including interviews and focus groups with individuals and organizational representatives; documents such as newspaper articles, organizational brochures and event programs; field notes collected by the researchers; and simple quantitative data (e.g., number of groups and meetings, number of members). A multiple case study of disability organizations in the urban Bamenda area was appropriate to obtain a picture of how these organizations were responding to the AIDS situation. The case study focused on community-based organizations, including NGOs and private organizations, which were dealing with disability issues, and to some extent the individuals who participated in these groups. The case study is represented in graphic form in Appendix C. A detailed plan of activities prepared for the study is in Appendix D.

It is important that a community-based research approach was used for this research. Therefore, a small advisory group of collaborators was established. The advisory group assisted with answering instrumental questions about how to collect and analyze information obtained through interviews, focus groups, document review, and observation.

Role of the researcher

The role of the researcher in case study research is to collect, analyze, and interpret information in such a way that a coherent story of the case and the issues under consideration emerges. It is somewhat like doing a complex puzzle – pieces have to be collected and fit together to create a picture of a particular situation. The researcher has to be adept at organizing a large body of information and selecting out what is most pertinent.

As an outsider to this situation, and one who comes from a very different context, I had to be aware in conducting this study that my presence and perspective influenced the information that I obtained. As a white, North American professional, my location is significantly different from those whom I was working with. I chose this topic because although I do not live in the NWP, I have visited several times recently over the past five years, including two visits in 2008 (two weeks and four weeks in duration), and also have prior experience in the area. I am in daily contact with a number of people in the province by email and phone.

During this time, I have developed working relationships with several disability and rehabilitation organizations, and was asked by them to work on research projects. In this study, I needed to work with a research assistant and a community advisory group to increase my understanding of the issues and nuances that arose.

As I planned and embarked on the study, I believed that my past involvement would increase levels of trust and openness, and improve my credibility with potential participants. This did appear to be the situation; many people whom I approached to participate readily agreed and thanked me for carrying out the study.

However, I am also aware that there can be many complex interpretations and possible misunderstandings of who I am as a researcher, and why I was doing what I was doing, which could influence potential participants' involvement or statements. Because the current study was one of several projects that I was involved with in this area, one challenge was to be to be clear that I was interviewing or talking with them specifically for this study. I believe I was able to do this well with all participants, as it was always clearly described as a PhD study that I was conducting, and was not a project that other organizations were involved in directly. In the remainder of this chapter, I also refer to my role in relation to specific decisions and tasks.

Research Assistant

Due to the location of the study and the fact that I did not live in Bamenda, a research assistant was employed for eight months over the course of the study. This person assisted in data collection, particularly with focus groups when I was not available to conduct these in person in Bamenda (these interviews and focus groups are discussed in more detail below). The research assistant was a young Cameroonian man, who has previous experience with community-based research and who had further training from me to conduct focus groups for this study, including in ethical practices. The research assistant signed a pledge of confidentiality (Appendix E).

Training of the research assistant included reviewing the research protocol in detail together; providing him with several background documents including a copy of the case study text book which was used for the study (Stake, 1995); conducting a focus group together with detailed feedback afterward; specifically reviewing ethical requirements and how the requirements for this study were similar to and different from other studies in which he had participated; and problem solving of anticipated issues that could arise as the study unfolded. I worked closely with him throughout the study, so that together we ensured consistency in the ways that the interviews and focus groups were conducted. The research assistant was also available to work with the Advisory group as necessary.

Advisory Group

The need for a community-based Advisory group in this study was an ethical issue as well as being methodological and practical. Ethically, there is increasing belief that research with disability communities and African communities needs to use participatory and collaborative approaches (see, for example, *Development in Practice 17 issue 4-5*). Constructing an advisory group for a study like this address, in part, issues of power and the risk of the outsider researcher not collaborating with the community to conduct research that assists the community with social change. A group of advisors also has the potential to strengthen all stages of the research process by providing insightful information about how the research can be conducted, including possible solutions to difficult logistic situations, and by assisting with interpretations of problems that occur.

Although I had intended the advisory group to be composed of approximately 5–10 people, some of whom were people with disabilities or leaders in the community, in the end there were primarily two people who took on this role. Due to the difficulties encountered with this aspect of the study (described in the next paragraph), and the fact that overall the study proceeded relatively smoothly, I did not feel the need for further efforts to work with other advisory group members. Members of the advisory group did not meet together throughout the course of the study; rather, I consulted with them individually. Their primary role was to provide guidance to the study. I turned to them particularly when I had concerns about my interpretation of the information I was gathering and when I had some difficulties contacting key informants.

The small number of advisory group members was due to several reasons. Potential members of the advisory group were invited through existing contacts in the area. I asked people with significant experience in the disability community, and who had an interest in the study and in research generally. Several of the people who might have been advisors were involved in the focus groups or interviews, and it did not seem appropriate to include them as advisors also. It was more challenging to find potential advisory group members than I had anticipated, as some candidates were not available due to time constraints and communication difficulties. Some of the potential advisors did not feel that they had sufficient background with this kind of study to be involved, and therefore declined. I had also intended that at least two of the advisory group members would be people who were HIV positive in addition to having another form of disability, but I had difficulty locating people with at least some expertise in conducting research as well as these characteristics. In addition to people with disabilities, members of the community advisory group could have included a local fon (chief), health professional, social service worker, or government representative. It was difficult to communicate with these people, but I would have pursued their involvement if the study had been more problematic.

The two active advisors were voluntary members of the study, and signed a letter of agreement and confidentiality about their involvement, after they had detailed discussion with me (Appendix E for Letter of Information and Agreement).

Interviews and Focus Groups

The presidents of four DPOs were invited to participate in this study, and all agreed to do so. Other executive members and, in some focus groups, general members of the group, joined them. Focus groups were used to collect information, as from previous contact with some of the groups, a preference had been expressed by group members that the executive members of the group be interviewed together in a study like this, rather than interviewed individually. As anticipated, these participants indicated that they felt more comfortable participating with colleagues, that there was shared learning which arose from the focus group discussions, and that a consistent perspective about the group was provided. Two focus groups were held for three of the organizations, and three focus groups were held for one organization for a total of nine focus groups. Two additional interviews were conducted, one with the president of one group, at his request. I conducted eight interviews with key informants.

Participants and Sample Selection

Participants and Sampling procedure

DPOs and community groups, associations or organizations that have been established to serve people living with disability were included in this study. Inclusion criteria were:

(a) The group had a focus on disability or rehabilitation issues, or both;

(b) The primary operations of the group took place in the Bamenda city area (could have included suburban areas such as Ntarinkon, Mendankwe).

(c) At least one year since formal date of group formation;

(d) At least 10 active members, and that the group was engaged in some tangible form of active work or program; (This criterion is somewhat arbitrary, chosen to weed out the groups which appear to be started with minimal membership and activity, simply with hopes of obtaining funding from charitable organizations.)

(e) A significant number of the members were people with disabilities, although the leadership did not need to be. The actual number of people with disabilities and the types of impairment and disability were not predetermined;

(f) The representatives were able to communicate in English or Pidgin.

Disability groups which met the inclusion criteria were included based on availability of representatives, access, and willingness of the leadership to participate in the study. Attempts were made to have participation from a variety of groups, both specific disability groups (e.g., blind or visual impairment) and pan-disability groups, as well as women's groups, religious, government supported, and nondenominational disability groups. Several different groups were invited to participate in the study, as described below. Using my existing knowledge of disability groups, convenience sampling, and word of mouth techniques were used to identify and select groups. Contacts were asked to identify groups meeting the inclusion criteria. A list of recognized disability groups was also obtained from the Ministry of Social Affairs. Either the research assistant or I obtained contact information for groups and made initial contact with them in person, by telephone, or in writing (using the study Information Letter). Group members in leadership positions were invited to participate in individual interviews and focus groups. Generally, these people had been with the group for a minimum of one year. No coercion or pressure to participate was used.

One inclusion criteria was that the participant needed to be able to speak and understand English or Pidgin English (i.e., not only a local dialect) to allow me to communicate directly with the participant (I am able to communicate in Pidgin) and to analyze the results. As necessary, the research assistant assisted with carrying out or interpreting both the English and the Pidgin focus groups, as some of the questions were difficult for participants to understand even though their spoken English was at a conversational level. Most residents of Bamenda do speak one or both of these languages, and often both English and Pidgin are used in the same conversation. Because there were no comprehensive studies of disability in the province to draw from, it was difficult to determine how representative informants were relative to the overall disability population. There are studies related to HIV prevalence and AIDS programs, but not about HIV and disability. Because this study did not intend to collect information specifically about HIV status, it was not possible to compare information about HIV status from these informants to the general population.

In addition to the members of the community organizations, eight key informants from other parts of the community were interviewed to provide different perspectives on community organizing in this area, health and social service practices, and other key topics that assisted me in understanding the situation. Two of these key informants were also members of the advisory group. The general questions, which were asked of these key informants through semistructured interviews, are included in Appendix F; the specific questions were adapted for each interview depending on the expertise of the respondent and the responses that they provided.

Sample size

Because there was no published documentation of the number of disability groups in this city at the time the study was planned, it was difficult to determine what a reasonable number would be to include as a sample. However, it was known that there were several disability groups of various kinds. In qualitative research, the number of participants is also determined by the situation and the nature of the information that is obtained. Therefore, the number of groups was not predetermined, but three groups were considered the minimum number. Four groups met the inclusion criteria, and all four participated in the study.

Recruitment

Through previously established contacts and word of mouth, I approached potential groups and key informants to provide initial information about the study. On previous visits, many people had expressed appreciation that I have made a commitment to these issues and interest in this type of research had been established, and so recruitment was not anticipated to be difficult. However, I took every precaution to ensure that groups participated voluntarily and understood the purposes of the study. Written information about the study was distributed to potential groups prior to in person meetings (Appendix G). I had anticipated that group leaders or members who heard about the study and who were interested in participating could either contact me directly, contact the research assistant, or convey interest to the research through a third party. In fact, I knew all four groups and no additional groups emerged during the course of the study. When a group expressed interest in participating, a meeting was held to discuss their involvement in more detail, and to obtain informed consent (Appendix H).

Ethical Considerations

Based on recognized codes of research conduct, including those of the African Studies Association (ASA) for researchers (African Studies Association, 2005), the following ethical principles were implemented during this study:

Informed Consent, Confidentiality and Respect for person (autonomy)

All participants were treated as autonomous and their choice to participate in this study respected. I sought to obtain the full voluntary and informed consent of all the people participating in this study; persons who were not willing to provide consent would not have been allowed to participate in the study.

All participants were asked for their informed consent prior to commencement of interviews or focus groups (Appendix H). The informed consent form was reviewed with all participants in detail, by the research assistant, with particular attention for any participants with lower literacy skills. Participants were clearly informed that they were free to decline further participation if they so chose at any point during the interview or focus groups, and that they would not be coerced into further participation. None of the participants left the study part way through.

Instruments to obtain informed consent that were appropriate to the cultural context of the research were developed by consulting with the research assistant (who had previous experience conducting research in this area). The ASA states, “Researchers should be cognizant of the real difficulties of securing informed consent in contexts of uneven power relations and should develop strategies or techniques for ensuring that such consent be entirely voluntary”. This guideline was followed, and the importance of voluntary consent was reiterated at the beginning of every focus group and interview. Institutional Review Board protocols were followed and permission was obtained from Walden University (#03-24-08-0309730), the National Ethics Committee of Cameroon (No.052/CNE/DNM/08), and the University of Toronto (#23008), because this is my institution of employment.

The underlying assumption of this study is that the principle of confidentiality would be respected. Participants were informed that, if they wished, their confidentiality would be fully respected, although, in keeping with the principle of autonomy and the fact that many of the participants could have been social activists who wanted their efforts to be attributable to them, they were given the choice of the level of confidentiality they would like. The consent form was provided in writing and verbally reviewed with all participants before conducting interviews and focus groups to ensure that concerns about the impact of this research were addressed. The importance of confidentiality was discussed with participants prior to starting focus groups.

Based on previous experiences, I initially anticipated that some participants would want to have their real names used, as they are proud of their work and are looking for opportunities to let others know what they are doing. This was the case with some participants. The participants' preferences for confidentiality were discussed as part of the consent process. Although some focus group participants expressed the desire to be quoted by name, not anonymously, after discussion with experienced researchers and the dissertation supervisor, I decided to provide participants and groups with pseudonyms, particularly in order to protect the confidentiality of those who requested it. The two exceptions were the key informants who requested that they be quoted by name, and this was agreed to as both are published authors, and appeared to be very aware of what they were agreeing to.

Non-maleficence (do no harm)

This study did not expose participants to any risk of physical stress or physical harm. Recounting stories of organizational practices were not anticipated to be emotionally stressful, and this appeared to be the case, as there were no instances of visible distress. In keeping with the guidelines of the ASA, I tried to be conscious of present and future risks, which this research may pose to participants and subjects. As a researcher, I have tried to be "well-informed about possible wider political, cultural, economic, religious, and social contexts of the work in order to ensure that the research will not put collaborators, research subjects, students, or assistants at risks that they do not have the information to assess" (ASA, 2005). I was committed, as far as possible, to respect, in these terms, prevailing local practices of collaborating, hiring, training, and using assistants and subjects, and to pursuing nondiscriminatory practices whenever possible.

Beneficence (do good)

I will attempt to maximize potential benefits to participants by sharing the findings of the study with stakeholders (i.e., disability and AIDS programs, Ministry of Social Affairs staff, other relevant ministries and relevant disability, women's or health organizations, others with an interest in these issues) who may make changes to improving the capacity of disability groups in the NWP to respond to the AIDS pandemic. A small token of appreciation in the form of a gift, not of great monetary value, was provided to each participant or each group, to acknowledge their contributions to the study.

Reciprocity, Equity, and Justice

The ASA states "members of the Association have a responsibility to support and encourage the professional activities of African collaborators and colleagues and, when appropriate, to build collaborative research and other professional programs with them. Our endeavors should build the capacity of our collaborators and their institutions through research programs, training, and professional development." The current study was one aspect of a broader research initiative. The participants will have the opportunity at some point in the future, to consider, in depth and detail, issues related to conducting research and education with people with disabilities in their local environments as well as more broadly. The focus of this study was on the development of organizational capacity, but through the process of reflecting on and sharing information about the research topic and research process, the individual capacity of participants was probably improved. No one under 19 years old was included in interviews for this study.

As much as possible and feasible, I explained fully the nature of this research collaboration, including issues of authorship, access to data collected, and intellectual property rights. Most participants did not ask about these issues, and as time was usually an issue, they were not discussed in detail. I anticipate that there will be further discussion in the next stages of dissemination of the results.

Open and Full Disclosure of Objectives, Sources of Funding, Methods, and Anticipated Outcomes

The ASA requires that its members be committed to open and full disclosure of their work to all cooperating African colleagues and institutions, graduate and field assistants, and the subjects with whom they work and study. Each of these should have full access to information about the objectives of the work, the sources of institutional support, sponsorship, other funding, the methods employed, and the anticipated outcomes of the research or professional endeavors. This information will be made available for anyone involved in the study who requests it.

Furthermore, the ASA points out researchers need to be thoughtful and critically aware of funding related issues, including the interests of funders, and uses of the outcomes of the study. This study was primarily self-funded. It was not funded secretly, will not be used for covert purposes, and will not have potentially negative consequences to the African colleagues involved. I have not, and will not, accept funds or sponsorship that benefit the sponsoring organization or government in self-aggrandizing ways, or that could compromise the integrity of my scholarly endeavors by influencing results of research, professional work, or the content of presentations. This research could not be reasonably construed as sustaining or strengthening the powers of Cameroonian governments in ways that would perpetuate violations of human rights.

Deposition of Data and Publications

Researchers should return the results of scholarly activities to the communities and the country in which research was conducted, including preliminary reports, papers, dissertations, and all forms of publication. The communities studied or engaged in the research should receive at least, a summary of the research and its findings in a form and language they can understand. This guideline will be followed as much as possible following the completion of the study. Preliminary reports were provided to several community members, and a clear language summary of the study will be provided to participants within six months of completion of the dissertation.

Another guideline put forward from the ASA, which may be in conflict with the ethical practices of the institutions with which I have primary affiliation (Walden University, University of Toronto) is that eventually and to the extent feasible, the researcher also should return copies of primary data sets and relevant notes to a responsible archive or depository in the country of research so that the data and materials can be made available to indigenous researchers. This is not currently possible in the Cameroon context, so I will hold the collected data in a secure location for the customary five-year period.

The identities of the persons who provided information will be kept confidential or disguised unless they have given permission for their identities to be revealed. The ASA also states that "Scholars and professional Africanists should make every effort to see that their publications or reports are not exploited for inordinate profit and that they are made available at charges that are reasonable to scholars, libraries, and higher education institutions in the appropriate African country/ies" (African Studies Association, 2005, ¶13). As stated earlier, and as possible, the results of the study will be made available to the appropriate colleagues and organizations in Cameroon with identities disguised.

Preservation of Cultural Heritage

Researchers in Africa have a particular responsibility to respect and protect the cultural heritage of the people in Africa, particularly in light of the growing illegal international trafficking in African art, archaeological artifacts, and other cultural materials (ASA). I will make every effort to follow this guideline. The research does not directly involve cultural artifacts, and the removal of archaeological artifacts is not part of this research.

Academic Freedom

As members of their communities, researchers in Africa have the rights and obligations of other citizens. The ASA states: "[Researchers] measure the urgency of these obligations in light of their responsibilities to their subject, their professions, their students, their colleagues, and the university or professional associations to which they may belong. As citizens engaged in professions that depend upon freedom for their health and integrity, Africanists have a particular obligation to promote conditions of free inquiry and the principles and public understanding of academic freedom." The current research was conducted in keeping with the principles of free inquiry and academic freedom.

Data Collection

I aimed to conduct 10 to 20 individual key informant interviews, and focus groups with at least three DPOs. As stated above, eight key informant interviews were conducted and focus groups were held with four DPOs. The assistance of a trained research assistant was used. The focus groups were conducted by the research assistant and me together, or by the research assistant alone. The research assistant was physically in the room with the participants, and I participated by telephone, using the loudspeaker function on the phone. I coordinated with the research assistant to be available for any questions that arose during the time that the RA was conducting a focus group alone. I conducted all of the key informant interviews alone.

Informed consent was reviewed and obtained from all participants. Interviews and focus groups were audio recorded, transcribed verbatim, and then analyzed (see next section on data analysis).

Cultural Awareness

I have had experience with Cameroonian culture, which assisted me to be able to conduct these interviews and focus groups in ways that were culturally sensitive and in a manner that attempted to put participants at ease to participate. Despite my previous experience, there were some instances where questions did not appear to be well understood. The research assistant and one of the advisory group members who were consulted about this concern stated they felt that many of the members of the DPOs were not familiar with being interviewed, and so the underlying purpose and intent of this type of questioning would not be familiar or fully understood by them. Throughout the study, I continued to try to expand my understandings of the context through readings about

Cameroon and through discussions with individuals who have been or are presently working or conducting research in Cameroon.

Participant Observation and Field Notes

During previous visits to the area, I had the opportunity to meet with several disability groups, and to talk with many people with disabilities in various contexts. In every instance, I have been warmly welcomed and invited back. Due to the timing of the study, I was not in the country during the months that I was collecting information, but I was familiar with many of the locations in which the focus groups were taking place, and many of the participants had met me several times in the past, so they were familiar with my goals, intentions, and interests. I anticipated that the prior relationships with some groups would allow me to establish a better rapport with them, and this appeared to be the case. The one group with which I was not familiar was also the focus group that was the most difficult to get into in-depth conversation. I kept field notes throughout the study to capture details of the situations (Stake, 1995) and my reflections of what was occurring.

Background Information

A brief profile on each participant was collected to assist with analysis and presentation of the findings. This information was collected immediately after the consent was obtained, prior to participation in the interview or focus group. Please see Appendix G for the background information form that was used.

Focus groups

Focus groups are discussions held with a small group of people. In this study, focus groups were composed of people who are members of the same group (usually the executive members of a disability group). There are two other reasons why focus groups were used. I anticipated that some participants might feel more comfortable participating with other members of their own group rather than alone, and focus groups can also elicit different kinds of information than individual interviews, as one person's comments can prompt a response from others in the group that might not arise in individual interviews. Both of these situations were apparent in the focus groups conducted in this study. Details of the focus groups are presented in Table 1.

Table 1.

Focus Groups

Group pseudonym	Number of focus groups and interviews	Participants	Gender of participants
Confidence Group	Two focus groups	President, Secretary and Treasurer	Two women, one man
Strong Group	Three focus groups (two solely with female members), one interview with President	President, Vice President, Secretary, three members	Three women, three men
Reliance Group	Two focus groups, one interview	President, Vice President, Sighted Secretary, one member	Four men
Unity Group	Two focus groups	President, Projects Officer, two Members	Four men, one woman
Summary:			
Four DPOs	Nine focus groups and two individual interviews	17 people (four presidents, seven other executive members, six general members)	Six women, 11 men

Focus groups took place at a location that was mutually agreed on by the participants and the researchers, and usually was the location in which the group regularly met. Information about the study was provided either prior to the meeting or at the beginning of the meeting as members were arriving. There was opportunity for discussion of any questions that participants had before consent was obtained.

As described above, focus groups were conducted by me and a trained research assistant, following guidelines suggested by Ulin, Robinson and Tolley (2005). We were well prepared with appropriate materials. The room was set up with seating and the audio recording device. Refreshments were available for some sessions, however, some groups requested that the funds that would have been used to purchase refreshments instead be donated to the group, and this was agreed to, so refreshments were not always present.

Chairs were arranged in a circle, either around a table or not, depending on the room. Participants were greeted as they arrived, given further information about the study and then consent was obtained. They were invited to complete the background information form and to have some refreshments (if they were available). Assistance for completion of this form was provided if requested.

We reviewed the purpose of the study, encouraged confidentiality and invited any questions that participants had. I followed the guided semistructured format, as described in Appendix I, adapting it for the specific circumstances and the group. The sessions lasted between 60 and 90 minutes. Open-ended questions were used, with probes such as "In what ways …", "Please say more about…" and "There is no hurry. Take a moment to say more about…". Silence was acceptable, but not often evident. Note was made of any questions that participants appeared to have difficulty with, so that revisions could be made for future discussions.

For informants in the focus group, attempts were made to ask them to discuss their thoughts and opinions with the others present, however, responses were generally made specifically to the questioner. At the end of the discussion, we thanked the participants, reminded them of how the information was going to be used and encouraged them to contact the research assistant if there were additional comments that they wanted to make later. The gift to the organization was made discretely. A written record of the details of each meeting were made.

Semistructured in-depth interviews

Eleven people were invited to be key informants, seven men and four women. Table 2 provides details of the key informants. Most of the interviews took place after the focus groups, with the intention of obtaining information that would help to understand further the points made in the focus group discussions. I selected potential informants based on previous knowledge of who was working in the area or familiar with disability issues, and from suggestions from others involved in the study, including the research assistant. Specifically, I asked most of the key informants and some of the focus groups whom I should speak with to get more information. All of the men who were invited agreed to participate. At least two of the men could be considered people with disabilities.

Of the four women who were invited, only one participated. Two women initially agreed but then did not participate, and did not provide reasons. One, an experienced community worker who is the parent of a man with a disability, did not respond to invitations after the initial acceptance. The other woman was an employee of the Ministry of Public Health who agreed to participate several times but was never available at the agreed on times. I stopped trying to conduct the interview after about eight attempts. The third woman did not participate, stating lack of time. The fourth woman agreed, but due to telephone network problems and power outages on several days when we were trying to hold the interview, and her busy schedule for finding other times, she finally decided to provide her comments by email.

For key informants, participation in the study consisted of a 30–90 minute tape-recorded semistructured interview. The location of the interview was agreed on by the participants, and could have been the person's home, a public location, or a private office space. Most interviews took place with the participants in their office space. I spoke with them by telephone. Participants were informed about the study, given an opportunity to ask any questions, and provided consent prior to the interview commencing. Participants were then asked to respond to the questions in Appendix F. Interviews were audio recorded, and then I transcribed them verbatim to increase validity of findings and to allow for detailed coding.

Table 2.

Key Informants

	Interviews with key informants (pseudonyms unless indicated) * denotes actual name	Gender	Description	Date of Interview
1.	Mr. A.B.	Male	Employee of large health care organization; familiar with disability issues	August 5, 2008 August 19, 2008
2.	Mr. C.D.	Male	Director of programs for a large INGO which funds rehabilitation programs	August 4, 2008
3.	Dr. Lotsmart. Fongong*	Male	University Professor, expert in civil society organizations in the NWP	August 16, 2008
4.	Mr. Colbert. Gwain*	Male	Community based AIDS activist and author in Bamenda	August 29, 2008
5.	Mr. H. L.	Male	Leader in the disability community in Bamenda	August 14, 2008
6.	Mr. O.P.	Male	Community member with involvement in AIDS issues	August 15, 2008
7.	Mr. S.A.	Male	Employee of Ministry of Social Affairs; familiar with disability issues and disability groups	September 20, 2008
8.	Mrs. R. T.	Female	Did not respond to requests for interview	Not completed: Initial request made July 14, 2008; follow-up for 3 weeks after
9.	Dr. U.V.	Female	Employee of Ministry of Public Health; Initially agreed but did not respond at agreed on times despite several attempts by phone and email	Not completed: July 23 – August 15 2008
10.	Mrs. I. J.	Female	Recommended by a key informant; Stated she was interested by lacked time to arrange interview.	Not completed: August to October 2008
11.	Mrs. W. W.	Female	Provided information by email	Email and attempts to do interview by telephone during period September 28, to October 24, 2008

Documents

Documents used for the study included organizational brochures or other materials, newspaper articles, and other documents that were publicly available. These documents were obtained through visits to the organizations, through the internet, or through other sources. These documents were analyzed through the coding process and added to other sources of information in the study.

Data Management

Qualitative research generates large amounts of textual and other information which needs to be organized in ways that allow the researcher relatively easy access. In this study, a combination of electronic and paper tools were used to manage the data. QSR NVivo Version 7.0.281 (QSR, 2007) and Excel software programs were used as finding aids to assist with retrieving information. A data collection form was developed to record information gathered in meetings (Appendix J).

A field notebook was kept to log a summary of the specific dates, times, locations, and forms of information collected, and this information was transferred to electronic files. Digital audio recordings collected by the research assistant were encrypted prior to sharing with me. Information collected in electronic form (e.g., field notes, interview transcripts) was stored on my laptop computer (password protected) with back-up on a data memory flash disk. Hard copies of information that were not in the public domain were stored in a locked box. Hard copies of other information from the public domain (e.g., organizational brochures, newspaper articles) were stored in folders that could be made available to community members who may want to review them.

Data Analysis

We wrote up observations and field notes regularly following focus groups or participation in other key events of relevance to the study (e.g., a public meeting). Stake (1995) promoted the use of detailed physical, social, economic, and cultural descriptions, to allow the reader of the case study to develop a clear picture of the context: “The entryways, the rooms, the landscape, the hallways, its place on the map, its décor…balance between the uniqueness and the ordinariness of the place. The physical space is fundamental to meanings for the most researchers and more readers” (p. 63), and he therefore advocated the use of a check off procedure, which allowed for some coded-data descriptions. These components were included in the data collection form, which we used to summarize meetings, interviews and focus groups (Appendix J).

In research, procedures for dealing with discrepant cases need to be anticipated and procedures developed ahead of time regarding how they will be dealt with. This case study explored the responses of disability groups in the Bamenda area to HIV and AIDS issues, and we expected that there would be variations in how different groups responded. Therefore, part of the analytical process involved identifying discrepancies to try to capture and understand why these responses had emerged in different ways. Complex adaptive systems theory requires the researcher to particularly attend to and reflect on what has led to different responses so that the underlying issues can be better understood, rather than reduced.

The software programs used in the analysis were Microsoft Word, Microsoft Excel, and QSR NVivo 7. Microsoft Word is a commonly used word processing program, which allows for large amounts of textual information to be retained and organized. It has word search functions that assist with information retrieval. We used Word for typing up some field notes, and preparing transcripts of interviews and focus groups. Excel was used as a cataloging system for information collection. QSR NVivo (2007) is a widely used software program that I used to assist with the data analysis. Systematic coding was done using both *a priori* coding lists and open coding to allow emergent themes to be identified.

Using NVivo, categories and themes were developed from the codes. Both holistic analysis and embedded analysis were used (Yin, 1989 cited in Creswell, 1998, p. 63). Fourteen main categories (*nodes*), each with subcategories (109 in total), were identified. I also identified approximately 50 *free nodes*, categories that were useful for analyzing the information gathered, but which did not relate specifically to the central research questions.

Each group was provided with a summary of the information describing their group, and requested to review the description and make changes as required. Due to the length of the draft report and the lack of availability of the members of the advisory group, many were not able to review the first draft report. A second opportunity was provided when the results were more complete and feedback was incorporated into the final discussion. The findings will also be discussed with as many participants as possible before a final clear language summary version is circulated to the community.

Summary

This chapter described the research design, including the case study approach as an appropriate form of inquiry to use to address the problem statement. Keeping in mind ethical considerations, the chapter has included how the study was carried out, detailing the participants, the sampling strategies, data collection methods, the inclusion of a community advisory group, and how analysis was conducted. The study was focused on understanding the capacity of disability organizations to respond to and cope with the HIV and AIDS situation in the NWP of Cameroon, and was conducted by a nondisabled, Canadian academic researcher. Therefore, issues related disability research work in an international development context are pertinent.

Based on many years working in to improve the lives of people with disabilities and to support DPOs, Albert (2006, p. 11) provided five lessons from the Disability Knowledge and Research Programme which he and his colleagues put forward as crucial for those who are undertaking research studies such as this one. I think they provide key points to summarize how these methods were carefully chosen as part of social change research, and so I address each one in relation to the current study.

1. “Disability is not about health status, it is about discrimination and systematic exclusion. It must be seen and addressed as a question of fundamental human rights.”

This study addressed fundamental questions of inclusion and discrimination by focusing on the complexity of how disability organizations were responding to the AIDS epidemic, or how they were excluded from fully responding. Access to HIV and AIDS information, testing and treatment (when needed) can be seen as a human right, which should be available to all people, including those with disabilities.

2. “Meaningful research to support sustainable development demands that disabled people and DPOs take a leading role and not simply be ‘included’ or ‘consulted’.”

This study is part of a larger educational, program development and research initiative in which PWD are leaders and facilitators, and which is consciously addressing strategies for sustainability. In this study, the participants with disabilities and the advisory group provided meaningful suggestions and direction to me for this study and for future research. Because of the nature of doctoral research, wherein the doctoral candidate must show individual research capacity, there is more of an orientation in this study towards consultation of disabled people and DPOs than full participation. However, the nature of the study will contribute to the evolving awareness of the research related resources and challenges of this local context, and how they affect development work.

3. “Development agencies themselves must set an example of good practice by drawing on the experience and expertise of DPOs in both the North and the South.”

This research focused on the experience and expertise of DPOs, in a way that has not yet been done in this province.

4. “DPOs need support which builds and sustains their capacity and not the capacity of the large corporate INGOs that all too often act as intermediaries.”

The current study, and the broader initiative of which it is a part, are intended to support capacity-building efforts of the grassroots DPOs in the NWP.

5. “Governments and development agencies need urgently to tackle the problem of policy evaporation which has meant that good policies on mainstreaming disability in development remain almost entirely trapped on paper.”

I hope that the study process itself, and having the results of this study available in several forms will encourage governments and development agencies to look more closely at their policies around mainstreaming disability issues. Participation in the study has assisted the participants through the opportunity to reflect on, and shift, their understandings of how disability organizations can contribute to ongoing AIDS efforts.

Based on the approach detailed above, the next chapter describes the results of the study. Four DPOs are described, and an overview of the political and social contexts in which they operate is provided. Several themes became evident through the analysis. These themes are presented in Chapter 4 and then discussed in Chapter 5.

CHAPTER 4: RESULTS

This study explored the organizational capacities of Cameroonian disability groups to deal with the AIDS epidemic. Using a multiple case study approach, the report describes four DPOs in the city of Bamenda and how they have responded to HIV and AIDS in the recent past. The study questions included identifying the factors that enabled or hindered the development of organizational capacity and responses. In doing so, the study identified how the groups developed collectively and individually, and illuminated the contexts in which they operate.

The process by which the data were collected, analyzed, and recorded is described in detail in Chapter 3. Interviews and focus groups were conducted with a total of 25 people, 17 representatives of DPOs and eight others. Documents, newspaper articles, and field notes provided additional context. The information gathered was entered into the software program NVIVO (QSR). Analysis was conducted using this software as an organizing tool. As analysis progressed, several organizational categories emerged: (a) The sociopolitical and chronological context; (b) Descriptions of the four DPOs that met the inclusion criteria; and (c) Five key themes that elucidate the organizational capacity of the DPOs.

The first section of this chapter describes the context within which these responses have taken place. It illustrates how disability groups have emerged in the city and presents a brief timeline of relevant key dates and events.

The second section of the chapter focuses on the four groups that met the criteria for inclusion in this study. All agreed to participate and all included men and women in their membership. The four groups were given the pseudonyms Confidence, Strong, Reliance, and Unity. The descriptions in these two initial sections are included because this information emerged directly as a result of this study and was not previously reported.

The final section of the chapter analyzes the five key themes that emerged with respect to organizational capacity and responses to HIV and AIDS from the perspective of complex adaptive systems. These themes are (a) the delineation of AIDS related responses in these groups, (b) marginalization and poverty limit capacity and responsiveness, (c) the lack of health education and understanding limits the capacity to respond to the complexity of AIDS, and (d) connections and relationships impact the capacity to respond to HIV and AIDS. The final theme, the forms of feedback and communication within and external to the system, is used to summarize the chapter. However, before presenting the results, issues of quality are discussed.

Issues of Quality

Every research study requires a plan for ensuring that the quality of the study will be high, and that the study protocol will be monitored and implemented as intended and approved. To maintain the study quality, the following steps were taken:

1. Regular communication and reports with the committee chair and the people who were acting as advisors occurred throughout the study.
2. Appropriate, frequent, and adequate training and supervision of the research assistant prior to and throughout the time of the data collection.
3. Systematic record keeping of all participants, including phone numbers (including an alternate if possible), mailing address, and residential or work location, as possible, in case subsequent contact needed to be made.

4. Consistent data collection forms were used throughout the study.
5. Records were backed-up on a separate computer disk with password protection immediately after data was collected (for electronic files) or by photocopy (hand written notes), and stored in a locked location separate from the main location.
6. Care was taken with data entry to avoid mistakes; consultation with a local expert or research assistant or advisory group occurred when there were questions about language.
7. Most interviews and notes were reviewed within 12 – 24 hours from the time of collection so that they could be clarified as soon as possible if necessary and appropriate.
8. Confidentiality of the data was maintained by restricting access to the completed data collection instruments and electronic storage media. Only myself and the research assistant had access to the data.

The Context of Disability Associations in Bamenda

The capacities and responses of the organizations to HIV and AIDS cannot be understood without an understanding of the environments and circumstances within which they operate. This section provides a brief overview of these contexts.

A starting point to understanding the context is a chronology of relevant events over time. A timeline of key events and dates related to governance, disability, rehabilitation, HIV and AIDS is presented in Table 4. This timeline become visible from this study, and illustrates that the current disability groups emerged over the past decade. Therefore, it is a fairly young community. This decade has also been a time of political, economic and health system change in the country (Cameroon Ministry of Health, 2006; Fongwa, 2002; Cameroon: Free ARV drugs, 2007; Republic of Cameroon, 2006) and has seen a significant increase in HIV incidence and prevalence (Measure DHS, 2004; Provincial Technical Group North West, 2006).

Table 3.

Chronology of Key Events Related to Disability, Rehabilitation, HIV and AIDS in the North West Province of Cameroon

1998	Health sector reform initiated as a result of 1988 evaluation (Ndumbe et al., n.d.) There does not seem be much attention to disability issues or rehabilitation services. Christian Fraternity forms sometime around this period. Confidence Group forms.
1999	1999-2009 declared The African Decade of Disabled People Strong Group forms.
2000	Major study conducted to compare disability experiences in Australia and Cameroon; illustrates the significant environmental limitations imposed on people with disabilities in Cameroon (Allotey et al., 2003; Reidpath, Allotey, Kouamé, & Cummins, 2001)
2001	Unity Group forms. September: Health system reform formally adopted and launched with "The Health Sector Strategy"(Ndumbe et al., n.d.)
2003	Reliance Group forms. Number of adults and children living with HIV and AIDS in Cameroon: 560,00 (low estimate = 390,00, high estimate = 810,000); Percent seropositive in NWP 5 % in rural areas, up to 30% in some groups in Bamenda (UNAIDS/WHO Epidemiological Fact Sheet – 2004 Update., p. 5)
2005	Reliance Group, CBC-HB and PTG carry out one of two phases of HIV and AIDS sensitization project in the 5 subdivisions of Mezam. This is first project to integrate disability and AIDS in the Bamenda area. The second and third phases were not funded so they were not completed.
2006	January: First forum for Mutual Health Organizations held to consider "health risk sharing programs" health insurance (Yufeh, 2006). January: Government announces HIV screening tests will be free for vulnerable people, including pregnant women, children under 15, school children and students, patients suffering from tuberculosis (the main opportunistic infection linked to HIV), and people in prison. It appears that no special provisions were made to include people with disabilities or to train AIDS workers on disability issues. May: ARVs to be available at no cost (Cameroon: Free ARV, 2007) July: 2 year Closing the Gap project begins. August: First Bamenda Conference on Disability and Rehabilitation, brings together many disability advocates and allows for a forum for information sharing. .
2007	DRELA forms August: Two Closing the Gaps workshops held. 1) frontline workers and representatives of disability groups and AIDS organizations, and 2) with key stakeholders from rehabilitation and health organizations. August 2007 Bamenda Conference on Disability and Rehabilitation. One of the key note speakers addresses HIV and AIDS in disability.
2008	March: 2 day Closing the Gap Train the Trainers workshop in Bamenda, with representatives from several organizations from around the province. April: Coordinating Unit of Disability Organizations officially launched. Aims to coordinate the advocacy efforts of DPOs. June: Confidence Group conducts first testing event in conjunction with PTG. 13 people of 85 (15%) tested were found to be HIV positive. Although this was not a systematic survey, it reflects a high level of prevalence in the population. December: International Day for People with Disabilities celebrated; Bamenda Conference on Disability and Rehabilitation

Bamenda is known as a centre for activism and civil engagement, with many small NGOs, CIGs, and associations, but relatively few large INGOs. The perception of the area as being politically active was evident in many of the focus group and interview discussions in the study. For example, Colbert Gwain, an experienced community activist, stated:

> Basically Bamenda is a civil society, and ah, so many people are excited about what it means, and ah, they go on to do what they believe, and then, ah, they just need mobilization …and then they go ahead, and do what [they want], they don't wait for central authority (Gwain, August 29, 2008).

Some participants mentioned that many large international NGOs and donors engaged in development work either have withdrawn from working in Bamenda or do not enter the area to begin with, because the city of Bamenda, and the province generally, have been seen as being unstable with an unreliable, unpredictable infrastructure, and lack of support from the central government. One key informant, Fongong, stated, "they [the international NGOs] are accountable to the taxpayers of the country that these NGOs come from….and people tend to not be very sure that they will be able to carry out activities as planned…. But it is red tape all over the country" (Fongong, August 16, 2008).

In this context, it is difficult for smaller, local NGOs and CIGs such as DPOs, to become established. It can be especially challenging for groups engaged in advocating for political or structural change such as those addressing human rights issues, political change, and social reform. Fongong stated:

> But, on the other hand, the other CIGs that are formed not on an ethnic basis, these are those that pressure and ask for true social, economic, and political change..…It is difficult for these organizations to develop into NGOs because they are hardly approved, the government will not easily approve these organizations, especially those who are fighting for rights, social [issues], raising the issue of social discrimination and such. Those ones do not easily get permission from government, and any assistance, technical assistance, which government is supposed to give to these groups, these ones do not get.
> And so they are hardly registered, they are really small, they don't get a lot of funding, because they are not toeing the line, they are not operating within the context in which government wants…. But if these CIGs are formed just for development, like, for improving agricultural, for improving bee-farming, the government will assist them by sending the technical workers of the ministries to go and assist them…So, I think the relationship with the government cannot, it is not smooth, there are instances where the relationships is good, there are some where it is bad, so it is not, you can not describe it as good or bad all the time.(Fongong, August 16, 2008)

For residents of Bamenda generally, membership in community-based associations is vitally important and deeply valued. Many people are members of one or more *njangi* groups (local savings and loans associations), church groups, or sporting clubs. Often formed along ethnic lines, njangi also serve a strong social function. Membership in associations such as njangi or church clubs can be perceived as being motivated by an individual's personal, social, and economic gain, rather than for collective social goals. Njangi groups do not tend to be involved in advocacy or social change work, but can be a venue for those wishing to carry out community education.

Tensions between the goals of individual citizens, and the goals of groups and associations were evident in participants' discussions about how associations develop and operate in Bamenda. These tensions include the differences between working for personal benefit as compared to the social good, the challenges regarding how information is obtained, shared and used, and the positive and negative effects of a range of economic and political factors on group development. The challenges faced by emerging DPOs reflect these tensions. Organizations try to balance the individual goals of members (many of whom are living in extreme poverty and want to increase their personal income) with the collective goals of advocating for social change, while also being mindful of the strong influences and constraints exerted by government and religious bodies. These issues are further discussed in the themes discussed in the third part of this chapter.

Compounding the difficulties for group development in the area, it became clear through this study that there is no readily available public listing of health, social services, and related services. One government representative stated that there was a government office that maintains a list of registered associations and CIGs, but it was not easily available. I was able to obtain a handwritten copy of the organizations dealing with disability and rehabilitation in the province from him. The list was written out by hand because, I was told, photocopies were not allowed. Others I talked with in the study did not appear to be familiar with how to obtain this list.

Participants stated that there is very little coordination or accountability of services and programs generally, and this includes disability, rehabilitation, and AIDS work. There are no publicly produced telephone, community resource, business, or organization directories. As a result, duplication of services occurs in some areas, because providers are not aware of opportunities for collaboration and coordination of their services (or perhaps do not want to collaborate). At the same time, other needs remain unmet. In this study, one way that this lack of coordination was evident was that many of the participants did not know about or did not want to discuss the activities of other disability groups in the city, and were only superficially aware of the work that other health, AIDS, and social service organizations engaged in. This lack of coordination appears to make it difficult for groups to refer their members to other organizations for needed services, and for interagency collaboration to take place.

For example, several participants from the disability associations displayed considerable lack of awareness and knowledge of HIV and AIDS organizations in the city, or how to find out about what AIDS related services were available to their members. One of the leaders who is well known in the disability community and who was involved with an AIDS awareness initiative three years ago, indicated he was not aware of what kinds of support were currently available to people living with HIV, and did not mention any government funded programs:

> Well, I cannot say much about the support group program. I know that it is under the canopy of, ah, Baptist Convention. That is where they are, they are employed there, they do some kind of activities, I don't know much. I don't know much about them, but they are under the canopy of Baptist Convention. (Mr. H.L., August 14, 2008)

Perhaps some of this wariness about sharing information is warranted. It is widely known that leaders at all levels often mismanage funds. Stories of government officials losing money that should have been spent on government services and programs came up in most of the discussions and in several newspaper articles that were published during the time of the study. For example:

> We also deplore a situation where those who manage Cooperative Societies and Unions today bought their way to the helm and once there, all they do is how to recover their money… We now have about 3,000 CIGs in the North West doing very little yet receiving funding. (Mbah Christopher Mongwe, General Manager of the NWCA as quoted in the Cameroon Tribune, July 24, 2008)

Another example of mistrust occurred in one interview while we were discussing why a particular program was not continued. The conversation reflected an attitude that was prevalent in other discussions with participants, but this participant was the most explicit:

> L: Did they tell you why they (Ministry of Public Health) were not funding it again?
> Mr. H.L.: No, it is just the mafia. I can say, that one is just a kind of a mafia. You know, Cameroon is what it is, so I don't want to think that the rest of the money went into individual pockets.

And a little later in this interview:

> L: They did not give you any specific reason, why it was not continuing?
> Mr. H.L.: No specific reason, no specific reason, whether they had already spent the money…but the money had been preserved already. (August 14, 2008).

This participant was careful not to accuse any particular ministry or person, but clearly suspected that funds were misspent several times over the past few years.

The pervasive suspicion that leaders will take off with funds also extends to disability organizations. It is commonly believed that many small associations and organizations are formed by people who are looking for some quick money by taking advantage of local and international interest in vulnerable populations – they collect membership funds, grants, and financial donations, and then disappear, leaving their membership with no resources to clean up the mess which is left behind. This tactic can be particularly evident with respect to people with disabilities and people living HIV and AIDS, as both groups are often seen to be especially needy and appealing to public sentiment, effectively garnering generous donations.

As a result, groups have tended to keep to themselves, not trusting other groups and not wanting to share information. When I asked for more details about the history of groups from Miss C. P., who has been a leader in the community for at least a decade, she stated:

> In short, I cannot say anything concerning any group. I would like to talk much about the group that I am concern. I don't want to stain the image of everybody. As you are working with them, you will keep on discovering everything for yourself. So, ask me questions concerning my own group, I will talk much on my own group. (Miss. C. P., July 2008)

This tendency towards isolation appears to be changing. In April 2008, the Coordinating Unit for Associations of Persons with Disability was officially launched, after several years of planning and organizing. Its goals include education and the creation of awareness on the status and rights of persons with disability, acting as an umbrella organization to other groups working in the domain of disability, empowering member groups by building their capacity to better manage their affairs; and promoting good governance by fighting mismanagement in funds meant for the interest of disabled persons (Constitution of Bamenda Coordinating Center, 2007).

This young association has not had the opportunity to engage in many activities, but it does appear to be having an impact on the disability community. Mr. H.L. talked about the gains that have been made in the past few years as the legitimate groups are starting to band together to strengthen their presence and prevent fraudulent disability organizations from developing:

> In the past, I would say in the past ten years, it was not like this [*meaning it was not collegial*]. But as time involved, now like this, it is of great significance, because at least we live in unity with the other associations. But the problems is that, the only problem we had was just that, there are some people who come under, there are some people who formed associations in the name of disabled people, who ended up in suitcases. (Mr. H.L., August 14, 2008)

In summary, despite the many challenges and the general lack of governmental support, the dearth of activity that disability groups have shown in the past, and the inability of groups to grow and develop, it appears to be a more optimistic time for disability organizations in Bamenda. Respondents from all four DPOs talked with pride about their organizational and collective achievements and their hopes for the future. Respondents reported more gradual social acceptance of persons with disabilities. Groups are managing to sustain themselves, and have been able to launch and maintain successful projects. There is a movement towards more inter-association collaboration, with what appears to be increasing levels of trust and coordination between some groups. The next section describes the four groups in more detail.

The Disabled Peoples' Organizations

Although the four organizations included in this study are all DPOs, they each have unique characteristics. The information gained from the focus groups and interviews allows for a description of each the groups. These descriptions are presented below, along with a summary of the groups' involvement in activities related to HIV and AIDS.

Confidence Group

Confidence Group formed as a CIG in 1999, and became a formally recognized association in 2007. The stated purposes of the group are empowerment and information about disability rights, improvement of social integration of persons with disabilities and those who are disadvantaged, and spiritual and religious evangelism. The group has several specific objectives, which include vocational training, education and advocacy about disability rights, the development of self-reliance, and community development. Christian evangelism is a large part of the group's work.

There are 13 executive positions in this group. Membership is open to men, women and children who have physical or visual impairments as well as to people who face poverty or other social disadvantage. Members do not have to have a disability. The group has approximately 50 members in Bamenda and about 175 members in other areas in the province. Monthly membership meetings are held in Bamenda, and the fee is 200 CFA ($0.50 USD) per year. Most of the operating funds for the organization come from sales of goods produced, memberships, donations from the public, and external grants. There are funding relationships and sponsorship for the organization from external agencies. The two primary funding partners are Christian organizations in the USA.

From the focus groups, it was apparent that the Confidence group allows for discussion in the group if members raise issues related to HIV and AIDS. The leadership stated that they aim to sensitize members on general issues of HIV and AIDS, including prevention, voluntary counseling and testing, care, and support, but have minimal training themselves with respect to how to talk about or carry out these activities. The group carried out a one-day screening for HIV event with the support of the Provincial Technical Group in the Fight against AIDS in July 2008 in Bafut, several miles outside of Bamenda. Thirteen of the 85 (15%) people tested were found to be HIV positive (personal communication, Ms. C. P., September 1, 2008). No details were available of who attended, how they were recruited, the types of participants' disabilities, or if follow-up counseling was provided.

Strong Group

The Strong Group was formed in December 1999. The group was founded on the principles of self-governance; it is a group of persons living with disabilities, for people with disabilities, and managed by people with disabilities. It was formed with the vision that disabled persons should be included in community development work. The group is nondenominational and nongovernmental. The purpose of the group is to empower people living with disabilities within the whole country (although most of the activities take place in Bamenda and the NWP), and to eliminate societal barriers and discrimination faced by people with disabilities. As stated in their written communications, their specific objectives include:

1. The unification of people with disabilities.
2. The promotion of business among handicapped persons.
3. The improvement of the living standards of handicapped persons.
4. Establishment of a resource center for the training of people with disabilities.
5. Creation of self–help income generating activities with people with disabilities.
6. Developing the individual and collective skills of the people with special needs.
7. Training those who haven't enough skills with other handwork by experienced members.
8. Creating awareness and helping in the fight against STDs and HIV and AIDS.
9. Encouragement and promoting formal and professional education to people with special needs.

There are seven executive positions: President, Vice President, Secretary, Treasurer, Publicity Secretary, Financial Secretary and Chief Weep [sic] (i.e., Whip or disciplinarian). There are two advisors assisting the executive. Membership is open to any persons with disabilities in Cameroon who do not practice what the leaders call "group prostitution" (which they defined as membership in more than one disability group). There are approximately 150 members in Bamenda and 200 in other areas in the country. Approximately 30 to 60 members attend monthly meetings. The annual membership fee is 1000 CFA (~$2).

Long-standing relationships include an ongoing funding relationship and sponsorship with a Catholic priest in Bamenda and a Catholic Missionary center of an archdiocese in Italy. Members of the archdiocese have come to Bamenda on several occasions to visit the group. Organizational funds come from memberships, percentage charges deducted from sales of members’ products, and donations from the Catholic sponsors and other individuals. Recently another partnership agreement was signed between Strong group and a small international NGO. This NGO provided equipment and material to facilitate the training of members.

Information gained during the focus group and interviews related to this group indicate the group’s responses to HIV and AIDS to date. Within the past year, they have included a specific objective related to HIV and AIDS in the organizational objectives. The leadership allow for ongoing discussions in the group as issues arise, and state that they have open acceptance for members who are HIV positive. The group has had fewer than five seminars on AIDS education in the past, with mixed success (some did not work well, and some did work well). There were no documents available from the seminars that I could review. The Strong Group has not had any other formal response (education, testing, counseling or other work) related to AIDS.

Reliance Group

The Reliance group formed in 2003. The stated purpose of this group is to restore hope and dignity in people who are blind or who have low vision, and to provide information and empowerment about rights of people with visual impairments. It also provides spiritual outreach. There are five executive positions, the President, Vice President, Secretary, Sighted Secretary, and Treasurer.

Membership is open to men, women and children who have visual impairments and to *well-wishers*. Well-wishers are sighted, nondisabled people who are supportive of the group. There are approximately 25 members in Bamenda, and about 200 members in other areas in the province. The Reliance group holds monthly membership meetings in Bamenda and the annual membership fee is 500 CFA (approximately $1). The focus group respondents emphasized the fact that many members find it difficult to find the funds for registration and for transportation to make it to meetings.

The Reliance group does not have an ongoing funding relationship from an external agency. It has done some contract and program work funded by the government (for example, training programs) which generated some income. Most of the organizational funds come from membership dues, sales of products (craftwork), and donations to the group from Reliance members and other community members.

Respondents stated that the leaders allow for ongoing discussion of AIDS issues in the group as these issues arise. The group was able to carry out one large-scale sensitization program in 2005 in conjunction with the Provincial Technical Group in the Fight against AIDS and the Cameroon Baptist Convention Health Board AIDS program. This initiative reached people in Bamenda and in the other subdivisions of Mezam. Members of the group reported that a written record of this initiative was done but a copy was not available. Members of the executive have attended several seminars and workshops sponsored by other groups, including ANAC (a national association for people who are blind), and the Closing the Gap workshops (discussed in more detail below). Two members have been trained in peer AIDS counseling, and were available to members when necessary. However, there were no funds available to pay them or to cover their expenses for this work. The executive reported that not many members have needed to take advantage of this specific counseling.

Unity Group

In the focus group discussion, respondents said that an early version of the group formed in 2001. According their website, the group formed in 2006. The group emerged from needs identified in a larger Cameroonian NGO, which has a focus on a variety of social programs. The leadership decided to start a disability group when they identified the need for such a group. According to the focus group discussions and the website, the purpose of the group is primarily to empower group members through income generation and a micro-credit program. The social component of the group is also very important to its members.

Because the Unity group is a project of a larger organization, its governance structure reflects that relationship. The project officer was hired by the larger organization, and is not disabled. She has an arm's length relationship with the group. The executive positions in the Unity group are President, Vice President, Secretary, and Treasurer. Membership is open to anyone in Bamenda who has a disability, but members are primarily those with physical disabilities. Currently, there are approximately 15 to 20 members in Bamenda. The group holds monthly meetings. There is no membership fee, which also reflects the philosophy of the larger organization, that they are providing a service to people with disabilities. As with the other groups, many members of this group also find it difficult to find the funds for transportation to make it to meetings, and the leadership reported that members often do not attend regularly.

Significant ongoing funding relationships from an individual expatriate sponsor and from North American groups support both the overall organization and the rehabilitation component of its operations. Most of Unity's organizational funds come from these external funders, and some comes from the income generated through the sale of products.

Responses in the focus group indicated that there is informal discussion in the group on a regular basis about HIV and AIDS and as specific issues arise. At the time of the study, there was no formal HIV or AIDS program within the disability group, although the host organization had a policy of mainstreaming HIV and AIDS in all of its programs. The disability group was not initially included in these programs, and it was not clear why this omission occurred. The project coordinator participated in the Closing the Gaps workshops, and stated that she plans to use those materials for members to become trainers for other parts of the organization.

The Groups and Their Responses to AIDS

As these descriptions illustrate, there are similarities and differences between the group's structures, operations, activities, and challenges. Three of the four groups have membership fees, and all accept members from outside of the city of Bamenda. Unity is the smallest of the groups, and is the only group of the four whose membership appears to consist solely of people living in Bamenda. None of the groups' membership is based on members' ethnic or village affiliation (as is the case with many other civic or community groups).

Figure 1 illustrates roughly how the groups are located in and outside of Bamenda. All of the groups have their central activities based in Bamenda, but reported having activities in other parts of the province, represented in the figure by the extension of the group box outside the circle of Bamenda. The Reliance group has ties to groups and programs that are national in nature. Although the Unity group is primarily focused in Bamenda, they are looking for opportunities to expand beyond the city, and their host organization is operating in several other locations. The Strong group is the only group that explicitly has activities for women.

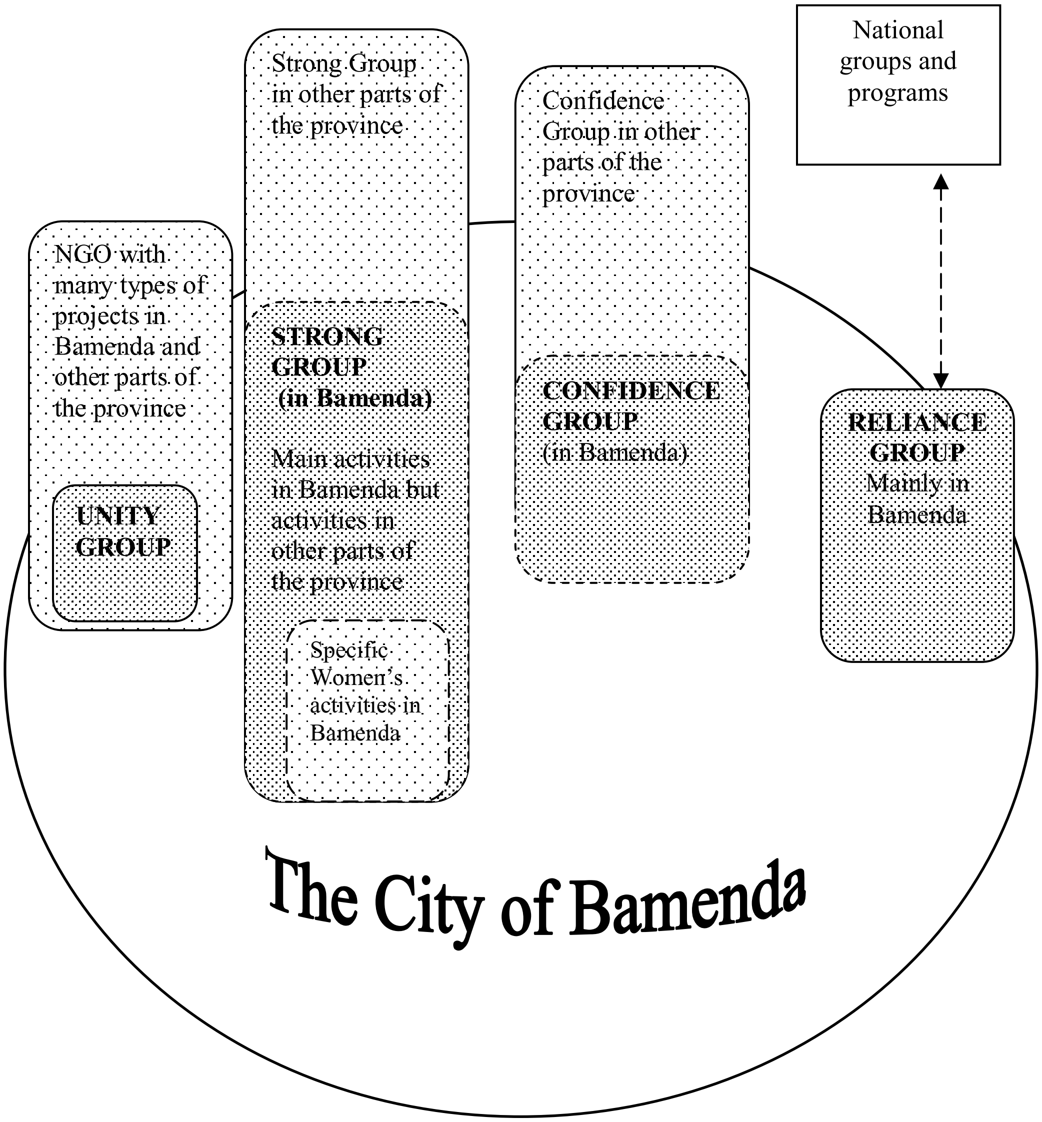

Figure 1. Representation of the DPOs in Bamenda.

It was clear that all groups believe that the planning of organizational activities must be flexible, as there can be a range of unexpected developments that influence an organization negatively or positively. A timeline of some relevant events was presented above in Table 3. This timeline emerged from the participants' responses and the document review. Participants reflected on previous and current goals and timelines in their organization, any shifts in plans over time, and on the events and influences regarding their responses to AIDS. Several respondents appeared to have difficulty responding to these types of questions, asking me to rephrase the questions, stating that they did not remember, or that they were not involved in the group at that time. Therefore, it is difficult to construct a meaningful assessment of these key events from the perspective of the groups, and this would be a topic for further study.

As mentioned in the descriptions of the groups above, all of the organizations have engaged in some activities to respond to the HIV and AIDS situation. I have loosely grouped these responses into four categories: informal discussion and support, sensitization and education for members, testing, and collaboration and networking with other groups.

Informal discussion and support

All of the groups indicated that members could raise issues related to HIV and AIDS at any meeting, and that occasionally this would happen. For example, one of the respondents from the Strong group said, “There is no, ah, rising up to really talk about it. So that is why, we talk about it only when it is, it is done by chance, once in a while, not all the time.” In one of the focus groups with two women, the importance of these opportunities to have informal discussion was emphasized. Women may discuss their questions and concerns while they are working together on sewing and embroidery in ways that they might not if men were present.

> Woman 1: Within our group, we discuss about abstinence from HIV, how to take care of ourselves, since we are disabled women, men like to just, men, we know the way when you are just sitting in your house, around 8 o’clock, you have to close your doors, all those types of things.

> Woman 2: And then to me, they know that we are unable to walk so they might just come, and have sex with us, use force, all those types of things, which we should be very careful for all those types of worrisome things. They should not be always being around us. We need to take proper care. (Strong Focus Group, June 26, 2008).

Sensitization and education of members to the issues

Several of the respondents discussed their efforts to sensitize their members to AIDS issues, and to provide informal education on HIV and AIDS. Leaders reflected a range of perspectives regarding how well informed they believed the general members are about HIV and AIDS issues. Some stated they believed their members are well informed, while others reflected concerns that members did not have adequate information. Generally, there appears to be a need for improved education to allow the leaders to talk about the issues.

The term *sensitization* was often used with respect to AIDS education, and appears to be a reflection of a word used more generally in the community to inform people about current issues. Sensitization was the focus of the first of the formal initiative carried out by the Reliance group in 2005. As described by the Reliance executive members, sensitization in that project aimed to increase awareness about basic understanding of what the terms HIV and AIDS mean, and also included "preparing the people's minds for a voluntary testing program" (Mr. R. P., Reliance, June 14, 2008). Sensitization was seen as the first step to making change. Mr. R. P. also said "[Our advisor] looked into the project and advised us that we should start with sensitization first before we come to voluntary testing, counseling and testing".

The term sensitization could also been seen to mean introductory education, including a basic understanding of how to prevent transmission of the virus, and what to do if one become positive. "… we used this money [from the 2005 initiative] in order to sensitize, to sensitize ah, disabled persons, particularly visually impaired persons, as to how they could live with AIDS, and how they could prevent AIDS." (Mr. H.L., Reliance, August 14, 2008). During another discussion, a leader from Reliance stated:

> We never went to those details because it was a day's seminar, it was only one day seminar. We could only introduce topics like means of transmission, HIV/AIDS prevention, cultural things that leads to spread of HIV/AIDS. Those were some of the topics we treated. So we never really went talking about relationships, how to begin a relationship, how to identify your partners. (Mr. R. V., August 11, 2008).

Deeper discussions did not seem to be occurring within the groups. One respondent said "the only thing that we de teach people be na make they abstain from sexual intercourse" (Mr. U.V., June 19, 2008). When asked to say more about how people responded, he did acknowledge that many people did not abstain, choosing instead to use condoms. The superficial nature of discussion was revealed in the comments from another respondent in another group who said, "We only discuss about it. We only discuss about abstinence. We have never done anything other than that." (Miss S. O. June 26, 2008)

There appeared to be a considerable lack of materials for groups to use in education. None of the groups had any written, audio or other types of educational materials, so most sensitization and education was done verbally and was not well recorded for future use. Only one of the visually impaired leaders talked about educating members about how the use of condoms could be adapted to accommodate for physical or visual impairments that might make usual usage challenging. Some study participants reported that there were group members who continue to hold the belief that the virus does not actually exist, reflecting a belief that remained in the community at large. Leaders are trying to combat this misconception. Leaders would like to be able to provide more education for their members, of several types, but stated that they are limited by lack of resources and lack of support from mainstream AIDS organizations.

Testing

All of the groups emphasized the importance of encouraging members to go for testing and to know their status.

> At the moment, we are putting out a strategy to see that all the members are tested. We want to make sure that all the members are, do their test for HIV, so that we should know actually the members that are negative and those that are positive.(Miss C. P., Confidence Group, June 18, 2008)

However, this encouragement appears to be having with limited success.

> But the problem now is living within the HIV/AIDS society because for the visually impaired persons, I will confess that I am fully aware that more than 99 percent of them, is not, does not know their status, almost I would say 99 percent, does not know their status. (Mr. R. V., Reliance Group, June 14, 2008)

None of the respondents could provide information about how many of their members had actually done testing. Although the Reliance leader's estimation of "99 percent" of the membership not knowing their status may be somewhat overestimated, it reflects the perception that there are still many people who are reluctant to go for testing, especially on a regular basis.

During the time that this study was conducted, the Confidence group organized a large HIV testing session. This was one of the two major initiatives that were identified as organized responses that occurred in any of the groups. When I spoke with the leader, Miss C. P., prior to the testing, the emphasis appeared to be primarily on providing an opportunity for people to be tested for HIV. The group did not intend to collect any information about prior testing, to find out whether this would be the first time for some people to be tested, or to gather any other information about their testing experience. Pre- and post-test counseling was to be provided by the Provincial Technical Group counselors; it was not clear how they were prepared to be attentive to any issues that might arise during or after the testing due to the impairments of those participating.

> And even the issue of, of convincing the members to do their free HIV screening is not easy because some of them feel that if they go and test it and it happens that they are positive and they will be stigmatized a, maybe they will be abandoned because they have HIV….So, so I mean, we really struggle a lot in order to convince them. All of them have accepted that on the 30th we will be down in Bafut to do the screening and then some of them needs to refuse because of ignorance. But as we keep on sensitizing them, and so on, a day, they develop the interest of doing it. (Miss C. P., June 18, 2008)

When I asked if some of these issues that she raised, like uncertainty about how to cope with a positive diagnosis in addition to being disabled, would be handled by the PTG counselors, the response was that raising these kinds of issues might not be well received by the counselors or their supervisors, and so they would not be addressed. “Because if you want to ask them many things at once, you will just spoil the whole show. So, I just want them to do this. After this, I will then meet them to discuss [disability issues] with them” (Miss C.P., June 18, 2008).

Collaboration and networking

The fourth kind of response is collaboration and networking between groups, which was only apparent in two groups. Generally, there appeared to be little collaboration or networking between the groups regarding HIV and AIDS activities, and so there was minimal awareness about what other groups are doing. As indicated earlier, one group leader refused to discuss anything to do with any other groups. One other group did not appear to be aware of the activities of the other groups, either generally or specifically about HIV, and mentioned that they have come to be aware of the existence of these other groups only recently. The remaining two groups were somewhat more aware of the other groups' activities, but did not comment on others' AIDS activities. When I followed up with group leaders in person some time after the focus groups, it became apparent that there was animosity between the leadership of some of the groups, and there were references to jealousy, unresolved conflicts, and the difficulties of communicating clearly.

Encouraging effective networking was one of the goals of the Closing the Gap project that many of the group leaders participated in over the two years previous to the current study, and which the leaders talked about in positive terms. Closing the Gap: HIV, Disability and Rehabilitation in International Contexts was a small project that attempted to work with providers to develop a model program integrating HIV and rehabilitation issues (Closing the Gap, June 2008). The first year of this project focused on an environmental scan, information gathering, and providing a few opportunities for networking in the province. The second year of the project included two workshops, one in August of 2007 and the second, a train-the-trainer workshop in March of 2008. At the time of this study, group leaders reported that they benefited from this project, but were still waiting for the follow-up written materials to be distributed so that they could use them with their membership.

The key informant from the Ministry of Social Affairs did not appear to be aware that groups were addressing HIV and AIDS issues. When asked what groups were doing to respond to AIDS, he stated that he did not think they were taking any actions as a group. He stated:

> No, for now, I don't have any disability group that really emphasizes on HIV AIDS as an activity that they want to carry out in their group… I would just believe that, it is just that, they don't have, they don't know that it is necessary for them to even sit like a group and even talk about it, maybe because they the topic, the radio talks about having AIDS to the whole public so they think that everybody is listening to it, so there is no need for them to specifically hold their own meeting to talk about it. (Mr. S.A., September 20, 2008)

Themes Regarding the Groups' Capacities to Respond to HIV and AIDS

The complex adaptive systems approach was a useful one for examining diverse cases in a collective way because it directed analysis to accommodate and organize the dynamic and detailed information that was gathered in this complex situation. Keeping in mind the central research question of this study (assessing the capacity of DPOs to respond to AIDS), carrying out detailed coding of the data using a constant comparative method, and referring to the complex adaptive systems framework, allowed for the identification of key themes that describe, and to some extent explain, the capacities of DPOs to respond to HIV and AIDS.

The five major themes that were identified from this process are (a) the delineation of AIDS-related responses in these groups, (b) marginalization and poverty limit responsiveness, (c) lack of health education and understanding limits responsiveness to the complexity of AIDS, (d) connections and relationships impacting the capacity to respond to HIV and AIDS; and (e) the forms of feedback and communication within and external to the system. The first theme identifies some of the boundary issues that became apparent in the analysis. The second and third themes identify the challenges that emerged repeatedly in the respondents' discussions about their capacities to respond to

HIV and AIDS. The fourth theme highlights the relationships that affect capacities and response. The final theme summarizes the first four themes, by exploring the feedback and communication processes that become apparent with respect to the groups' capacities to respond to HIV and AIDS.

What delineates AIDS related responses in these groups?

Every case study has to have a boundary to identify the limits of the case. In this study, I intended to focus primarily on the AIDS related activities of disability groups in Bamenda, a large urban city. Therefore, there are three aspects to be explored with respect to this delineation: first, the AIDS-related work of the organization, and how the responses to AIDS intersected with the other work of the groups; second, the essential nature of a DPO i.e., who is allowed to be a group member and who is not (the question of what the membership boundaries are, of insider or outsider status, and identity with respect to disability and HIV); and third, the organizational activities taking place in the city of Bamenda as compared to what the groups are doing in other geographic areas. Just as complex adaptive systems theory predicts (Olney, 2005), the boundaries of what is AIDS work, and what is other work, where it takes place, and who is involved in carrying it out, can indicate places where significant communication, challenge, and adjustment occur. The fluidity of each of these three boundary issues is apparent in this study.

First, what is the AIDS-related work of the organization, and where does it take place? Although all of the organizations were based in Bamenda and focused much of their work there, the leaders also talked about AIDS-related activities extending beyond the geographic boundaries of the city and their perceptions of the need to engage with people and groups in the rest of the province. Having a clearly defined geographic boundary was not a concern for any of the groups, whether it was for their work generally, or for specific AIDS work.

How do the responses to AIDS intersect with the other work of the groups? None of the groups had a clearly defined and ongoing AIDS program. Much of the work related to AIDS, such as individual support and informal discussion during meetings, appeared to overlap with the other work of the groups in the areas of psychosocial support, income and economic support, and occasional education sessions. Most of the respondents talked about how their groups deal with HIV and AIDS primarily when members bring up the topic, or when external opportunities arise, such as participating in the Closing the Gaps workshops.

Secondly, these groups are associations of people who are disabled. Who is allowed to be a group member and who is not raises questions of what the membership boundaries are, of insider and outsider status, and of identity with respect to disability and HIV. Membership in these groups is often loosely concentrated on a particular form of impairment or disability (e.g., visual or mobility impairment), although those who are not perceived as disabled are, in some groups, welcome to participate as members (for example, the disadvantaged members of the Confidence group) or to work as supporters of the group (for example, the well-wishers of the Reliance group). There was some variation in perceptions of whether people living with HIV or AIDS should be considered to be disabled, but most groups did not see people with HIV as being disabled, and therefore were not candidates for membership in their disability associations.

> Because at first we did not include those of the AIDS among us fully. At first we used to reason as if people like that should stay in their own way, they should not

> be interacting with people and so on. But now, we have come to see that all of us are the same. (Mr. S. P., August 18, 2008)

A couple of respondents did see the possibility that HIV could be a disability, but none of the groups had any members who joined using this definition of disability. A person living with HIV did not appear to be specifically welcome in the groups as a disabled person, so as compared to some of the other delineations which are more flexible (such as age or place of origin), there seemed to be a relatively clear demarcation that joining the groups was not for people who have been disabled by HIV or AIDS.

Thirdly, it became clear that there is no clear delineation along geographic boundaries for these groups and their activities. Each group sees its geographic mandate somewhat differently, but none of them restricts its activities to the city of Bamenda. All of them extend their reach to the rest of the province, and three stated in different ways, that their group identity extends to the whole country.

Marginalization and Poverty Limit Responsiveness

The theme of how vulnerable people with disabilities and their organizations are to marginalization and humiliation in society emerged repeatedly in interviews, focus groups and newspaper reports. Marginalization is the process of being relegated to unimportant or powerless positions within a society or group, and being excluded from participation in meaningful social activities (Hall, 1999; Lynam & Cowley, 2007; McAllister, 2008). It is not an experience that applies equally to all persons who identify as being members of a specific group, such as those who have impairments and disabilities, but rather is dependent on one’s social location and the relationships held with others in the social context. The participants talked repeatedly about how people with disabilities and their disability organizations were seen by others as unimportant and not included in meaningful activities with respect to AIDS work.

This marginalization is recognized at high levels. For example, the Cameroon Minister of Social Affairs recently acknowledged that relevant data about disability have not been collected, and that people with disabilities face high levels of discrimination in educational institutions, training programs, and the job market.

> Although there is no current data on the number of handicapped persons in Cameroon, Minister Catherine Bakang Mbock noted that handicapped persons in Cameroon are victims of discrimination and do not benefit from professional training that can enable them have access to the job market (Yufeh, July 3, 2008).

Mr. S.A., from the Ministry of Social Affairs in the NWP, supported the perception that people with disabilities were deemed unimportant in mainstream institutions, and were therefore treated with disrespect. He described how government employees condone discriminatory behaviors, ignored people with disabilities, and did not provide the services to which they are entitled:

> The public institutions, no, because you know, very well, you have been here, you know how are our people can be, how they despise the disabled, you know how they despise the disabled and the like. The problem is that [in some] certain institutions, some areas, someone could stand there or stay there the whole day... We need sensitization to the, on the staff too who are taking of, when they see this, this class of people, to also pay attention, because this too are equally like any other person (Mr. S. A., September 20, 2008).

These kinds of institutionalized attitudes were apparent in anecdotes from participants about how they were marginalized when trying to carry out legitimate activities. For example, one participant who was blind told a story of how government employees refused to be polite or provide any assistance with navigation:

> And [another time] we went to meet the Government Delegate of this Bamenda eh? He was in and asked us to meet his assistants. And of which, we were not even given help to move out the office to move to the next office. Because we pleaded with the secretary to provide some assistance to [show us the way to] the next office. The Secretary asked us how did we come in, that we are needing assistance now to go the next office [and refused to provide assistance].
> So those for some of the difficulties and the belief that society has that people with bad visual impairments are beggars, giving us a, a lot of set backs, … [That humiliation] is still fresh in my memory, because I am still suffering the kind of behavior I had to suffer that day, and the setback that is given to some of my programs … fearing of the same reaction. Although we are trying, but it is still hard when you have to make a decision to go. (Mr. R. P., June 14, 2008)

As indicated in the quote above, and in many other responses to the study questions, for many people with disabilities, marginalization goes hand in hand with poverty. The social perception has been that people with disabilities are beggars, unable to contribute productively to their communities.

> [There are] so many people in our society are taking advantage of people with visual impairment, and harassing us, even sexually (Mr. R. P., August 11, 2008).

> I know people who, some people who are already HIV AIDS positive, they know that they are already, maybe like, they feel that they are about to die. So they say that they cannot die alone. So if they move around, they see that there is no person that they can attack, they can easily come back to people with disability because they know that if they attack him here, you might not be able to escape…at least two of our members have put to birth due to rape (Mr. S. P., June 17, 2008).

> Because the society has made them to understand that they are beggars, they have nothing to offer. And some of us then too, accept that idea. So we try now to say, how we can say, no, those ideas are not good. You cannot only be bread receivers, you can also be bread givers by doing something. Being a disabled does not mean the end of life. You have many other things to do. (Miss C. P., June 18, 2008)

One participant provided specific examples from his own experience, and related how much courage people with disabilities have to muster to continue to engage in advocacy and public information work.

> I went to negotiate for a visit in one of the churches around town. I came up and heard that people were at the veranda talking, so when I greeted… the pastor was

> there. He never answered…he never answered until the woman, until the wife came out of the house and was bullying me, because she thought I was coming to beg money. And she had to bully at me and after, she and the husband they climbed on the bike, and the wife told me that they were going to church. You see, that was a kind of a humiliation and it gave us a lot of ..ah… rethinking. (Mr. R. V., August 11, 2008)

One of the key informants, a well educated man in his early thirties, who does not have a disability, talked about how his own beliefs reflected the social attitudes around him, and how these have only recently started changing:

> My assumptions before…was that all disabled were not well educated, (i.e., given formal or informal education by parents or family members). This assumption certainly is as a result of the neglect my aunt's daughter faced and is still facing. But [since] I personally came across persons living with disability who have acquired both formal and informal education [I have changed. Now I am aware] that some of them still complain about preferential treatment, discrimination of various sorts by parents, relatives, and so on. (Mr. O. P., August 15, 2008).

The vulnerability to exclusion provides additional challenges to organizational leadership for a number of reasons: they may have internalized social beliefs about their own self-worth, they have relatively few experienced, confident and courageous members to draw on to develop programs within the group, and many members need considerable moral support to engage in even basic group activities. Social marginalization extends to exclusion from workplaces. Often people with disabilities are unable to find work that allows for a reasonable standard of living, and there is no reliable social security income. Knowing that their members have extremely limited financial resources, groups tend to have low membership fees, usually less than the equivalent of one or two dollars a year. These low organizational budgets in turn limit the organizational funds available for the groups to provide and develop programs.

The lack of inclusion and oversight regarding inclusion in social and governmental activities extends to DPOs as they were often not included as valued members in AIDS initiatives, and appeared to be rarely invited to participate in broad AIDS activities. None of the groups talked about being included in mainstream AIDS events, nor were they asked by the Provincial Technical Group or other AIDS organizations to become involved in collaborating on AIDS projects. Mr. C.D. saw this exclusion from AIDS work as reflective of the larger issue of marginalization:

> I think that it is more a broader issue. You know in Cameroon, even though you have texts and regulations, but most programs are not inclusive. And so at the times that these programs are developed, these programs are developed by people who have no knowledge of disability and rehabilitation issues. So, obviously there is an oversight, it is an oversight when these programs are being developed. And I think it is really not just AIDS programs, but it is basically with most, if not all, mainstream programs. (Mr. C.D., August 4, 2008).

One key informant who has been active in AIDS work for many years stated, “You know AIDS workers especially here are not trained on the special needs of these kinds of people. So, most AIDS workers here hardly even go as far down as dealing directly with people with disabilities” (Gwain, August 29, 2008). The use of the phrase “go as far down” is notable in this context as it reveals the ongoing lack of status that disability issues have. AIDS workers do not appear to be well prepared to deal sensitively or respectfully with people with disabilities. In talking about the discrimination and stigmatization he has seen in AIDS programs, including in interactions between the PTG and people with disabilities, Gwain also stated

> So much, You can’t find words to describe them but there is a lot of discrimination, a lot… As I can tell you, even PTG, the umbrella that is the government policy making, implementing organ of the HIV/AIDS and general

> health policy in the province, they have very little ah, ah, space in their program for people with disabilities. They don't have, they don't. (Gwain, August 29, 2008).

As indicated earlier, in total, respondents talked only about two specific projects in Bamenda that involved mainstream AIDS organizations working with disability organizations, and each of these were one-day events. In 2005, the Reliance Group worked with the Provincial Technical group and the Cameroon Baptist Health Board on a sensitization project, which took place in Mezam division, and included a one day seminar in Bamenda. The second event was a screening day carried about the Confidence Group, which actually took place in Bafut (about 30 minutes drive from Bamenda) in June 2008. Many people had to travel, with difficulty, from Bamenda to Bafut to participate in this day.

One participant told a story about the project in 2005, which focused on the lack of response from the PTG when the group asked to continue their involvement in AIDS outreach:

> After our first phase, we deposited and submitted all the reports, and even the videotape, the tape, we even presented it to them, thinking that it would facilitate the next phase, but we waited, went there numerous times to no avail…. We actually, we are one of the people who had the best, best report. We went there with a videotape to actually that show it was something we were doing in the field. (Mr. H.L., August 14, 2008).

Another initiative which all of the organizations mentioned is the Closing the Gap project, carried out by the Cameroon Baptist Convention Health Board in partnership with two Canadian organizations from 2006 to 2008. Disability groups were invited to participate in this project, and many did participate as learners, but did not have direct control over the planning, focus, or other aspects of this project. As one of the group leaders stated:

> Yes, ah, I would like to suggest that for most people who have the interest really to work with disabled as a whole, when they come they should go and have partnership with disabled themselves. Because this time around, like in the past, they only put us behind programs which makes us, we don't really fully participate.…My group was expecting to must have had at least have a partnership, so that it should not be that they just come on the way and take us. But we see that they sign partnership with the missions, and sometimes the missions too are a barrier to disabled programs. They don't implement them directly sometimes, and well the way we expect. (Mr. S. P., June 17, 2008)

In summary, marginalization appears to be reflected in how mainstream agencies miss opportunities to develop the organizational capacities and opportunities of disability organizations. As a result, the capacity of disability organizations to respond to HIV and AIDS are underdeveloped, overlooked and neglected.

Lack of Education and Understanding of Health Limits Responsiveness

Many participants discussed the lack of opportunity for both formal and informal education for people with disabilities. An understanding of basic health issues is required to be able to understand HIV and AIDS; many people with disabilities report that they have received only a few years of formal schooling, and did not have well developed understandings of health and illness.

> You know, at first, we looked at HIV as taboo. And everybody was sooo afraid. Maybe even giving the wrong image about everything, so people did not even like to go close to people with HIV. So it is now that the public is getting to know much and maybe even interacting with people who have HIV, and persons with disability did not know much about, because they do not even have access to information and so on, because of all the barriers around us. So, it is now that persons with disabilities are trying to have idea on what is going wrong, ah going on, and they are trying to pick up, and I believe that we will do our best to make sure that they really follow up everything well. (Miss C. P., June 18, 2008)

It appears that many of the messages regarding AIDS are conveyed in simple terms and concepts to accommodate this general lack of knowledge. Without detailed understandings of reproductive health, sexual health and general health, it is difficult to develop what has been termed *health literacy*. For example, to understand what a virus is, how AIDS is similar to and different from other illnesses, how medications take effect, and so on, requires foundational understandings of health and illness, referred to as health literacy. Health literacy is defined in *Healthy People 2010* as: "The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (as cited by Glassman, 2008).

> Health literacy includes more than the ability to read, and extends to being able to understand instructions on prescription drug bottles, health education brochures, doctor's directions and consent forms. It also includes the ability to negotiate complex health care systems. If someone has health literacy, they have a complex group of reading, listening, analytical, and decision-making skills, and the ability to apply these skills to health situations (Glassman, 2008).

Contrary to the belief of officials that people are well aware of AIDS issues, these community leaders identified that their members did not have adequate information, and it was also apparent that in some cases their own understandings were limited. For example, one leader, in talking about members of his group who were HIV positive, stated, “No, the cases that we have had, it is just ah, just, they need treatment on and off” implying a lack of understanding of how ARV’s need to be taken consistently. Another respondent listed several questions that remained in her mind, despite several conversations about AIDS: “We would like to know how people can make [*a life*], how can you live with, how long you can live with AIDS, how, how will you do, if, if you are positive? If you are positive, how will you do to survive?” (Miss S. O., June 26, 2008).

One of the Reliance group leaders talked about their efforts to make AIDS information meaningful and understandable to the members. He said,

> You know, visual disability deals with touch and feel. So, we were able now to make the bring their senses, to the touch and feel ideas of getting information and the messages on HIV/AIDS, the use of condoms and some other, ah, things that really touches on HIV/AIDS. What, you know, they were not like kind of fully aware of some of the things really leads to HIV and AIDS, especially sex education, was a big problem to be addressed…Dealing with people with visual disabilities, so they find it difficult in really understanding how HIV/AIDS is transmitted through sexual relationships (Mr. R. V., June 14, 2008)

Although I was aware of the heavy emphasis placed on testing from previous work in this area, the concern and even misinformation about testing was a surprising theme in some of the responses. There appeared to be a general belief that “getting tested” and “knowing your status” covers much of what is needed to respond to AIDS. Being tested and knowing one’s status appeared to be more important than public education and prevention, counseling, or understanding the complexities of treatment and transmission. For example, one group leader stated that their main goal is to encourage testing:

> And at the moment, we are putting out a strategy to see that all the members are tested. We want to make sure that all the members are, do their test for HIV, so that we should know actually the members that are negative and those that are positive. (Mr. S. P., June 17, 2008)

Despite the emphasis on testing, respondents reported that there was still significant reluctance for many people to be tested. According to the participant from the Ministry of Social Affairs, no one engaged in the free testing event held to coincide with the International Day for People with Disabilities and organized by the Ministry of Social Affairs and the Provincial Technical Group in December 2007. He attributed this lack of engagement to shyness at being seen when being tested:

> Yes, maybe they were shy, because they would reveal themselves, ah, maybe they have a complex, before the population that they would see that they are coming for those types of things, maybe that's why they didn't turn up. (Mr. S.A., September 20, 2008).

However, for many people, poverty and even hopelessness may be more the reason they are reluctant to be tested. A poignant response was made by one of the women who explained why many of the women she knew did not want to be tested. First, she talked about the range of beliefs that many people, herself included, still hold:

> Some will say that they don't even want to hear because they don't believe that such a thing [AIDS] can be. Some will say that it is the scientists, it is the scientists' knowledge. Some will say that it is the anger of God. Some will say that it is the, it is the, the end of the world. [laughter]… When we are discussing, they will talk about, they will talk how, they will, they will tell members to do the screening, to do their tests, then some will be refusing. (Miss S.M., July 7, 2008)

Then she talked about how difficult disabled women's lives are, with little education, very low incomes, high vulnerability for abuse, and ongoing discrimination from other community members. This woman's interpretation of why women didn't want to be screened and tested was closely linked to the poverty, poor quality of life, and the many daily challenges that many disabled women already experience. She stated that for many women, there is a perception that one can have a sense of wellness up until the time that one actually tests positive, and once they find out that they are positive they would not able to cope with their very limited resources:

> Many will refuse because they are, because they are afraid of it. And as they are refusing to test it, they will say that don't want to test because immediately that you know that you have it, that is the beginning of your illness. That is when you are beginning to sick because it is already in your mind. If you do not know it, you will be fine. But immediately you just know it, every day your thoughts will be disturbing you, disturbing you and you will not live a good life. That is why they are refusing to do the tests…I know that that would be the biggest problem because they will be thinking of two things: they are disabled, and now they are

> HIV positive. How are they are going to cope? So, I will say that will be, it will difficult for them to test. (Miss S. O., June 26, 2008)

Recognizing this concern, many of these DPOs are beginning to make a link between mutual support, economic issues, and income generation as important aspects of their AIDS work.

Connections and relationships which impact the capacity to respond to HIV and AIDS

Analyzing the interconnected web of relationships in a complex system is crucial to developing an understanding of the system (Olney, 2005). Relationships are seen as forming a web involving many agents and forces, both internal and external to the system under study. In this study, several key types of relationships emerged repeatedly in the focus groups, interviews, and documents, that have a bearing on how the groups have responded to HIV and AIDS. These relationships can be viewed on a continuum from more internally focused to more externally driven connections. The types of relationships are listed here, and then discussed in more detail in the following paragraphs.

Relationships included:

1. Interpersonal relationships within groups
    a. Relationships between leaders and members,
    b. Relationships between group members.
2. Relationships between each disability groups and other groups
    a. Relationships between disability groups within Bamenda and the whole province,
    b. Relationships between disability groups and other community and NGOs in the Bamenda area.

3. The relationship of the AIDS community with the disability community.
4. The relationship of religious organizations and ideologies on the formation and maintenance of disability organizations.

Interpersonal relationships within groups

The relationships between leaders and members is important with respect to HIV and AIDS, because the leaders set the tone for what can and cannot be discussed. The leaders of the DPOs appear to see their roles as primarily providing education about HIV and AIDS, and for some, providing support for those who have disclosed that they are living with HIV or AIDS. However, only one of the leaders received significant specific training in counseling related to AIDS, while the others gradually gained information in occasional workshops or other events.

The relationships between group members is variable, as would be expected for any group of people with different backgrounds and personalities. Some people talked about how the relationships between group members can be very supportive, especially with regard to behaviors intended to prevent the transmission of HIV. There were also indications that there is some reluctance and stigma to confront HIV and AIDS issues within groups, leading to reluctance to discus AIDS related issues, and the impact and extent of these concerns would be worthy of further explorations. In addition, some participants talked about the disbelief and distrust that some people have about AIDS being a disability or illness; as described earlier, it did not appear that anyone could join a DPO on the basis of having AIDS as a disability.

Relationships between each disability groups and other groups

Relationships between disability groups within Bamenda and in other parts of the province

Perhaps not surprisingly, given the extreme lack of resources for communication and transportation, there do not appear to be strong relationships between the Bamenda disability groups within the city or with other disability groups in the province. One of the participants stated:

> Yeah, if I can recall well, I think the last ten years in Bamenda, the associations that you find, or groups of people with disabilities that you find in Bamenda today were not like, eh, 1998, because in 1998 the groups were so limited. For the past 10 years in Bamenda, there were not so much associations in Bamenda. Why? Because the disabled people, or people with special abilities did not actually see a reason of joining an association, since they were feeling inferior and things like that. But as time was unfolding, then people started hearing much about the disability groups, how they can come together and share their problems, and in one way or the other, then they will be comfortable. They started coming together and maybe building, coming up with so many groups of disabled people started coming up forcefully ….
>
> And if I was going to add a third one, it would be bringing the groups together, that networking, focused the first one that mentioned is income generation, the second one is advocacy, and the third one is coordination, bringing the groups together under a single umbrella, and then getting themselves a bit more organized, kind of a bit more coordination, so that there can be some degree of focus, and shared responsibilities. (Mr. A.B., August 5, 2008)

Although the groups appear to be gradually becoming more coordinated now that the Bamenda Coordinating Unit for Associations of Persons with Disability has been established and other activities are encouraging collaboration, the intergroup relationships are not present between all groups, nor are they all positive. For example, when I asked the Unity group about their links and collaboration with other organizations, they reported that they did not collaborate with other groups:

> L: Do you have any partnerships with other organizations?

X: Not at all. (Mr. U.P., September 6, 2008)

For example, the recent testing event that was carried out by the Confidence group was not open to other DPOs. The Strong group has stated that members should not engage in group prostitution by joining other groups. None of the groups seem well versed or interested in what other DPOs were doing with respect to HIV and AIDS, or perhaps they just did not have the skills, resources, or capacities to come together in collegial ways around the often difficult topic of AIDS. What was clear was that there were no indications that groups learned from each other or collaborated on AIDS initiatives.

Relationships between disability groups and other types of organizations in the Bamenda area

Few of the groups talked about positive relationships with other types of community or civil society groups, and so these relationships did not emerge as a strong component of the system.

The relationship of the AIDS community with the disability community

Although there is an active AIDS community in the city and the province, there appeared to be very few connections between the DPOs and AIDS organizations (support groups, intervention programs, youth oriented programs and so on). Few respondents mentioned nongovernmental AIDS organizations, although there are several in the area. Neither practical nor conceptual links between AIDS work and disability work were articulated. In the focus groups, there were very few spontaneous references to AIDS groups by the disability group leaders.

In some of the focus groups, participants were questioned about AIDS initiatives, but many of the leaders could not describe what was occurring with respect to AIDS programming beyond some of the testing and educational activities of the Provincial Technical Group. This lack of knowledge appears to be a result of their exclusion from mainstream AIDS work.

Religious organizations and ideologies and disability organizations

Religion and church ideologies have a significant impact on life in Bamenda generally. As Gwain stated:

> Basically, Bamenda is a traditional set-up, but the mainstream churches, like the Catholic and the Protestant churches, and the religious leaders are as influential as the traditional leaders. It is just my opinion over here, and so, the Catholic faithful they listen to what the church says, I mean to an extent. But basically, even other Christians here, most of them, they use condoms, even couples, they use condoms. And as I am saying, that is not the official position of the church. (Gwain, August 29, 2008).

Through the discussions, it became clear that religious influence extends to the operation of the DPOs. Three of the four groups have a clear relationship to Christian organizations and ideologies. For example, the Confidence group is a religious, evangelical group receiving financial support from American evangelical organizations. The Strong group has a relationship with the Catholic church both locally and in Italy. Although the Reliance group doesn’t appear to have support from a church, it does include religious evangelism as part of its mandate. Unity Group is the only one of the four groups that separates religion from its work.

The historical influence of external missionaries on these developments was noted by Fonjong, who stated:

> I was saying that the missionary activities in the North West also played a fundamental role in the emergence of these groups. Because if you take the Baptist Mission and the Basel Mission, those were the missionary hospitals that the missionaries started, what they did, they were very, very interested with these disabilities, that's why you can, you find the Achatugi hospital in Acha, that was for vision. If you go to Banso, you will find a hospital to take care of, what do they call it, leprosy, we have leprosy hospital in Mbingo. So, that type of activity gave inspiration to the community organizations to form groups, those communities that were farther away, could now form disability groups that could benefit from the expertise of these missionaries or foreign assistance. So, the missionaries create an awareness of the, ah, awareness to this population, and that is why I think it facilitated their formation. (Fonjong, August 16, 2008)

In this description, Fongong implies that there were no organized services for people with disabilities prior to the interventions of the missionaries, who came with a more benevolent approach towards impairments and disabilities. From this perspective, their influence created a community space for such groups to form. This impression, viewed in conjunction with the responses of the other participants, who did not provide any indications that the government has supported the development of disability organizations, suggests that disability organizations probably would not have been as well developed as they are without the influence of religious leaders and organizations. Mr. C.D. and Mr. H.L. both support this view:

> But then I discovered that the main thing that led that group to people having their separate groups, is that, you know, that group was in the Mission, in the Catholic church diocese, and it looks like the reverend Fathers were actually influencing a lot of things in the functioning of those groups. And the desire for people to want to be in control of their issues, they had gained quite a bit of experience working together. And so each group now singled out themselves. First, it was in terms of disability, like look at [Reliance Group] is more blind focused. (Mr. C.D., August 4, 2008).
>
> In fact, I can say, some of this sensitization has been done by missionaries, has been done by missionaries, for example, this handicap centre in Bafut, you know they used to visit churches too and talk about people about people with disabilities, the reverend sisters.(Mr. H.L., August 14, 2008)

Notably, the influence of religion is not all positive for DPOs. Several people talked about the negative views that leaders in the church have towards people with disabilities, and provided stories about how they had been belittled and excluded from everyday church activities.

> Another aspect which I have learned is the relationship between religious bodies and disabled organizations. My assumption was that churches were role models and pacesetters in addressing issues of disable persons with them as key actors. Far from it, most disabled has regrettably complained about how churches and ministers of these congregations treat them with disrespect, scorn and shame. (Mr. O. P., August 15, 2008)

However, it was not clear from the discussions how these relationships have affected the groups' capacities to respond to AIDS, as they did not specifically make connections between their religious ideologies and their AIDS work in their responses. This lack of connection may reflect the general lack of in-depth knowledge described earlier and may also reflect the tensions that religious groups experience in dealing with HIV and AIDS prevention, testing and counseling issues. For example, the Strong group's AIDS sessions were organized and facilitated by Catholic Church leaders. As the president stated: "The resource person [for the AIDS seminar] was Sr. Agatha, from the Catholic, is the Catholic, ah, she is with our patrons in Ngomgham, and is a Catholic catechist." (Mr. S. P., June 17, 2008). He stated the focus of these seminars was on the importance of getting tested and knowing one's status, and did not recall the details of what was actually discussed during this seminar.

There can also be a conflict between public health and religious views of HIV and AIDS, for example in the recognition that unmarried people often have sex (which is against the teachings of many churches that sex should only be for married couples), and the use of condoms (as they can be seen as an unacceptable method of birth control). This area of tension was not well explored in the focus groups, and requires further study to better understand the complexities of these issues.

Another issue raised by the strong influence of religion in the DPOs is that, apart from the Unity Group, which is focused on economic activities, there do not appear to be associations for people who are non-Christian to join. For example, there are no disability groups in Bamenda which focus on members from the Muslim community, although there is a large Muslim community in the city.

Summary

This study attempted to explore and document emerging patterns and ways in which grassroots community-based disability groups organized themselves to respond to HIV and AIDS issues. The most predominant HIV and AIDS related responses and patterns were lack of response, informal discussions at meetings sometimes based on little or incorrect information, and a few occasional, formal educational initiatives. The theoretical perspective of complex adaptive systems recognizes that systems display patterns of behavior that reflect the ability to organize itself using self-ordering rules (Kernick, 2002) through a bottom up process. Complex systems are not controlled centrally, rather they are self-organizing (Trochim et al., 2006). As I gathered information, the self-ordering of the individual groups did become apparent, and the ongoing organization within the city and the province also became clearer. Each of the groups displayed attributes of how they are organizing themselves generally (e.g., executive members, regular meetings). What was less developed were the responses to

HIV and AIDS, and these responses clearly are not subject to any central control; rather each group appears to have to find its own strategies and resources to be able to respond to the AIDS situation.

Feedback loops are crucial for complex adaptive systems. Olney (2005) states that feedback loops "carry information, material, and energy among agents in the system. If feedback loops are well designed, they facilitate change and adaptation of the system" (p. S59). During the analysis, I looked for instances of how information and energy were shared within and between each disability group and within the system as a whole, and how feedback was shared. There appears to be relatively little information sharing or feedback between agents in the system, but there is shared personal energy as some participants talked about links that they made over the years individually and between their groups, which is leading to an increased focus on goals and shared work on activities.

> We're still struggling to get close to other organizations out of people with disabilities, but for anywhere we find people with disabilities, we try to network with them so but as of now, talking about getting close to other organizations….We haven't yet reached that level because we have been trying to launch appeals and nobody is yet heeding to those appeals, so we may have to readdress the approach so as to bring other organizations closer to Reliance Group (Mr. R.P., June 14 , 2008).

So, information sharing, although minimal with regards to HIV and AIDS, does appear to be greater for other areas of concern, such as community events and advocacy. One of the presidents stated:

> Other organizations, they invite us for, maybe sharing, learning and some activities. We usually participate in International Days with other organizations. (Mr. S. P., June 17, 2008)

The groups therefore do appear to be organizing themselves in some ways, but not with respect to health or HIV and AIDS issues.

This chapter has provided the results of the study organized into several sections. It began with historical and contextual background and then provided specific information about four disability groups in Bamenda. All of the organizations have engaged in some activities to respond to the HIV and AIDS situation, but none had extensive or detailed programs. These responses were grouped into four categories: (a) informal discussion and support, (b) sensitization and education for members, (c) testing, and (d) collaboration and networking with other groups. The findings were framed within an understanding of the situation as a complex adaptive system. Themes related to the fluidity of the boundaries of AIDS-related work, how marginalization and poverty limit DPOs capacities to respond, and the impact of a myriad of relationships within and external to the groups emerged from the participants responses.

The next chapter, Chapter 5, draws from these results to provide implications, recommendations, and suggestions for further study. The research answered many questions, but raised several more. Chapter 5 also includes suggestions of other areas for exploration, and provides specific suggestions for social change in the areas of practice and policy. These recommendations take into account the complexity of the situation, the difficulties in communication and information sharing, and the significance of the problems faced by these groups.

CHAPTER 5: CONCLUSION, RECOMMENDATIONS, AND SUMMARY

Introduction

This study assessed how DPOs in Bamenda, Cameroon responded to the HIV and AIDS situation. A qualitative, multiple case study was conducted using eight individual and seven focus group interviews, with document analysis to provide additional information and context. Twenty-five people from a variety of backgrounds participated in the study. Some members of the community knew me through my previous work in this city. Most of the people who were invited to participate readily agreed to do so. Two potential key informants did not agree to participate and did not provide reasons for declining. A local research assistant was involved in facilitating the interviews and focus groups. Interviews were conducted primarily in English, and were audio recorded and transcribed verbatim.

In addition to interviews and focus groups, documents such as program brochures and newspaper articles were reviewed. Analysis was done using a systematic coding process, with both *a priori* coding lists and open coding, which allowed for new codes to be created. An iterative process was used from the beginning of the data collection to code and analyze the information obtained. Categories and themes were constantly revised as the study unfolded. The QSR NVivo program and the Microsoft Word program were used to organize the information and themes in the study.

Although much has been written about HIV and AIDS, there has been relatively little research about how DPOs in Africa have responded to the pandemic, nor assessments of their capacities to do so. No previous health studies in this province explored issues related to DPOs and their responses to the AIDS situation. It is important to understand the role that civil society groups, including DPOs, can play with respect to HIV prevention, education, testing, and treatment. As the primary researcher, I spoke directly with the leadership and members of these groups as well as other key informants from the community, to obtain a better understanding of the realities, difficulties, and opportunities which these groups experience. The participants represented a diverse cross section of men and women who live with a variety of impairments, as well as people without disabilities. Reflecting the nature of the disability community in Bamenda, many of them are relatively young – under 40 – and represent a range of ethnic and religious groups. Their responses present significant insight into the challenges and opportunities facing these groups, and the substantial contributions they could make to stemming the spread of HIV and AIDS.

Case Study Approach

The purpose of this case study research was to assess the organizational capacity of community-based disability groups in the city of Bamenda, Cameroon to deal with the AIDS epidemic. The research used a multiple case study approach to explore, conceptually and practically, how community-based disability organizations have responded to AIDS issues in the past, what has been effective and less successful in these responses, and identified outstanding needs and recommendations for further development. Four primary groups met the inclusion criteria and were included in the study. The use of the multiple case study approach allowed for the examination of both the capacities of these specific groups, and of the situation in the city of Bamenda as a whole.

The case study approach also enabled data collection from a variety of sources, and encouraged the analysis of the variety and complexity of issues apparent in this area. This approach allowed for a detailed picture to emerge of how these organizations are responding to the AIDS situation within the urban Bamenda area. Detailed and in-depth information was collected from a number of sources including interviews and focus groups with individuals and organizational representatives; documents such as newspaper articles, organizational brochures and event programs; field notes collected by the principal investigator and the research assistant, and simple quantitative data (e.g., number of groups and meetings, number of members).

Discussion of Findings: The Struggle of DPOs to Survive and Thrive

In summary, this study has shown that DPOs in Bamenda are young, struggling to survive, and face diverse and significant obstacles. Therefore, they have been unable to take significant action about HIV and AIDS. Despite the obstacles they are facing, there is also evidence of optimism and resilience that the situation will improve.

It should be noted that this study reflects my interpretation of the capacities of DPOs to respond to HIV and AIDS, and what delineates AIDS related responses within these groups. Other researchers or community members could have a different interpretations of what to include under the umbrella of HIV and AIDS in this context. My focus remained fairly narrowly concentrated on HIV and AIDS as they were identified by the participants, and did not include for example, broader initiatives that the groups might have engaged with respect to other health or disability issues. For the most part, I followed the lead of the respondents to articulate what they felt should be included about HIV and AIDS. The following sections provide an opportunity to explore these findings in more detail as I reflect on what emerged in the study.

Organizational capacities of the groups generally

Each of the four groups described in this study has unique characteristics, which have developed over the time that the group has been operating. This was the first study in the province to document the origins and current perspectives of these groups. Looking at the groups from the perspective of the city as a whole, the disparate groups appear to be managing some uneasy challenges, particularly balancing the tensions which arise when trying to meet the goals of their individual group, with the benefits of advocating and working collectively for positive social change.

Each of the DPOs is struggling to survive with a significant lack of resources. All of the groups are fairly young. Although there were indications that other disability groups had come and gone before them, there were no disability groups in the city that had managed to actively survive for more than a decade. Three of the groups do not have enough funding to pay a staff person, have dedicated space, or develop ongoing programs. Unity, because of the support of their host organization, has a paid support person, program development, and the resources for a comfortable meeting space. However, although it is an association of people with disabilities, it would not, strictly speaking, be considered a DPO, as it is not led and managed by disabled people; it is a program of the larger organization. However, for the purposes of this discussion, I will continue to use the term DPOs to include all four groups.

As a whole, the DPOs in Bamenda appear to be moving forward on the path of working together while also carving out and maintaining their uniqueness and separateness. With the start of the Bamenda Coordinating Unit for Disabled Peoples Associations, the collective activities of the disability groups appear to be gradually changing. Because the Coordinating Unit is still a young and underfunded organization, its practical impact so far has not been significant. The President of the Coordinating Unit is a respected and experienced leader in the community who is also the Vice President of one of the disability organizations and who promises to make change in spite of the many difficulties which lie ahead.

The findings from this study can be further understood by comparing them to other studies of the capacities of DPOs. The study of organizational capacity in DPOs by Ncumbe (2005) in Mozambique identified many similar findings to what emerged in the current study. Ncumbe found that many people did not have adequate education available to help them develop leadership capacity, that there was significant poverty among the leaders and members, and in some cases, the ability to network effectively and relate with other organizations was limited.

A study comparing DPOs in the North (the United Kingdom and Northern Europe) and the South (South Africa and Zimbabwe) also found similar concerns (Dube & Charowa, 2005). Many DPOs in this study relied on membership fees for their operating funds, and found it difficult to obtain resources from governments and funding bodies. Most people with disabilities did not have opportunities for education, leading to dependence on family and friends for everyday subsistence and limited employment and leadership opportunities. This study report provided the survey that was used; it would be useful to carry out a similar, more detailed study of the organizations in Bamenda to explore their capabilities and capacities more fully.

Organizational capacities to respond to HIV and AIDS

Although all of the groups indicated some capacity to respond to HIV and AIDS issues, the study revealed that there have been very few formal, sustained, or significant programs or initiatives. All the executive members display good intentions, but their groups reflect the significant lack of opportunity and resources to develop leadership expertise and experience, particularly with respect to developing capacities to respond to HIV and AIDS.

The results of this study suggest that there are few connections between these groups with respect to AIDS, hence hindering the development of group capacities to deal with AIDS. No doubt, to a large extent, this lack of networking reflects the limited financial resources of the groups. Because HIV and AIDS issues are so significant and complex, coordination and collaboration to reduce the spread of the virus and the impact of AIDS might be an area that the groups could reach some consensus on, and use as a springboard for growth in this region.

The specific social location of exclusion and marginalization that DPOs appear to have with respect to HIV and AIDS work and the subsequent lack of organizational capacity, can be seen as an extension of the marginalization of people with disabilities that has been apparent at the individual level generally in this province. It is also noteworthy that there are no specific HIV or AIDS support groups in the city for people with disabilities. And vice versa, there are no disability groups specifically for people with HIV and AIDS. Several of the respondents suggested that a group with such a dual focus would be very helpful for some people. However, the challenges of obtaining support and being able to maintain the group would be significant.

This study makes some suggestions about the barriers faced by these organizations as they attempt to construct meaningful and organized programs to respond to the needs of their members with respect to HIV. I now discuss three broad barriers – poverty and marginalization, lack of education and health literacy, gender issues – in relation to other information about Cameroon and Africa.

Marginalization and Poverty on DPO capacities and the lack of governmental responses

One of the key themes which emerged in this study was the negative impact that poverty and marginalization, of not being able to participate in the everyday social, economic and civil society activities of the community, has on the DPOs' capacities to respond to HIV and AIDS issues. Education (or lack of education) appears to be closely linked with poverty and disability. Many people with disabilities have not been able to have more than a few years of primary schooling, limiting their abilities to become effective leaders in their community or to understand the complexity of issues such as HIV and AIDS.

Many disabled parents do not have adequate income to send their children to school. Poverty also prevents families with disabled children from sending children to school. The poverty of resources (including mismanagement) in the school system prevents teachers and schools from being able to provide educational opportunities for children with a range of impairments. Although there are a few schools in the province for children who are blind or deaf, these students represent a very small number of the many who need these kinds of specialized education.

Although it is difficult to get reliable statistics about school attendance for children with disabilities (because it is not collected), the general perception is that most children with disabilities do not go past primary school, often entering late or stopping early. Many children with disabilities therefore, are illiterate and have very few years of schooling. Although children are generally expected to be in school until age 14, compulsory education extends only to the end of primary school which is generally age 11 (UNICEF, 2008), parents are not held to this expectation. In reality, many children, particularly those with impairments, do not attend school on a regular basis.

If students with disabilities do make it to school, teachers are not prepared for them. Teachers have had no or very little training on special needs education, and therefore children are not well accommodated in schools. One disabled participant in this study talked about his experiences at a residential treatment centre and school as being very disempowering; another talked about the difficulties he experienced as a disabled teacher at a church–run school, because people would not take his abilities seriously. A new school, known as SENTTI (for Special Education Needs Teacher Training Institute), recently opened in Bamenda, and is one of two teacher training schools for special education in Cameroon.

A final point relates to the inequities developing with the education system in the province. What appears to be occurring is a growing divide between those who are financially poor (which includes many people with disabilities) compared to those who are well off and well educated. Some families do have a source of regular income, from business or employment, and increasingly from family members who have managed to move abroad and then send money back as “remittances”. The World Bank reports that official remittances to Cameroon have increased from $35 million USD in 2002, to over $100 million USD in 2006 and 2007 (Ratha and Xu, 2008). Many families place hope in sending one or more of their members “out” so that they will send money back to support those left behind. Families who do not have a regular income, whether through employment or other family sources, feel their disadvantage.

This divide is impacting the education system, as more private schools are emerging supported by those with income, while the quality of teaching in the public schools continues to deteriorate. Disabled parents often do not have the income to send their children to private schools. Children with disabilities often have to attend public schools where the already low standard of education is further compromised by teachers’ lack of ability to accommodate impairments.

Therefore, although legally persons with disabilities are officially afforded certain rights (i.e., Loi n. 83-013; D´ecret n. 90-1516 du 26 Novembre 1990), the perception of many of the participants in this study was that the implementation of these laws is rarely seen in actual practice. This view has been supported by other research. Hashemi explored disability policies and practices in 2006 and found little evidence that the disability laws were being implemented (Hashemi, 2006). A recent report by the US government stated:

> The law provides certain rights to persons with disabilities, including access to public buildings, medical treatment, and education, and the government was obliged to provide part of the educational expense of persons with disabilities, to employ them where possible, and to provide them with public assistance when necessary. Access to public secondary education is free for persons with disabilities and children born of poor parents with disabilities. In practice, there were few facilities for persons with disabilities and little public assistance; lack of facilities and care for persons with mental disabilities was particularly acute. Society largely tended to treat those with disabilities as outcasts, and many felt

> that providing assistance was the responsibility of churches or foreign NGOs. (US Bureau of Democracy, 2008)

Even the Ministry of Social Affairs, which has the mandate to improve the lives of people with disabilities, seems to face significant challenges in making improvements. In a newspaper article that was published during the time of this study, Mr. Soh Rodolphe, Director of Social Protection of Disabled and Older Persons at the Ministry of Social Affairs, was quoted as saying that “jobs for handicapped persons are scarce in Cameroon” and that “handicapped persons need more access to education and training to better fit in the job market” (Yufeh, July 3, 2008).

A particularly ironic and dramatic illustration of the lack of attention to the needs of people with disabilities is apparent in the location of the offices of the Ministry of Social Affairs in Bamenda. The offices are located on the second floor of an office building. The only way to get to the offices is to walk up a dimly lit and irregularly constructed staircase. This staircase precludes many people with physical impairments from visiting the offices. Because the staff of the office cannot meet people with physical impairments in their own offices, other arrangements are sometimes made, including holding meetings in the street below, or people are not seen at all.

What became clear in these responses was that poverty and exclusion wears people down, with or without recognized disability, so that when HIV comes along, they often have very limited energy or optimism to respond. As I was talking in one of the focus groups, I reflected back to the group on what I had been hearing:

> But you know, what has been said about how some people with disabilities…that their lives are so difficult that they don’t care if they have HIV because maybe it will just help them to have a shorter life. If you look at how “they” are trying to

> stop the spread of HIV, that is a very important piece [of information] to understand. Because I wonder if it is not only people with disabilities, but also people who living in poverty or in a very difficult family situation who have that perspective – "why should I care if I have HIV or go for testing, if it will not, you know, if it doesn't make my life better if I have testing?" (June 17, 2008).

The response from the group validated this interpretation. Have depression, emotional pain, and pessimism been adequately considered in public health strategies to combat AIDS in Cameroon and in Africa? It was clear that these issues were not well addressed in this area of Cameroon. Although the pessimism that comes from living in a corrupt and inefficient country is pervasive, it would be fruitful to engage in more scholarly work exploring the relationships and links of these concerns to HIV and AIDS concerns. Conceptualizing poverty as more than an economic issue as has been done by Sen (2000), Nussbaum (2003, 2006) and others could also help to better understand the situation.

Some of the respondents talked about "encouraging" their members to go for testing, but there appeared to be little understanding on the part of the leaders of how psychological factors could deter someone from choosing to be tested, nor of how to deal with them should those kinds of concerns become evident. The representative of Social Affairs attributed lack of willingness to go for testing to "shyness", and believed that making the testing location less visible would be sufficient to attract more people. In the city of the Bamenda, there are extremely few mental health or counseling services, and most are closely tied to AIDS work (for those who have tested positive) and to faith-based services. There appear to be very few options for women and men who are dealing with the constellation of emotional issues that come up in their lives, and even fewer for those who are attempting to cope with the added challenges of impairment and disability.

Lack of health literacy limits DPOs capacities to respond to HIV and AIDS

If adults do not have a good grasp of health related issues and health literacy, there is a significant impact on understanding of HIV and AIDS. If a basic understanding of health and illness are not present, then it is even more difficult to understand the complexities of what the human immunodeficiency virus is, how it is transmitted and affects the biological, physiological and other systems within a person, and how treatment works or doesn't work. The related impacts of how HIV and AIDS related illnesses cause impairments, or affect preexisting disabilities, can therefore also be difficult to comprehend. Over and over again as I conducted the interviews and focus groups, I was aware that the underlying health and prevention assumptions of the questions I was asking were not well understood by some of the participants. This seemed to be particularly acute with people who had few years of formal education.

The concept that there may be an inverse relationship between health education and infection rates is not well established in the province. In fact, what has caused a lot of discussion and speculation over the past several years, but which does not appear to be well explained is that the NWP, with the highest prevalence in the country, also identifies women with higher levels of education having higher prevalence rates (DHS, 2004). The HIV prevalence is believed to increase with level of education, especially among women; women who have primary, secondary or higher education were assessed to be more than twice as likely to be infected than women with no formal education (Measure DHS, 2004). The DHS study also found that people who were unmarried and had lower incomes (characteristics which describe many people with disabilities) also had lower rates of infection. However, disability information was not collected in the DHS study.

The suggestion raised in this study (supported by the results of the recent testing that did occur in Bafut) that those with lower educational levels, which would include people with disabilities, might have a significant risk because they do not have the background to understand the complexities HIV and AIDS, are supported by research emerging from other parts of Africa. Recent studies suggest that in sub-Saharan Africa a shift is occurring: what appears to be emerging is that people with higher educational levels (who previously had higher rates of infection) now seem to have lower rates of infection than the least educated groups (Hargreaves et al., 2008; Poundstone, Strathdee, and Celentano, 2004). Poundstone and colleagues presented a model of how social factors, such as stigma and lack of education can lead to high-risk behaviors and subsequent infection. It could be useful to use these kinds of social epidemiological perspectives in future research to understand better the relationships between a variety of factors and risk behaviors for people with disabilities. This kind of analysis could improve the capacities of DPOs to take specific and effective action with their members.

A literature review conducted by the World Food Program (2006), examining education and HIV, makes a strong case for focusing attention on the impact of general education, (not just AIDS related education) especially of children and younger people. As a result of their review, the authors state:

> The less educated are becoming increasingly vulnerable to HIV infection. While the effect of education on sexual behaviour such as condom use, multiple sexual partnerships and the age of first sexual experience may differ depending on the affected sub-population, and while all the evidence correlating levels of education and HIV prevalence is not yet conclusive, higher levels of educational attainment are increasingly correlated with safer sexual behaviour and thus lower HIV prevalence rates. With the changing face of AIDS, an appropriate response to this recent evidence would be to increase the educational opportunities available to

> young people, particularly for those children least likely to receive them. (World Food Program , 2006, p 13)

Certainly, children with disabilities would be included as being at risk of not receiving education; they are one of the groups least likely to obtain educational opportunities, in Cameroon and in other parts of Africa. Therefore, general inclusive education is an area that requires significant attention.

Influence of religion

This study found that there has been a significant impact from religion and religious institutions on disability organizations. This finding is not surprising, given the cultural and social context. This impact and the relevant relationships have not been well studied or critiqued from a disability rights perspective. Further exploration into the history, current implications of religious influence, and the impact of collaborations could also assist with obtaining better understandings of how the organizational capacities of disability groups have developed as they have to HIV issues.

Gender issues

Both men and women participated in this study through the focus groups, and were invited to participate in the interviews. It is evident that women are showing leadership in some of the groups. For example, the president of the Confidence group is female. The Strong Group has the commitment to having a male to female balance between the President and the Vice President, and at the time of the study, the VP was female. All of the groups have both male and female members.

What is interesting to note is that I did not select focus group members or key informants based on gender but rather based on who had awareness and expertise about disability groups, AIDS issues and related information. Twenty-five people participated, seven women and 18 men. Six of 17 focus group participants were female. Of the 11 key informants contacted, seven were men and all of them participated. Of the four women who were contacted, two did not participate although they initially agreed to. The third woman was a leader in AIDS work and was suggested by one of the male key informants, who said he was going to arrange for her participation. However, she was too busy to participate. The fourth woman also had trouble finding time to participate, and eventually provided her responses in writing rather than in person. Therefore, female perspectives are limited in the study.

It is interesting to consider how this gender imbalance happened, and whether it can at least partially be explained because it reflects the gender imbalance of the people in key positions. I approached all of the people who appeared to be involved in disability organizations in the city, and asked for suggestions of who should be included as key informants. My impression is that most of the female leaders were included in the focus groups because they are currently members of groups. With a few exceptions, disabled women are not in positions in the NGOs, government, or academic work. However, I do have to question whether I missed some women in Bamenda who are well aware of the issues of DPOs and HIV. There were women who were members of the disability groups who did not participate, and community women not affiliated with the groups that I did not approach. When I spoke with some of the women separately about their perceptions of the issues, they were very clear that there is a significant lack of health related understanding, specifically about HIV and AIDS, amongst many of their members. It is also noteworthy that there are no specific groups for women with disabilities, although for some women having a safe place where they could discuss issues might be very useful.

Applicability of the Study for Practice and Social Change

Recommendations for organizations and service providers

This study explored the ways in which DPOs have responded, and been excluded from responding, to HIV and AIDS situation in Bamenda. The findings suggest the need for social change on several levels, and these are discussed in this section on practice, and in the following section addressing research. Participants in the study made several recommendations, and recommendations also emerged from the analysis. Although these recommendations are presented as a list, it is important to remember that they emerge from a complex situation that has developed over time. It is hoped that these findings, the analysis, and the recommendations can be used to continue building on the fledgling efforts that became apparent through the course of the study.

An underlying assumption of these recommendations is that people living with impairments and disabilities have the same human rights as other people; this may mean challenging dominant assumptions in the NWP about what people with disabilities are able to contribute, who should receive funding for the development and implementation of programs, and how organizations, associations and institutions can work together for the optimal benefit of the whole community.

1. Support for DPOs: The DPOs need material, financial and moral support for the work that they are doing. Nothing can be done if the basic organizations' structures are not functioning well. For example, INGOs and governmental

ministries, particularly those involved in health, AIDS, social service, and educational initiatives could do this in several ways. They could plan to involve DPOs more strategically in their own work in order to build DPO capacity through mentoring processes; they could sponsor DPOs directly, providing material assistance; they could make a point of consulting with DPOs for program planning and evaluation, about both disability and non-disability issues, thereby raising the status of DPOs in the broader community.

2. Based on needs, and what is known about effective interventions, organizations and government should develop better responses. A more detailed and complete assessment of the situation regarding HIV and AIDS in the disabled community, and what has been useful in the past could help to plan future programs. There does not appear to have been any detailed needs assessment conducted within the disability community, nor an assessment of how the needs of people with disabilities have been addressed in AIDS programs. Therefore, it is not clear how new initiatives can be connected to and build on previous efforts.
3. Urban and rural disability organizations could develop better understanding and links between themselves so that information about successful AIDS initiatives can be shared and developed. There were several indications that more attention should be paid to the relationships between rural and urban issues. For example, because most of the rehabilitation programs in the province are based in rural areas, there appear to be several strong disability groups in many parts of the province. Several of the Bamenda DPOs also have links or collaborate with rural

groups, and taking advantage of these connections could significantly increase effectiveness of AIDS programming.

4. The leaders of DPOs should be aware of how to confidentially make a referral for appropriate services and support groups. Many of the leaders in this study did not appear to be aware of the full range of services and support groups in the area. Because communication between groups can be difficult (e.g., phone lines are not reliable), expensive, and is not well coordinated, confidentiality may be compromised. It would be beneficial to assist community leaders to have a more complete understanding of these resources and how to access them.
5. There should be better education undertaken with DPO leadership about health issues generally, and about HIV and AIDS and related disorders specifically, to improve their capacity to support their members. Many of the leaders, as well as the group members in this study do not have accurate understandings of HIV, AIDS and other health issues. Members often appear to rely on the leadership for information, and leaders may provide misinformation, not realizing that it is incorrect or to maintain their status, rather than admit they do not have appropriate or current information.
6. There is a need for information materials about a variety of AIDS-related topics that are appropriate to people with various types of impairments and levels of education. For example, people who are blind or who have low literacy levels should have access to audio or Braille AIDS and health information. It was surprising and difficult to learn that most people with disabilities have no consistent access to information that they can refer to in the privacy of their own

homes or with trusted friends. Although the tradition of learning orally is to be acknowledged and respected, it is not sufficient for everyone. People need to have materials to return to when new questions arise

7. More education is needed for AIDS workers: Many mainstream AIDS workers do not have education about disability issues or rehabilitation. They may hold stereotypes and prejudices regarding people with disabilities, and may behave in stigmatizing ways. These attitudes and behaviors may limit how accessible AIDS education, treatment and follow-up actually is, and may discourage people with disabilities from participating in AIDS services. AIDS workers also do not appear to be familiar with appropriate rehabilitation responses to the impairments and disabilities that arise from AIDS. If they have more skills and knowledge, these impairments might be handled more appropriately.
8. There is a need for sensitive and appropriate counseling and mental health promotion. Although there appears to be some AIDS counseling available for some people, it does not seem to sufficient to meet the need, to be appropriate for people with disabilities, or to be reaching everyone who needs it. Some of the participants reported feeling very anxious and worried about their vulnerability to HIV, but did not have many options to address their concerns. Mental health promotion could include a number of strategies such as increasing coping and work skills for improved income, assisting people to develop social support through strengthening their current relationships in the DPOs, and by creating new relationships. These strategies could enhance people’s sense of belonging, empowerment, and resilience.

9. Perhaps the most challenging concern is the poverty and vulnerability that so many participants talked about in one way or another. Given the many difficulties facing community and world leaders regarding the apparent intractability of poverty, perhaps the most we can hope for is that the links between poverty, vulnerability, disability and HIV become more recognized and discussed in mainstream AIDS programs in this area. Attention could be given to the hidden costs of disability such as extra transportation costs, medication and health costs, and loss of wages.

The literature review indicated that the issues facing people with disabilities and DPOs are similar in many places in the world. These findings and recommendations may therefore be beneficial to organizations and service providers in other parts of Cameroon, Africa, and other developing economies.

Recommendations for Future Research

There are several suggestions for future research that emerge from this study. The first area addresses one of the key functions of public health: to assess the public's health. It appears crucial that there be more research to address the lack of information about incidence and prevalence of HIV infection, treatment, and related health issues with respect to disability and rehabilitation. More data should be collected about what is happening, and which programs are effective for reaching people with disabilities. It is important to gather information about what the current rates of HIV infection are among people with disabilities in the province (including by subgroup), and what specific factors increase their risk of infection or avoidance, but this is not sufficient to understand the way forward. Research could also be undertaken to answer questions such as: What are the circumstances that increase vulnerability in women and men with different forms of impairment? For example, are people who are visually impaired more vulnerable and do they have higher than average rates of infection? What effect do sociodemographic factors such as employment, income and age have on the vulnerability of people with disabilities? How can various rehabilitation approaches affect the spread of HIV, income, and the quality of life for people living with HIV and with AIDS? Qualitative and mixed methods studies would be useful for developing more complete and detailed understandings of the experience of people with disabilities who are living with HIV, the impacts of impairments on quality of life, and to understand the perceptions and responses of health and social service providers. Based on these findings, and information from other places, best practice guidelines for providers could be developed

The second potential area for future research is the need to explore issues to the integration of DPOs in civil society and health programming. Because of the difficulty that many respondents appeared to have in responding to what influenced their groups' past goals and activities, it is difficult to construct a meaningful assessment of these key events from the perspective of the groups. Future studies could document more fully how these groups have developed, what barriers they have overcome, and how AIDS as well as other health issues have influenced them. It would be fruitful to address in more detail issues related to why the disabled community and DPOs have not been included in AIDS initiatives more fully. How do stigma and discrimination play out in this context, and what are the responses and resistances? What would be required to bring about more inclusion of these groups into HIV and AIDS work, in the public sector, as well as the private and faith-based sectors? What specific forms of leadership training and capacity building could improve their abilities to act effectively within the city and the province? Gender issues could also be explored with respect to the groups. What are the specific issues facing men and women in forming, leading, and maintaining DPOs?

One possible approach would be to adapt the framework identified by McColl and Boyce (2003) to understand these groups in more detail. In a study of disability advocacy organizations in Canada, five factors were identified that can be used to describe or categorize groups. The three ideological factors were the explicitly stated purpose of the organization, the tactics and methods used by the organization to achieve its purpose, and the organization's perspective on the position of people with disability in society. The two practical factors identified were the membership (the people who make up the organization), and the availability of human and material resources to support the organization. All of these factors were evident in the responses of the Bamenda groups. It could be useful to explore the histories and practices of these groups more broadly (as the current study focused on HIV and AIDS) and in more detail to compare them to DPOs in other places.

A related area of organizational research could be comparative studies. What are the similarities and differences between urban and rural DPOs? How do DPOs compare to other civil society groups in terms of inclusion and exclusion in AIDS efforts – perhaps many other groups are not included as well.

Public health policy and plans should support all individuals in a community, as well as supporting community health efforts. Therefore, a third area for potential study could be to explore how advocacy and change efforts could be carried out in the province, and if some approaches might be more effective than others to support better public and organizational policy development. Given the ongoing problems with the public health system and the potential benefits of reducing HIV rates amongst people with disabilities, it would be particularly important to find effective ways to improve service provision. For example, there is some evidence that traditional leaders have been supportive of DPOs, and advocacy efforts with individual leaders (fons and chiefs) and with the Fons Association might be successful. Evaluation of health communication strategies, such as radio programs or pamphlets distributed to the public through social groups, could also be assessed. However, advocacy efforts with government programs and with the large private health care organizations could also prove to be effective if done carefully and strategically. Since government policy is developed centrally at the national level, effective advocacy efforts could potentially benefit many thousands of people throughout the country if change was implemented.

Finally, intervention studies to carry out research on innovative solutions to these health problems are important. There are many positive indications that the disability community is maturing, and innovative, collaborative interventions might yield significantly positive results in a relatively short period if carried out well. Research to trial new programs, and to improve existing programs, could potentially lead to better outcomes. What would happen, for example, if AIDS community workers routinely visited DPOs as part of a nonthreatening education program about AIDS that was available to all DPOs across the province? Alternatively, if a full range of accessibility guidelines were followed when planning community AIDS education, testing, treatment, and follow-up programs? Several participants spoke of the need for better education about disability and rehabilitation for health and AIDS service providers – a study to evaluate the impact of appropriate training could be useful.

Strengths and Weaknesses of the Study

Several aspects of the study can be considered weaknesses. Four groups were included in this study, with the participation of 15 group members. Most of these people held leadership positions within the groups, and therefore the perspectives of the membership may not be fully represented. Not all of the executive members of each group participated in the study and it is not clear from the information provided about how those who did participate were chosen, although it appeared to be that for the most part, it was that they were simply available at the time of the focus groups.

The language use in this study was predominantly English, and most of the participants had at least conversational abilities in English. Some parts of the focus groups occurred in Pidgin because the participant had difficulty understanding the question in English. Although using English allowed for direct communication with the participants, many of them either directly or indirectly indicated that they were not able to fully understand all of the questions and sometimes had difficulty responding in English. Using a research assistant to facilitate the interviews and focus groups was beneficial overall, but also had certain drawbacks. Despite attempts to provide training in the initial stages of the study, and to provide supervision and debriefing as the study continued, there were a few times that his questions did not reflect the intent of the study. The differences in my social location and race, and therefore the perceived authority or influence, might have also influenced the responses given.

Most of the focus groups and interviews were conducted by telephone, making nonverbal communication more difficult to assess. The research assistant was present in person with participants for all of the focus group sessions, and this helped with reading the nonverbal communication that occurred. Any weaknesses created by the research assistant appeared to be more than balanced by the contributions he made to the study, through his ability to engage participants, his ability to provide input regarding the cultural interpretations of responses, and his own reflections on the study, which he willingly shared with me.

Unfortunately, despite numerous attempts, there was no representation in the key informant group from public health programs, and this could be considered a weakness because several groups discussed their concerns about working with the Ministry of Public Health and other AIDS programs. Public health perspectives would be an area for further investigation. Respondents repeatedly discussed the important role played by those involved in mainstream public health AIDS efforts, and the perceived need for better inclusion of DPOs in HIV and AIDS programs.

A strength of the study was the different sources of information that were used. By talking with insiders, those who are members of the groups as well as those outside of the groups, and the use of documents, more depth was achieved with respect to understanding the complexity of the situation in Bamenda and the organizational capacities of the specific groups. This detail and depth would not have been possible with the use of quantitative measures. The flexibility of the open-ended interview process meant that we could ask additional questions when warranted, and that we could ask for clarification as the conversation unfolded.

Summary

This study provides a snapshot of the complexity in how prominent DPOs in Bamenda, Cameroon have responded to the AIDS situation over the past several years. Despite their desires to do so, these groups have not been able to mount appropriate and adequate responses to ensure the health and safety of their members. Groups have been able to identify some of the needs of their members, but have lacked the array of resources required to address these needs.

The results of this multiple case study clearly illustrate that DPOs were not well included in mainstream AIDS initiatives in this urban centre, and their members may therefore be highly vulnerable to contracting the virus. Although these groups face many challenges, they are looking for ways to meet the needs of their organizations, integrate with other programs, and hold on to optimism that they can be part of the efforts to stem the devastation caused by the virus and its sequelae. Their optimism and resilience should be supported and celebrated in continuing efforts to address the AIDS pandemic.

Although the study has focused on one city, the implications and questions raised may be useful in many other contexts and can inform global social change efforts. Silence about HIV, AIDS and related health and social issues appears to be receding, but misinformation and lack of information remains pervasive. This situation needs to change in order for an adequate response to the AIDS epidemic to occur. Community leaders, including those in positions of power in government, public health, and private health organizations need to take measures to ensure that all people with impairments are included in AIDS education, screening, testing, and treatment initiatives.

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APPENDIX A: MAP

Map of Cameroon showing location of Bamenda

City of Bamenda, Capital of North West Province (now Region), Cameroon

Source: https://www.cia.gov/library/publications/the-world-factbook/geos/cm.html

APPENDIX B: ACRONYMS

List of Acronyms

AIDS	Acquired Immunodeficiency Syndrome
ART	Anti-Retroviral Therapy
CBC HB	Cameroon Baptist Convention Health Board
CBR	Community Based Rehabilitation
CWGHR	Canadian Working Group on HIV and Rehabilitation
DPO	Disabled People's Organization
HIV	Human Immunodeficiency Virus
ICDR	International Centre for Disability and Rehabilitation
ICF	International Classification of Functioning, Disability and Health
NGO	Nongovernment Organization
NWP	North West Province
PHA, PLWHA	Person(s) Living with HIV or AIDS
PRSP	Poverty Reduction Strategy Paper
PWD	Person(s) or People Living with Disabilities
SSA	sub-Saharan Africa
SWP	South West Province
UN	United Nations
WHO	World Health Organization

APPENDIX C: GRAPHIC OF THE STUDY PLAN

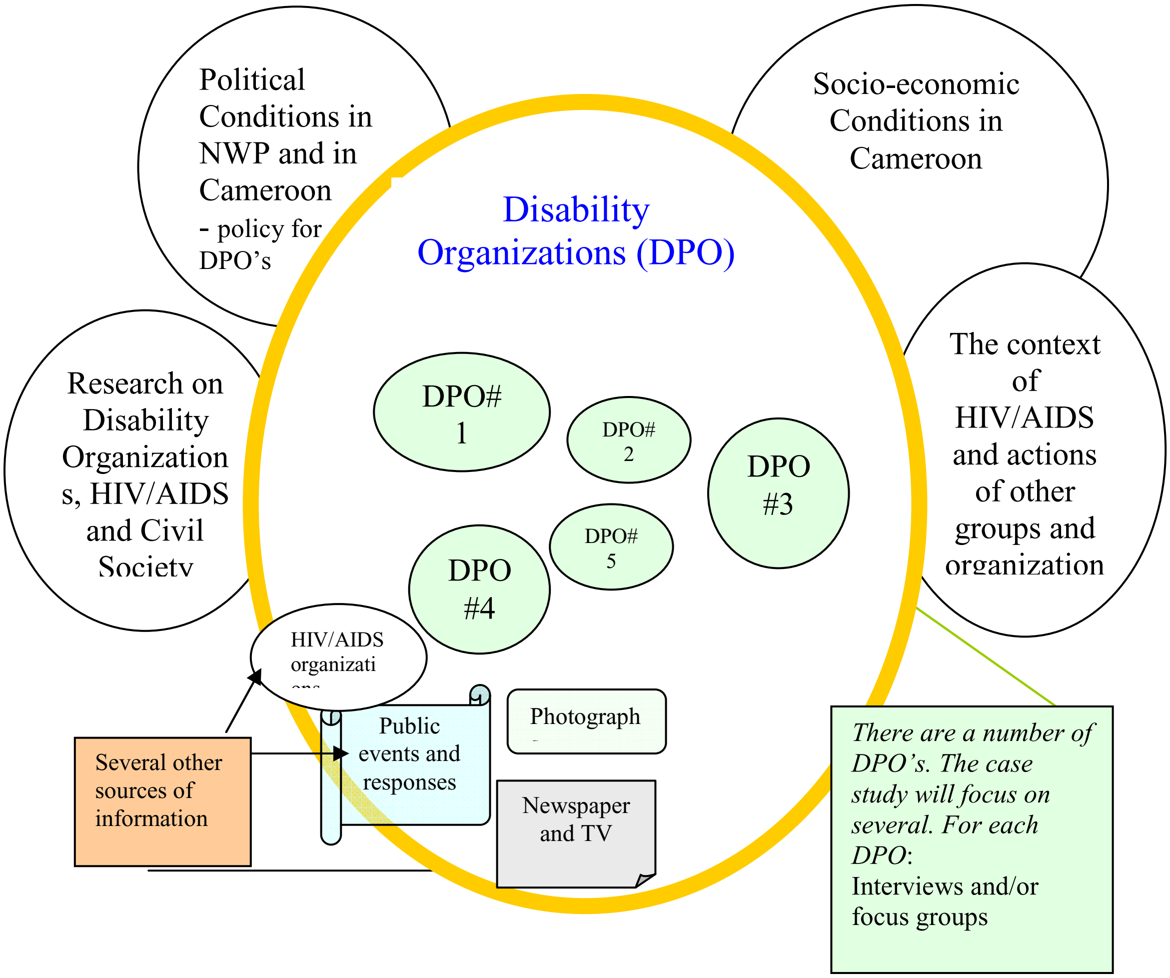
This diagram presents a graphic representation of the plan for *Collective Case Study: The Response of Disability Organizations in Bamenda to HIV and AIDS*

Issues

- People with disabilities may be left out of HIV/AIDS initiatives
- Women and men have significantly different experiences
- There are few opportunities for disability organizations to engage in capacity building, esp. regarding HIV/AIDS
- There is little systematic research linking these issues

Main Research Questions

1. What have disability groups in NWP done (and by extension, what has been missing or prevented) to develop their organizational capacities to address HIV/AIDS issues? What are the contextual factors which have influenced organizational capacity?
2. What could disability groups in NWP do to develop their organizational capacities to address HIV/AIDS issues?
3. From the perspective of disabled peoples groups, what could AIDS service organizations do to support the development of capacity within disability organizations to address HIV/AIDS issues?



There are a number of DPO's. The case study will focus on several. For each DPO:
Interviews and/or focus groups

Adapted from Stake, 2005, p 446 (in Denzin & Lincoln, Handbook of Qualitative Research)

APPENDIX D: INITIAL PLAN FOR THE STUDY

Description	Duration	Location	Communication Format	Comments
Establish advisory group and plan for communication with them	This group will be established early in the study, and will remain for the duration of study (approx 10 months)	Initially Bamenda	Phone, in person, email	This will be a small group of people who can assist with running and organizing the study; will not be members of any groups participating in the study
Contacting potential organizations regarding involvement in the study	3 – 4 days	Bamenda	phone, letters, in person	
Meeting with group leaders to inform them of the study and obtain consent	3 – 4 days	Bamenda	In person	
Interviews or focus groups (obtaining consent at each)	1 – 2 for each person or group; time will be dependent on availability (approximately 8 - 20 days)	Bamenda	In person	Will use semistructured interview guide Approximately 10-20 interviews and 3 or more focus groups
Document collection (public documents such as newspaper articles, organizational brochures)	Ongoing through the duration of the study; to formally end in spring 2008 – date to be determined	Bamenda, internet	Through organizations, internet, newspapers, contacts in the area	
Review of data collected	To begin once IRB approval is	Bamenda and Toronto	Will be done primarily by	

(interview and focus group transcripts, public documents, field notes)	received		researcher alone. Some communication may be made with advisory group for clarification.	
Member checking with participants	approx. 2 months to distribute and collect responses	Bamenda	internet/email and in person, as possible	
Write draft report as dissertation and in clear language	Approximately 3- 4 months	Toronto	By researcher	
Share draft report(s) with Committee	Variable, depending on feedback		Email	
Share report with participants	1 – 2 days	Bamenda	In person meeting with participants, and in writing	
Complete and defend Dissertation			By phone	

APPENDIX E: PLEDGE OF CONFIDENTIALITY AGREEMENT FOR MEMBERS OF ADVISORY COMMITTEE AND RESEARCH ASSISTANT

The Responses of Bamenda Disability Organizations to HIV and AIDS: A Collective Case Study

Name of Signer:

During the course of my activity in participating in the Advisory Committee as an interpreter for this research: ***The Responses of Bamenda Disability Organizations to HIV/AIDS: A Collective Case Study*** I will have access to information, which is confidential and should not be disclosed. I acknowledge that the information must remain confidential, and that improper disclosure of confidential information can be damaging to the participant.

By signing this Confidentiality Agreement I acknowledge and agree that:

1. I will not disclose or discuss any confidential information with others, including friends or family.
2. I will not in any way divulge, copy, release, sell, loan, alter or destroy any confidential information except as properly authorized.
3. I will not discuss confidential information where others can overhear the conversation. I understand that it is not acceptable to discuss confidential information even if the participant's name is not used.
4. I will not make any unauthorized transmissions, inquiries, modification or purging of confidential information.
5. I agree that my obligations under this agreement will continue after termination of the job that I will perform.
6. I understand that violation of this agreement will have legal implications.

Signing this document, I acknowledge that I have read the agreement and I agree to comply with all the terms and conditions stated above.

Signature: **Date:**

Letter of Information and Agreement about the Community Advisory Committee

Name of Signer:

> I have been asked to participate in as a community advisory committee member on the research project titled: I understand that my role is as a voluntary advisor, and I will not be reimbursed for my contributions. I understand that my role will be to assist with providing information that could help the researcher, Lynn Cockburn, with improving the study (e.g., sources for information, dealing with difficulties which may arise). This committee will be active for approximately 6 – 8 months during 2008.
> As I may have access to information, which is confidential and should not be disclosed, I will agree to sign a confidentiality agreement

Signing this document, I acknowledge that I have read the agreement and I agree to comply with the terms and conditions stated above.

Signature: **Date:**

APPENDIX G: INVITATION TO PARTICIPATE IN STUDY AND INFORMATION LETTER

(This letter will be provided in writing, and also be discussed verbally)

Dear President:

The (*I will insert name of organization*) ____________________________is invited to take part in a study of how disability organizations in Bamenda are responding the HIV/AIDS situation. The name of the study is "A Collective Case Study: The Response of Disability Organizations in Bamenda to HIV/AIDS".

Your organization was chosen for the study because it is a disability organization that has been operating in the Bamenda area for more than one year.

This study is being conducted by myself, Lynn Cockburn. I am a doctoral student at Walden University, and this study is part of my doctoral work. As you may know, I live in Toronto, Canada and I am also working with several disability and rehabilitation groups in the Bamenda area. I travel to Bamenda once or twice a year, and am in touch with many people here on a regular basis.

If your organization is willing to participate in this study, please identify at least **one leader/executive member** and **one general member** of the organization who could participate in either an interview or a small focus group discussion with me. More people from the organization are welcome to participate.

Participants should be able to communicate easily in English or in Pidgin.

You can discuss with me (Lynn) exactly who will participate, what they will be asked, and any questions you have about the study.

Please contact me at 7794-3097 or speak to me in person if your organization would like to participate.

Background Information:

The purpose of this study is to look at how community based disability organizations have responded to the AIDS epidemic in the North West Province of Cameroon.

The study will focus on community-based disability organizations. NGO's and private organizations which are dealing with disability issues.

A small advisory committee will assist Lynn with structuring and carrying out the study. People on the advisory committee will agree to keep all personal information that they learn from this study confidential.

A number of sources will be used for information. These will include

- interviews and focus groups with people representing the disability organization,
- documents such as newspaper articles and organizational brochures, and
- field notes collected by the researcher.

It is also possible that participants or members of the advisory committee will provide notes, which could be included.

The study will provide a written record of what these groups have done in the past and are currently doing. It will also make recommendations to disability groups and others.

Procedures:
If your organization agree to be in this study, the representatives will be asked to:

- Sign a consent form
- Participate in one or two interviews and/or a focus group to discuss your organization. The interview/focus group will be between 30 and 90 minutes long. These interviews and focus groups will be tape recorded and written notes will also be made.

Participants will also have the opportunity to comment on the final report if they chose to do so.

Voluntary Nature of the Study:
Participation in this study is voluntary. This means that everyone will respect the decision of participants as to whether or not they want to be in the study. No one should feel pressure to participate.

Thank you very much for your consideration of this request. I look forward to hearing from you at your earliest convenience,

Sincerely,

Lynn Cockburn

Doctoral Student, Walden University

Assistant Professor, Department of Occupational Science and Occupational Therapy
University of Toronto

APPENDIX F: INTERVIEW GUIDE FOR INTERVIEWS WITH KEY INFORMANTS

Thank you very much for agreeing to participate in this study. (Ensure that invitation letter has been fully discussed and that consent letter is signed/witness has signed).

Review Consent Form and ensure forms are signed:

a. Voluntary
b. Can withdraw at any point
c. Don't have to talk about that you are not comfortable discussing.
d. Confidentiality
e. Risks/benefits
f. Ethics approval

As you know, I am focusing on how disability groups are dealing with the HIV/AIDS situation. I would like to start by talking about your perspective on disability organizations more generally to make sure that I really understand your involvment, and then we will talk about the AIDS responses specifically and what you see for the future. I will be asking some questions, but please feel free to talk as much as you like. I am really interested in your perspective and opinions.

Purpose of the disability groups in Bamenda

Are you aware of groups which address disability issues? Rehabilitation issues? HIV/AIDS issues?
What do see are the primary purposes of disability group in Bamenda?
What kinds of groups are they?

Membership

Can you describe what you know about the membership of different groups, in whatever ways you would like.

How do groups get new members?

HIV/AIDS

As you know, HIV/AIDS has had a big impact in Bamenda. We are interested in how disability organizations have responded to this new situation. Can you please tell me what you know about what disability organizations have done in the past and what they are currently doing?
Have these activities been successful? What has led to success or difficulty?

What links are you aware of between disability groups and HIV/AIDS programs or support groups?

What would you like to see in the future?

Is there anything else about disability organizations and HIV/AIDS that you would like to tell me?

Future
What do you think could happen in the area of disability, disability groups, and HIV/AIDS over the next few years? Are you optimistic about what will happen?

APPENDIX G: BACKGROUND INFORMATION

Background Information Form for The Responses of Bamenda Disability Organizations to HIV/AIDS: A Collective Case Study

Please provide the following information as background to the study.

What is your age? ____________

What is your gender? Male Female Other

If you have a disability, please describe it: _______________________________

What is your role with [*insert name of organization that the individual will be responding about*] _______________________

- ☐ President
- ☐ Vice president
- ☐ Treasurer
- ☐ Secretary
- ☐ Other executive member: (please specify)
- ☐ General Member
- ☐ Other (please specify)

How long have you been a member of this organization?

What is your profession or job?

Are you currently working?

APPENDIX H: CONSENT FORM

CONSENT FORM for The Responses of Bamenda Disability Organizations to HIV and AIDS: A Collective Case Study

If you would like to discuss this study and consent form in Pidgin, please ask Lynn Cockburn, the researcher, to do so. Either she or a colleague of hers will tell you about it in Pidgin.
You are invited to take part in a study of how disability organizations in Bamenda are responding the HIV/AIDS situation. Your organization (*insert name of organization*) ______________________________was chosen for the study because it is a disability organization that has been operating in the Bamenda area for more than one year. As an individual, you have been chosen to participate in this study because of your involvement with *insert name of organization*) ______________________________and to talk about the organization. Please read this form and ask any questions you have before agreeing to be part of the study.

This study is being conducted by a researcher named Lynn Cockburn, who is a doctoral student at Walden University. Lynn lives in Toronto, Canada and is working with several disability and rehabilitation groups in the Bamenda area. Please ask her any questions you might have about how this study relates to other work that she and her colleagues are doing.

Background Information:
The purpose of this study is to look at how community based disability organizations have responded to the AIDS epidemic in the North West Province of Cameroon.

The study will focus on community-based disability organizations. NGO's and private organizations which are dealing with disability issues are included.

A number of sources will be used for information. These will include

- interviews and focus groups with people representing the disability organization,
- documents such as newspaper articles and organizational brochures, and
- field notes collected by the researcher.

It is also possible that participants or members of the advisory committee will provide notes, which could be included.

The study will provide a written record of what these groups have done in the past and are currently doing. It will also make recommendations to disability groups and others.

Procedures:
If you agree to be in this study, you will be asked to:

- Sign this consent form
- Participate in one or two interviews and/or a focus group to discuss your organization. The interview/focus group will be between 30 and 90 minutes long. These interviews and focus groups will be tape recorded and written notes will also be made.

You will also have the opportunity to comment on the final report if you chose to do so.

Voluntary Nature of the Study:
Your participation in this study is voluntary. This means that everyone will respect your decision of whether or not you want to be in the study. No one at (*insert name of organization as indicated above)* ____ will treat you differently if you decide not to be in the study. If you decide to join the study now, you can still change your mind later. If you feel stressed during the study you may stop at any time. You may skip any questions that you feel are too personal.

Risks and Benefits of Being in the Study:
There are very few risks to participating in this study. Some of the discussions may bring up difficult feelings or memories for you. The benefit of this study will not be to you directly but will inform how disability organizations can respond to public health issues, particularly HIV/AIDS.

Compensation:
There will be a small monetary gift provided to your organization as a thank you for participating in this study. Each individual will also receive a small gift of food as a token of appreciation. You will receive this gift when the interview or focus group is completed, even if it is cut short if you decide to withdraw.

Confidentiality:
Any information you provide will be kept confidential. A pseudonym will be used for your organization and for you, unless you specifically request that your own name be used. The researcher will not use your information for any purposes outside of this research project. Also, the researcher will not include your name or anything else that could identify you in any reports of the study unless you specifically request that she do so.

Contacts and Questions:
The researcher's name is Lynn Cockburn. The researcher's faculty advisor is Dr. Jeanne Connors. You may ask any questions you have now. Or if you have questions later, you may contact the researcher via (237) 7794-3097 or l.cockburn@utoronto.ca or the advisor at jeanne.connors@waldenu.edu. If you want to talk privately about your rights as a participant, you can call Dr. Leilani Endicott. She is the Director of the Research Center at Walden University. Her phone number is 1-800-925-3368, extension 1210.

The researcher will give you a copy of this form to keep.

Statement of Consent:

☐ I have read the above information. I have received answers to any questions I have at this time. I am 18 years of age or older, and I consent to participate in the study.

Printed Name of

Participant ____

Participant's Written or

Electronic* Signature ____

Researcher's Written or ____

Electronic* Signature ______________________________

Electronic signatures are regulated by the Uniform Electronic Transactions Act. Legally, an "electronic signature" can be the person’s typed name, their email address, or any other identifying marker. An electronic signature is just as valid as a written signature as long as both parties have agreed to conduct the transaction electronically.

APPENDIX I: INTERVIEW GUIDE FOR FOCUS GROUPS

The Responses of Bamenda Disability Organizations to HIV/AIDS: A Collective Case Study

Semistructured guide for Interviews and Focus groups

Thank you very much for agreeing to participate in this study. (Ensure that invitation letter has been fully discussed and that consent letter is signed/witness has signed).

Review Consent Form and ensure forms are signed:

g. Voluntary
h. Can withdraw at any point
i. Don’t have to talk
j. Confidentiality
k. Risks/benefits
l. Ethics approval

As you know, I am focusing on how disability groups are dealing with the HIV/AIDS situation. I would like to start by talking about your organization more generally to make sure that I really understand what it does, and then we will talk about the AIDS responses specifically and what you see for the future. I will be asking some questions, but please feel free to talk as much as you like. I am really interested in your perspective and opinions.

Additional information for focus groups:

What to expect:

m. Time - How long the discussion will last
n. Ground Rules – no right answers, being respectful, talking one at a time, giving everyone a chance to speak
o. The session will be tape recorded.
p. Taking notes
q. At the end I will summarize and prioritize the topics discussed so that we can be sure everyone is on the same page.
r. Any questions?

Purpose of the group

What is the purpose of your group?

What do you say to people to describe your group?

How does this group address disability issues? Rehabilitation issues? HIV/AIDS issues?

What kind of group is it?

Membership
Who are the members of your group?
Where do they come from?
What kinds of diversity do you have in the group? How are people in the group similar and different?

How long have you been a member of the group?
How long have the other members of the group been part of the group?
Why did you join the group?
Has your involvement increased, decreased or stayed the same since you join the group?

What are some of the skills and strengths that members of the group have?
What do you think are the things that this group does well?
What are the problems that this group has?

Average number of members attending meetings in last year and percentage of members serving on subcommittees (Florin et al., 2000)

Attendance rates—measure of group participation; ranked committees by attendance rates and then created high and low attendance groups using a median split (Chinman et al., 1996)

How does your group get new members?

What kinds of participation:
We are interested in the different things that people do in this group. What kinds of activities do people engage in? e.g., developing plans, managing money, organizing the meetings, contacting others who aren't in the group.

Level of participation—classified each participant into one of five levels of participation determined by role and degree of involvement; categories included: Max leaders, Active leaders, Worker members, Active members and Nominal members (Prestby et al., 1990 Granner and Sharpe)

Kinds of participation and number of hours a month, on average that you participate in this group – what do you do with the group? What do others do?
Are there barriers that prevent you from participating in the ways that you would like to? What are they, please describe.

The work of the group
How many committees does your group have? Please describe them.

> Probes: purposes, frequency of meeting, leadership and members, are there other committees?

How do you feel about this group? (probe: pride, frustration, care…)

(How) Do you feel supported by other members of this group?

Is this group successful?

Leadership

How does the leadership of your group communicate with other groups and people in the community?

For example, does the group have contact with common initiative groups, farmers clubs, cultural associations, village associations, community development groups, credit groups or njangis, village/town co-operative groups?

How is your group seen by other groups in this community?
How does your group work with other groups in this community? Does your group ever work on projects jointly with other groups?

Cooperation and networking—How do the partnerships that your organization made has increased cooperation, networking and information exchange with other groups?

Can you talk about how women/men are involved in your organization?

HIV/AIDS

As you know, HIV/AIDS has had a big impact in Bamenda. We are interested in how disability organizations have responded to this new situation. Can you please tell me what your organization has done in the past and is currently doing?

Probes:

Has your group addressed HIV or AIDS specifically in the past? If so, please tell me as much as possible about what they have done, and how successful you feel these activities were.

Are there any materials that we could look at regarding HIV/AIDS?

What do the members think about HIV/AIDS? Do they believe that they are vulnerable to HIV?

What are the biggest problems with respect to doing HIV/AIDS work with your organization? With people with disabilities?

What would you like the organization to do in the future with respect to HIV/AIDS?

Does your organization have any links with HIV/AIDS programs or support groups?

What would you like to see in the future?

What are most proud of with respect to your organization and HIV/AIDS?

What do you think other people in your organization have the most difficulty talking about with respect to HIV/AIDS?

How many of your members are HIV positive? Have died from AIDS? Where did they receive treatment? Are there any problems with this from a disability perspective?

Is there anything else about your organization and HIV/AIDS that you would like to tell me?

Connections to other groups
What methods do your group use to link to other groups or organizations? Do you/other members of your group also participate in other groups? What are they/purposes – how does that help or not this group?

What impact does your group have on people and on your community?
What impact does your group have on other groups in your community?

Future
What do you think will happen with this group over the next few years? Are you optimistic about what will happen?

Do you think you yourself will continue to be involved in this group, and what would you like to be doing?

APPENDIX J: RECORD OF INTERVIEWS AND MEETINGS

The Responses of Bamenda Disability Organizations to HIV/AIDS: A Collective Case Study

FORM*: Record of Interviews/Focus Groups/Meetings/Public Events*

Researcher	Time	To:
Date	Time of write up:	
Location (full details)		
Consent Y/N	If no, comment:	
Pictures Y/N	Comment	
Who was present?		
Synopois of the meeting/interview/focus group	**Summary of key issues raised re: HIV/AIDS**	
Description of room/location The Group's space ☐ public space ☐ borrowed space ☐	Why this location for this meeting? Accessibility?	

Description of organizational orientation		
		other specific issues will be added
self-help	uni-disability	
advocacy	cross-disability	
coalition	disability is one part of group activities	

Description of respondents perspective on HIV/AIDS programming:

Reference made to:
other specific issues will be added

APPENDIX K: DOCUMENT ANALYSIS FORM

The Responses of Bamenda Disability Organizations to HIV/AIDS: A Collective Case Study

<table>
<tr><td>Date of review

Is it fully coded/analyzed or just reviewed?</td><td colspan="2">Full Citation</td></tr>
<tr><td>Source (how was this document obtained?)</td><td>Current Location (how do I find it again?):
Electronic storage (my computer) ☐
Hard copy (my files) ☐
Return to source ☐
Other ☐</td><td>Type of document
Personal communication
Newspaper
Unpublished Research report
Journal
Organizational material (specify):

Other(specify):</td></tr>
<tr><td>Does the document address….?</td><td colspan="2">What does the document say about….?:</td></tr>
<tr><td>☐ Organizational capacity</td><td colspan="2"></td></tr>
<tr><td>☐ Disability</td><td colspan="2"></td></tr>
<tr><td>☐ Rehabilitation</td><td colspan="2"></td></tr>
<tr><td>☐ HIV/AIDS</td><td colspan="2"></td></tr>
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</table>

Curriculum Vitae

Lynn COCKBURN
Assistant Professor, Non Tenured
Associate Member, School of Graduate Studies
CAOT Registration # 29809
COTO Registration # G9301326
OSOT Registration # 10718

1. DEGREES

DESIGNATION	**INSTITUTION**	**DEPARTMENT**	**YEAR**
PhD (Candidate)	Walden University	Public Health – Community Health Promotion and Education	PhD *Expected* 2009
	Dissertation Title: *The Responses of Bamenda Disability Organizations to HIV/AIDS: A Collective Case Study*		
MSPH	Walden University	Public Health	2007
M.Ed.	OISE/University of Toronto	Curriculum	1996
B.Sc.	University of Toronto	Occupational Therapy	1986
B.Comm.	University of Guelph	Hotel and Food Administration	1981

2. EMPLOYMENT HISTORY

a) University of Toronto

DATE	RANK/POSITION	SCHOOL/DEPARTMENT/DIVISION	FACULTY
2005 - present	Assistant Professor	Department of Occupational Science and Occupational Therapy	Medicine
2003- 2005	Lecturer	Department of Occupational Therapy	Medicine
2001- 2003	Senior Tutor	Department of Occupational Therapy	Medicine
1997 -2001	Tutor	Department of Occupational Therapy	Medicine
1994 - 1997	Lecturer	Department of Occupational Therapy	Medicine
1993 - 1994	Community Liaison	Department of Occupational Therapy	Medicine

b) Other Professional Appointments/Contracts

DATE	**RANK/POSITION**	**INSTITUTION**
2001 - 2004		Lynn Cockburn and Associates (Community- based education and consulting in occupational therapy and health)
2001- April 2003	Self-employed Occupational Therapist	COTA Community Rehabilitation and Mental Health Services, Toronto, Ontario
1998 - 2000	Consultant to Mental Health Planning Group	South Riverdale Community Health Centre, Toronto, Ontario

1998	Occupational Therapist	Four Villages Community Health Centre, Toronto, Ontario
1992 - 1997	Occupational Therapist	Clarke Institute of Psychiatry, Toronto, Ontario
1995	Occupational Therapist	Four Villages Community Health Centre, Toronto, Ontario
1989 – 1990	Occupational Therapist	Riverdale Hospital, Toronto, Ontario
1986 - 1989	Occupational Therapist	Clarke Institute of Psychiatry, Toronto, Ontario

1. HONOURS / AWARDS / SCHOLARSHIPS

2007	Northrup Frye Award presented to the InterFaculty U of T and Centre for the Study of Pain Curriculum. I am a member of Core Planning group and Co-Chair of the Evaluation SubCommittee of this group.
2006	ALCA Canada (Alliance of Cameroonians in Toronto) Excellence Award
2003	Educational Excellence for Community Health Care Award, Faculty of Medicine, University of Toronto
2002	Canadian Association of Occupational Therapists Award of Merit
2001	10 Years Volunteer Service Award, Government of Ontario, for volunteer contributions at Toronto East End Literacy

Nominations

2006	Research supervision, Department of Occupational Science and Occupational Therapy
2006	Dave Davis Award, Faculty of Medicine

2. SCHOLARLY AND PROFESSIONAL ACTIVITIES

MEMBERSHIP IN ACADEMIC / PROFESSIONAL SOCIETIES

Associate	The University of Toronto International Centre for Disability and Rehabilitation
Member of:	College of Occupational Therapists of Ontario Canadian Association of Occupational Therapists World Federation of Occupational Therapists Wilson Centre for Research in Education World Federation for Mental Health Canadian Mental Health Association, Toronto Branch OT Psychiatric Interest Group Canadian Public Health Association Ontario Public Health Association Canadian Society for International Health Canadian Coalition for Global Health Research (CCGHR) African Studies Association Canadian Society for African Studies

REVIEWER

2007 - present	Reviewer: Disability and Rehabilitation Book Reviewer, Journal of Occupational Science Book Reviewer, Critical Public Health (Journal)
2006 - present	Reviewer: World Health and Population; Equity in Health; Health Care Policy

2004 - present	Reviewer, Canadian Journal of Occupational Therapy
2003 - present	Reviewer, Canadian Association of Occupational Therapists Conference
2005	Reviewer, World Federation of Occupational Therapist Congress

OTHER

2004 - 2006	Stepping Stones Teacher Training Certificate, Centre for Faculty Development, University of Toronto
1993 - 2003	Chair, Archives Committee, Canadian Association of Occupational Therapists
1999 - 2001	Vice-President, Association of Canadian Occupational Therapy University Programs

SELECTED SIGNIFICANT ADMINISTRATIVE DUTIES AT UNIVERSITY OF TORONTO

a) Department of Occupational Therapy

2001- present	Chair	Professional Curriculum Committee (*Research leave 2005*)
2006, 2002 - 2004	Member	Accreditation Committee
2001 - 2003	Member	Promotions Committee
2000 - 2001	Co-chair	Masters Program Planning Committee

b) Faculty of Medicine

2004 - present	Co-chair	Cameroon Working Group, International Centre for Disability and Rehabilitation
2007	Member	Scholar's Initiative Task Force
2007 - present	Member	Research Committee, International Centre for Disability and Rehabilitation, University of Toronto
2006 - 2008	Member	Dean's Excellence Fund for Innovation in Health Professional Education Adjudication committee
2003, 2004, 2006, 2007	Member	Atkins Teaching Awards Committee
2004 - present	Member	Steering Committee, International Centre for Disability and Rehabilitation
2004 - present	Member	Resource Committee, International Centre for Disability and Rehabilitation
1998 - 2004	Member	Board of Examiners for Occupational Therapy and Physical Therapy
1996 - 2000	Member	Interdisciplinary Transcurricular Committee, SmartRisk/Heroes Initiative

c) University of Toronto

2007 - present	Member	InterFaculty Curriculum Committee
2005 - present	Co-chair	Evaluation Subcommittee, InterFaculty Pain Curriculum, U of T Centre for the Study of Pain
2002 - present	Member	InterFaculty U of T Centre for the Study of Pain, member of Core Planning group and Evaluation Subgroup

2002 - 2005	Member	InterProfessional Education Management Committee

d) External

2006 – Present	Board Member	Bamenda Coordinating Centre for Studies in Disability and Rehabilitation, Bamenda, Cameroon, Founding Board Member
2006 - Present	Board Member	Toronto East Counselling and Support Services, Toronto
1985 - 2006	Volunteer	East End Literacy, Toronto (Research collaboration, Board member, Tutor, Women's Group Facilitator, other group involvement)
1993 - 2003	Chair	Archives Committee, Canadian Association of Occupational Therapists
1999- 2001	Vice-President	Association of Canadian Occupational Therapy University Programs

3. UNDERGRADUATE RESEARCH PROJECT SUPERVISION:

Occupational Science & Occupational Therapy (NB: The Department offered an undergraduate degree up to 2002. Beginning in 2001, it became a graduate program and now confers a MScOT.)

	Completed	In Progress	Total
Research Projects	16		16

Examples:

Faith, Jessica. B.Sc. OT, University of Toronto. The early days of Occupational Therapy at the University of Toronto, 1926-1939, 2002

Wright, Kimberly. B.Sc. OT, University of Toronto. The effectiveness of a website on student OT's knowledge and attitudes of potential OT roles with survivors of landmines, 2002

Reddy, Veda B.Sc. OT, University of Toronto. The effectiveness of a website on student OT's knowledge and attitudes of potential OT roles with survivors of landmines, 2002

Bower, Jennifer. B.Sc. OT, University of Toronto. (Co-supervisor: Michelle Lertvilai.) Outreach Efforts to Aboriginal Students, 2002

Skippon, Johanna. B.Sc. OT, University of Toronto. (Co-supervisor: Michelle Lertvilai.) Outreach to First Nations Students, 2001

Tsui, Meinwen. B.Sc. OT, University of Toronto. Establishing a work co-operative with mental health consumers: A participatory research project, 2000

4. GRADUATE SUPERVISIONS

	Completed	In Progress	Total
Research Projects	19	3	22

Most recent	Successfully Completed	In Progress

K. Chow & H. Aspiras (2008-2009) The experience of living with a physical impairment and disability in the Northwest Province (NWP) of Cameroon		X
C. Monchesky (2008-2009) Evaluation of a Participatory Research Training Course		X
N. Reid (2008) Consumer and Occupational Therapists Responses to a Resource Tool about Occupational Engagement for Adults with Mental Health Issues *Recipient of the OT Psychiatric Interest Group Book Award*	X	
J. Goncalves & T. Copp (2007) Occupational Therapy and Assertive Community Treatment: the experiences of ACT O.T.s in Ontario	X	
K. Wilson (2007) Annotated Bibliography on meningitis and implications for Disability and Rehabilitation	X	
Lisa Wechzelberger (2007) Media portrayals of Stigma, Discrimination, and Employment of Mental Health Consumers: A Review of the Literature	X	
S. Alibhia (2006) Development of an Evaluation Framework for the Immigrant Women Integration Project, East End Literacy	X	
M. Clarke and S. Marwaha (2006) Looking at advocacy and social justice work with an occupational lens: Implications for practice	X	
L. Dart. (2006). Pilot project: Living with a disability in Cameroon (development of book proposal)	X	

5. a) COURSES TAUGHT AT UNIVERSITY OF TORONTO:

Graduate Professional Stream

Year	**Course No.**	***Course Name***
2009 - 2006, 2004	OCT 1262Y	Enabling Occupations with Adults, Part 2 Coordination and Instruction shared with Deirdre Dawson and Pat McKee
2005		*Research and Study Leave; no teaching responsibilities*
2003, 2004	OCT1261H	Enabling Occupations with Adults, Part 1

2003	OCT 1262Y	Enabling Occupations with Adults, Part 2 Coordination and Instruction shared with Deirdre Dawson and Anne Hunt
2002	OCT1261H	Enabling Occupations with Adults, Part 1

Undergraduate

Year	**Course No.**	***Course Name***
1998, 1999, 2001, 2002	OCT 266H	Occupational Therapy Practice in Community Settings selective course. In 2002 Co-instructed with Gita Lakhanpal (Not offered in 2000)
1997	OCT 264H	Community Mental Health, selective course
1995 – 2001	OCT 122Y	Planner and Tutor, Unit 2 Person-Environment Relationships; 1998 - 2000 – Occupational Analysis Labs
1996-2001	OTP 109H	Half Day Fieldwork, Unit 2. Coordination shared with Iris Greenspoon, COTA, and in 2000-01 also with Jill Stier
1996-97	OCT490Y	Trends in Community Health, Coordination shared with Angela Colantonio

b) COURSES DEVELOPED AT UNIVERSITY OF TORONTO:
Graduate Professional Stream

Year	**Course No.**	***Course Name***
2003, 2004	OCT 1262Y	Enabling Occupations with Adults, Part 2
2002	OCT1261H	Enabling Occupations with Adults, Part 1

Undergraduate

Year	**Course No.**	***Course Name***
1995 – 2001		Planner, Unit 2 Person-Environment Relationships

Continuing Education

Year	***Course Name***	**Contact Hours**
2008	Course Planner and Instructor: *Participatory Research in Community Mental Health Settings: How to Develop a Proposal*	3 Day workshop, approx. 21 hours
2006	Member of Planning Committee and Facilitator, *Occupational Justice and Occupational Therapy Practice*, February 16, 2006.	4 Hours

6. EXTERNAL RESEARCH FUNDING

GRANTS RECEIVED AND IN PROGRESS

YEAR	**GRANTOR, PURPOSE OR TITLE, INVESTIGATORS**	**AMOUNT**
2009 - 2011	*Socio Economic Empowerment of People with Disabilities in the*	29,000,000

	North West Province of Cameroon With the Bamenda Coordinating Centre for Studies in Disability and Rehabilitation	FCFA (approx. $71,000)
2008	M. McGillion, J. Watt-Watson, J. Hunter, A. Dubrowski, J. Stinson, L. L. Raman-Wilms, A. Cameron, L. Cockburn, M. Schreiber & T. Dao. ($20,000) *A pilot non-inferiority randomized controlled trial of three simulation learning conditions for interfaculty pre-licensure education pain assessment*. University of Toronto Centre for the Study of Pain	$20,000
2007	COTF, Marita Darybe Award. *The Occupational Engagement Calendar*.	$1,000
June 1, 2006 - July 31, 2008	*Investigation Of An Epilepsy Epidemic In Cameroon.* Funding: Bloorview Children's Hospital Chair in Pediatric Neuroscience **PI:** O. Carter Snead III, M.D., Division of Neurology **Co-I's Sick Kids** Shelly Weiss, M.D., Division of Neurology Irene Elliott R.N. PNP, Division of Neurology Mary Lou Smith, PhD, Department of Psychology Derek Stephens, MSc. Clinical Research Support Unit **Co-I's University of Toronto** Jay Keystone, M.D., Department. of Medicine (Tropical Medicine); Lynn Cockburn, Department of Occupational Science & Occupational Therapy **Co-I's Other** Victor C.W. Tsang, Ph.D. Centers for Disease Control and Prevention, Atlanta, Ga. Marie Fongwa, Ph.D. School of Nursing, University of California, Los Angeles, Innocent Takougang, M.D., Faculty of Medicine & Biomedical Sciences, Departmen Public Health, Yaoundé, Cameroon; Ambanibe Jerome Akeneck, Association of Orphans and the Disabled, Teze, Camero	$41,500

GRANTS COMPLETED

YEAR	**GRANTOR, PURPOSE OR TITLE, INVESTIGATORS**	AMOUNT
2006 – 2008	Canadian Society for International Health (CSIH) and the Interagency Coalition on AIDS and Development (ICAD), *Closing the Gap: HIV, Disability and Rehabilitation in International Contexts*, Canadian Working Group on HIV and Rehabilitation (E. Zack, G. Bone), International Centre for Disability and Rehabilitation (P. Parnes, L. Cockburn) and Cameroon Baptist Health Board (P. Tih, E. Benuh)	$99,880
2002 - 2006	Social Sciences and Humanities Research Council *The Social Construction of Work Integration with Regard to Persons with Mental Illness: Is there a Canadian Context?* B. Kirsh (PI), T. Krupa, J. Bickenback and L. Cockburn	$69,570
2003	McGraw-Hill Ryerson Teaching Technology Integration Fund – to develop web-based curriculum resources for DCM and research related teaching	$ 1890
2001	Lil Hewton Memorial Bursary Fund, Museum of Mental Health Services (Toronto) Inc. Occupational Therapy in Mental Health: The Early Years in Canada. B. Trentham, L. Cockburn, J. Friedland, I. Robinson, (CAOT Archives committee)	$2,500
1999 - 2001	Workplace Safety and Insurance Board. Participatory Research by Injured Workers: From Reflection to Action on Compensation and Return to Work Issues, B. Kirsh (P-I), B. Beardwood, L. Cockburn,	$130,266

	C. Duran, C. Fenech, A. Jean-Baptiste, C. Krever, G. LeBlanc, P. McKee, M. Polanyi	
1999 - 2000	Canadian Occupational Therapy Foundation. Does the Model Matter? A Review of the Literature on Vocational Outcomes for Persons with Severe Mental Illness. B. Kirsh (P-I) & L. Cockburn (co-PI)	$5,000
1998-1999	Ethnocultural Academic Initiatives Fund, University of Toronto. Expanding Ethnocultural Diversity in the Occupational Therapy Curriculum. L. Cockburn (P-I)	$6,600

GRANTS SUBMITTED

YEAR	GRANTOR, PURPOSE OR TITLE, INVESTIGATORS	AMOUNT REQUESTED
2008	Health Canada	$39,000 Pending
2008	Social Sciences and Humanities Research Council, Standard Research Grant	Pending
2005	Social Sciences and Humanities Research Council, Doctoral Funding	Not funded

10. PUBLICATIONS

LIFE-TIME SUMMARY

Chapters in Books	3
Peer-Reviewed Journal Articles	20
Peer Reviewed Abstracts / Presentations at Professional Meetings and Conferences	60
Workshops/Tel-Ed.	12
Popular Articles	6

CHAPTERS IN BOOKS

1. **Cockburn**, L.**,** Trentham, B. (in progress). Meaningful occupation and health. Invited chapter in N. Thapa-Gorder & S. Boight-Radloff (Eds.) *Occupational therapy in prevention and health promotion*. Stuttgart, Germany: Georg Thieme Verlag Publisher.

2. Townsend, E. **Cockburn, L.**, Letts, L., Thibeault, R., Trentham, B. Chapter 6: Enabling social change. In Townsend,& E., Polatajko, H. (2007) *Enabling Occupation II***:** *Advancing an Occupational Therapy Vision for Health, Well-being & Justice through Occupation.* Ottawa: CAOT/L'ACE.

3. Trentham, B. & **Cockburn, L.** (2004). Participatory action research: Creating new knowledge and opportunities for occupational engagement. In F. Kronenberg, S. Algado & N. Pollard, eds. *Occupational therapists without borders: Learning from the spirit of survivors.* Elsevier Science.

PEER-REVIEWED JOURNAL ARTICLES

1. Krupa, T., Kirsh, B., Cockburn, L. & Gewurtz, R. Understanding the stigma of mental illness in employment. *Work*. Accepted.
2. Sobowole, G., M.G., and Cockburn, L. George's Journey: Developing a Career Path with Supported Employment. *Work*. Accepted..
3. Hashemi, G., Cockburn, L, and Ndiforchu, V. Exploring disability related policies and services in Cameroon. Submitted July 2008.
4. Cockburn, L. Disability and Rehabilitation in North West Province of Cameroon. Manuscript under revision, Disability and Rehabilitation, June 2008.
5. Judith Hunter, J., Watt-Watson, J., McGillion, M., Raman-Wilms, Cockburn, L., Lax, L., Stinson, J., Cameron, A., Dao, T., Pennefather, P., Schreiber, M., Librach, L., Kavanagh, T., Gordon, A., Cullen, N., Mock, D., & Salter, M. An Interfaculty Pain Curriculum: Lessons learned from six years experience, Pain, in press.
6. Kirsh, B. and Cockburn, L. The Canadian Occupational Performance Measure: A Tool for Recovery-Based Practice. Psychiatric Rehabilitation Journal, in press.
7. Trentham B., Cockburn, L. & Shin, J. (2007). Health Promotion and Community Development Applications in Primary Health Care Occupational Therapy. Canadian Journal of Community Mental Health. 26 (2), 53-69.
8. Sedgewick, A., Cockburn, L. and Trentham, B. (2007). Occupational Therapy and Mental Health in Canada 1930-1950: Emergence of a Profession. Canadian Occupational Therapy Journal, 74(6), 407-417.
9. Kirsh, B. & Cockburn, L. (2007). Employment outcomes associated with ACT: A review of ACT literature. American Journal of Psychiatric Rehabilitation. 10 (1), 31-51.
10. Trentham, B., Cockburn, L., Cameron, D., Iwama, M. (2007) Diversity and inclusion within an occupational therapy curriculum. Australian Occupational Therapy Journal (s1), s49-s57.
11. Kirsh, B., Krupa, T., Cockburn, L. & Gewurtz, R. (2006) Work initiatives in Canada: A decade of development. Canadian Journal of Community Mental Health, 25 (2). 173 - 19
12. Cockburn, L., Krupa, T., Kirsh, B., Bickenbach, J., Gewurtz, R., Chan, P., & McClenaghan, M. (2006). Conceptualizations of work and psychiatric disability in Canadian disability policy. Canadian Public Policy, 32 (2),
13. Kirsh, B., Cockburn, L. and Gewurtz, R. (2005). Best practice in occupational therapy: Program characteristics that influence vocational outcomes for persons with serious mental illnesses. Canadian Journal of Occupational Therapy. 72 (5), 265 – 279.
    Reprinted in Rehab Review, Fall 2006, 12 – 23.
14. Cockburn, L., Trentham, B. & Kirsh, B. (2005). Educating tomorrow's practitioners: Influences on community mental health occupational therapy education. The Bulletin of the World Federation of Occupational Therapy, 52, 16 – 24.
15. Krupa, K., Kirsh, B., Gewurtz, R. & Cockburn, L. (August 2005). Canadian Public Policy: Special Issue. *Improving the Employment Prospects of People with Serious Mental Illness: Five Challenges for a National Mental Health Strategy*, pp. 59-64. Available from http://economics.ca/cpp/en/specialissue.php
16. Cockburn, L. (June 2005). Providing occupation to prisoners of war in World War II: The contribution of Canadian occupational therapists. Canadian Journal of Occupational Therapy.
17. Cockburn, L. and Polatajko, H. (2004). Using the divergent case method. Medical Education, 38, 550 – 551.

18. Polanyi, M. and Cockburn, L. (2003). Opportunities and Pitfalls of Community-Based Research: A Case Study. Michigan Journal of Community Service Learning, 9 (3), 16 –25.
19. Simó-Algado, S Mehta, N., Kronenberg F, Cockburn, L & Kirsh B. (2002) Occupational therapy intervention with children survivors of war. Canadian Journal of Occupational Therapy, 69(4), 20-29.
20. Cockburn, L. and Trentham, B. (2002) Participatory action research: Integrating community occupational therapy practice and research. Canadian Journal of Occupational Therapy, 69(1), 20-30.
21. Renwick, R., Cockburn, L, Colantonio, A., and Friedland, J. (1997) Preparing students for practice in a changing community environment: An innovative course. Occupational Therapy International, 3(4), 262-273

INVITED PRESENTATIONS AND KEYNOTE ADDRESSES

1. Cockburn, L. (April 23, 2008). Mental Health, HIV and Workplaces: Emerging Issues. Convergence on "Mental Health in the Workplace", University of Toronto and CAMH, Toronto.

2. Cockburn, L., Kirsh, K. and Krupa, T. (October 24, 2006). Research on Canadian Disability Policy Lynn Cockburn Canadian Human Rights Commission Prevention Forum, Holiday Inn Plaza de la Chaudière, Gatineau

3. Kirsh, B. and Cockburn, L. (September 12, 2006). A Working Future: Linking Research and Practice on Work, Mental Health and Mental Illness. PSR/RPS Canada Conference, Kingston, Ontario.

4. Cockburn, L. (June 7, 2006). Supported Employment: Mental Health and Work – Shifting the Focus to a Recovery Journey. Keynote Address: A Journey to Work and Recovery VRTF/TECSS/WIN Information Day, Toronto, Ontario.

5. Cockburn, L. "Be your own best friend". One day workshop, East End Literacy, Toronto, Ontario, April 2, 2005.

6. Cockburn, L. Developing Healthy working relationships: Guidelines for community workers. Workshop with members of the Immigrant Women Integration Project, East End Literacy, May 10 and 17, 2004.

RECENT PEER-REVIEWED ABSTRACTS / PRESENTATIONS AT PROFESSIONAL MEETINGS AND CONFERENCES: (Presenter(s) = underlined)

(Lifetime: 60)

1. Parnes, P., Bone, G., Cockburn, L., Zack, E., Benuh, E. and Bambo, D. Closing the Gaps Between HIV/AIDS, Disability and Development. Presented at the Rehabilitation International Conference, Quebec City, August 2008.
2. Raman-Wilms, L., Cockburn, L., Hunter, J., Watt-Watson, J., Lax, L., Waterston, R. Dao, T., Librach, L., Regehr, G., Pennefather, P., Grad, H., Schreiber, M. Evaluation

of an Interfaculty Pain Curriculum for Health Science Students, 2008 AACP/AFPC Annual Meeting and Seminars, Chicago, Sunday, July 20 and Monday, July 21, 2008

3. Baptiste, S., Friedland, J., Head, B., Cockburn, L., Townsend, E. and Trentham, B. Oral Histories: A valuable tool Paper presented at the Canadian Association of Occupational Therapists conference, Whitehorse, NWT, June 2008.
4. Suffling, K., Nshiom, K., Cockburn, L., Suh, P. and Yuh, S. Preventing disablement, improving workers rights: The Healthy Hands project. 2007 Bamenda Conference on Disability and Rehabilitation. August 18, 2007.
5. Cockburn, L. Building a Collaborative Community Based Disability and Rehabilitation Research Program in the North West Province Bamenda Conference on Disability and Rehabilitation. August 17, 2007
6. Hashemi, G. and Cockburn, L. Disability related policies and resources in North West Province, Cameroon". Paper presented at the Canadian Association of Occupational Therapists conference, July 2007.
7. Cockburn, L. Bambo, D., Benuh, E. Bone, G., Parnes, P, Zack, E. Understanding the links: Disability, Rehabilitation and HIV/AIDS Issues in Africa. Graduate Research Symposium July 18, 2007 College of Social, Behavioral, and Health Sciences, Walden University, Minneapolis, Minnesota.
8. Cockburn, L. (Chair) Mainstreaming Disability Rights in Africa: Can Canadian Universities be Allies? Panel 29, Canadian Association of African Studies, Toronto, May 20, 2007.
9. Cameron, D., Parnes, P. and Cockburn, L. Building Networks to build Inclusion, Canadian Association of African Studies, Toronto, May 20, 2007.
10. Suffling, K., Nshiom, K., Cockburn, L., Suh, P. and Yuh, S. Preventing disablement, improving workers rights: The Healthy Hands project. Canadian Association of African Studies, Toronto, May 20, 2007.

NON PEER-REVIEWED PUBLICATIONS

1. Canadian Working Group on HIV and Rehabilitation (Elisse Zack and Gillian Bone) Cameroon Baptist Convention Health Board (Ezekiel Benuh and Denis Bambo) International Centre for Disability and Rehabilitation, University of Toronto (Penny Parnes and Lynn Cockburn) (March 2008). Closing the Gaps: HIV, AIDS, Disability and Rehabilitation in an International Context: Curriculum for the North West Province, Cameroon.
2. Closing the Gaps: HIV, AIDS, Disability and Rehabilitation in an International Context. FACILITATOR'S GUIDE by the Canadian Working Group on HIV and Rehabilitation, Elisse Zack and Gillian Bone; the Cameroon Baptist Convention Health Board, Ezekiel Benuh and Denis Bambo; and the International Centre for Disability and Rehabilitation, University of Toronto, Penny Parnes and Lynn Cockburn
3. Guidelines for Planning Accessible and Inclusive Meetings, Seminars, Workshops and Conferences in the North West Province of Cameroon. Prepared by the Closing the Gap Team, 2007.

4. Cockburn, L. (2008). Collecting occupational therapy stories enriches retirement for Catherine Brackley, OT Now, 10 (1), January/February 2008.
5. Cockburn, L. (Spring 2007). HIV, Disability and Rehabilitation in International Contexts http://www.apha.org/membergroups/newsletters/sectionnewsletters/public_edu/spring07/HIV+disability+and+rehabilitation+in+international+contexts.htm
6. Cockburn, L, and Friedland, J. Working With People, Figuring Out Possibilities: Pat Fisher.
7. OT Then Column. OT Now, September 2006, 8 5), 27-28.
8. Cockburn L. Kirsh B. Krupa T. Gewurtz R. Mental health in the workplace: why businesses are paying attention. Occupational Therapy Now. 2004 Sep-Oct; 6(5): 2p.
9. Cockburn L. Kirsh B. Krupa T. Gewurtz R. Mental health and mental illness in the workplace: occupational therapy solutions for complex problems. *Occupational Therapy Now. 2004 Sep-Oct; 6(5): 9p.*
10. Kirsh B. Cockburn L. Gewurtz R. Doing work well: preserving and promoting mental health in the workplace. *Occupational Therapy Now. 2004 Sep-Oct; 6(5).*
11. Cockburn L. Kirsh B. Krupa T. Gewurtz R. Occupational therapists' impact on mental health in the workplace. [Journal Article] Occupational Therapy Now. 2004 Sep-Oct; 6(5): 3p. AN: 2005103772.
12. Kirsh, B and Cockburn, L. Boost Employee Mental Health — Boost the Bottom Line! Workplace Today, workplace.ca (http://www.workplace.ca), Friday, October 01, 2004.
13. Cockburn, L (2004) “Worker co-operatives”. Encyclopaedia of Disability. Albrecht, G. Ed. Sage publications.

RECENT WORKSHOPS

1. Cameron, D. and Cockburn, L. 2006. University of Toronto International Health Program Health and Human Rights conference. (presenter)
2. Occupational Justice workshop, (organizer and presenter) University of Toronto, Feb 16, 2006.
3. Kirsh, B. and Cockburn, L. June 7, 2005. Improving Employment Outcomes: Focusing on Characteristics. Invited presentation to the Employments Works! Committee at the Centre for Addiction and Mental Health, Toronto, Ontario.

POPULAR ARTICLES

1. Kirsh, B., Cockburn, L., & Gewurtz, R. What do we know about "doing" at work? An occupational perspective on mental health in the workplace. Sense of Doing column in OT Now, September 2004.
2. Cockburn, L, Kirsh, B., Krupa, T. & Gewurtz, R. OT Now, (September 2004) Mental health and mental illness in Canadian workplaces: OT Solutions for complex problems.
3. Cockburn, L. (2003). Have you got a couple of minutes? Academic Medicine, 78: 876.
4. Cockburn, L. (2001). The greater the barrier, the greater the success: CAOT In the 1940’s, OTNow, 3(2), March/April, 2001.
5. Cockburn, L. (2001) The Professional Era: CAOT in the 1950’s and 60’s. OTNow, 3(3), May/June 2001.
6. Cockburn, L. (2001) Change, Expansion and Reorganization: CAOT during the 1970’s. OTNow, 3(4), July/August 2001.