

**Vulnerability and Agency: Reframing Disability Through the
Capabilities Approach.**

A case study of women with physical disabilities in Lusaka, Zambia

by

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ABSTRACT

This study explores the concepts of vulnerability, agency, and actors with relation to the capability development and deprivation of women with physical disabilities in Lusaka, Zambia. Based in the human development paradigm and Sen and Nussbaum's Capabilities Approach, it seeks to critically explore what impact being born, raised, and living as a woman with a physical disability in a developing country has on the development of capabilities. It also seeks to identify and analyze the involved processes, actors, and environmental factors. A main finding is that capability deprivation for women with physical disabilities is not simply caused by disability, or by gender, but by a multitude of factors. These include: the environment, social contexts, and relative poverty in which the women live; the particular cultural repertoires that surround them; and the actors with whom they interact. However, disability can, and often does, exacerbate the complex life situations in which the women find themselves.

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ACRONYMS

CA	Capabilities Approach
CRPD	Convention on the Rights of Persons with Disabilities
CSO	Central Statistical Office Zambia
DALY	Disability Adjusted Life Years
DIF	Disability Initiative Foundation
DPO	Disabled Persons Organizations
EWDNA	Ethiopian Women with Disabilities National Association
FNDP	Fifth National Development Plan
GoZ	Government of Zambia
IMF	International Monetary Fund
ICF	International Classification on Functionings, Disability, and Health
IGA	Income Generating Activity
INGO	International Non-Governmental Organizations
MCDSS	Ministry of Community Development and Social Services
MDG	Millennium Development Goals
NGO	Non-Governmental Organization
NTD	National Trust for the Disabled
PRSP	Poverty Reduction Strategy Paper
PWD	person(s) with disabilities
SAP	Structural Adjustment Program
SNDP	Sixth National Development Plan
UN	United Nations
UNDP	United Nations Development Program
WB	World Bank
WHO	World Health Organization
WRD	World Report on Disability
WWD	wom(a/e)n with disabilities
YLD	Years Lost to Disability
YLL	Years Life Lost
ZAFOD	Zambian Federation of Disability Organizations
ZAMDHARP	Zambia Disability HIV/AIDS Human Rights Program
ZAPD	Zambian Agency for Persons with Disabilities
ZNADWO	Zambian National Association of Disabled Women

CHAPTER 1: INTRODUCTION AND BACKGROUND

Disability is part of the human condition. Almost everyone will be temporarily or permanently impaired at some point in life, and those who survive to old age will experience increasing difficulties in functioning. Every epoch has faced the moral and political issue of how best to include and support people with disabilities.

- WHO, World Report on Disability, 2011:3

On 3 May 2008, the Convention on the Rights of Persons with Disabilities (CRPD or the Convention) came into force with 50 ratifications and 137 signatories, with 81 of these coming on the first day. In fact, the Convention came into effect in just over one year, a feat rarely achieved. The Convention is seen as a paradigm shift, from characterizing people with disabilities (PWD) as objects of charity to firmly entrenching them as equal human beings and active members of society. However, necessary changes in attitudes and breaking down of societal barriers are longer to take root than a change in international rights covenants. Consequently, PWD are still subjected to stigma and abuse that lead to limitations in the development of their capabilities and functionings¹. Although this recognition of human rights and equality is an important step forward, we do not consider this to be enough to enact lasting change and improvements in the lives of people with disabilities around the world.

In 2011, the World Health Organization (WHO) and the World Bank (WB) released the first *World Report on Disability and Health*. It was also the first update to global disability data in over 30 years. It is undoubtedly an important contribution to the disability advocacy movement, but it is also a clear indication of how disability issues previously were not a concern to the global development agenda. The report indicated that, worldwide, there are more than 1 billion people, or about 15% of the world's population, that live with some form of disability. This estimate includes severe, moderate, and mild physical, mental, or sensory impairments. Within that, between 110 and 190 million people live with severe disabilities (equivalent to conditions such as quadriplegia, severe depression, or blindness). (WHO WRD, 2011)

Around 80% of people with disabilities live in the developing world and experience social and economic disadvantages and abrogation of their human rights. (WHO, 2008) PWD are in fact the largest minority in the world and account for some of the most marginalized people in the world. (WHO, 2008) On the whole, they are more likely to be

¹ Capabilities are understood as practical opportunities for a person to do and be what they want while functionings are understood as the actual achievements the person can be or do. (Sen, 1999)

poor than those without disabilities due to exclusion and accessibility issues. Many people with disabilities live in worse socio-economic conditions than those without disabilities: they have higher rates of poverty, lower rates of employment, and are generally less educated. (WHO WRD, 2011) Likewise, poor people are more likely to develop a disability due to limited access to health care, less awareness of the issues leading to disabilities, and generally riskier behaviors through the drive to survive. (WHO WRD, 2011) Despite this, the inclusion of disability in development and international global health initiatives has been severely neglected. Furthermore, there is unfortunately very limited gender-disaggregated data and an estimate of the number of women with disabilities, of particular interest to our research, is unavailable.

The challenges faced by women with disabilities (WWD) in developing regions, such as sub-Saharan Africa, are of particular concern since, as a group, they suffer the multiple prejudices of gender, poverty, disability, and, in Zambia, our country of focus, HIV and AIDS. (WHO WRD, 2011) The importance of women in the development of society is undeniable as they are often the sole providers of care, food, water, health and education to wide networks of children, as well as sick and elderly persons – irrespective of their own health and mobility. “The limited role of women’s active agency seriously afflicts the lives of *all* people – men as well as women, children as well as adults.” (Sen, 1999:191) When these women are marginalized, their role is limited and development can stagnate.

While the types of disabilities and their severity are varied and have different effects depending on the context in which the person with the disability lives, our research will focus only on physical disabilities that lead to mobility impairments. The causes of physical disabilities in the developing world are wide-ranging and can include: wounds from armed conflict, injuries, HIV/AIDS complications, polio, leprosy, malnutrition, chronic diseases, maternal health conditions, developmental disabilities and congenital disabilities. Many of these factors are present in Zambia. (World Bank, 2004; WHO, 2008) Moreover, disabilities can have a very important impact on health indicators. As mentioned, those with disabilities are more vulnerable to health issues as they have to deal with accessibility issues, limited access to economic markets, social exclusion and discrimination, and possibly weaker health due to underlying causes. (WHO WRD, 2011) It has also been shown that PWD around the world are more vulnerable to sexual violence, which can lead to a variety of health issues including HIV, as they are viewed to be asexual, less than human, or virgins and easily taken advantage of. (Groce, 2004)

Although men also suffer a wide variety of disabilities, women are more vulnerable to acquiring disabilities due to domestic violence, substandard maternal health services, and their general lack of value in society. (Elwan, 1999; Nosek, 2001; Human Rights Watch, 2007) Furthermore, there is lack of health education, prevention, and promotion for persons with disabilities in general. Environmental changes also lead to increased vulnerability for PWD that may find it more difficult to adapt. (WHO WRD, 2011) Finally, with regard to the Millennium Development Goals (MDG), the UN General Assembly has admitted that the particular situation of persons with disabilities was not taken into account during their formulation. There has recently been an effort to make the MDG more inclusive of PWD, however, this will likely not happen before the 2015 deadline. (UN Enable, 2009)

As the above clearly shows, PWD, and women with disabilities in particular, fall within the framework of 'vulnerable groups'² subject to extreme poverty. (Ruof, 2004) This curtails their ability to develop the capabilities and functionings they wish and to live a life they value. Despite these challenges, PWD and WWD are often overlooked when project proposals, funding, and implementation take place. The concept of vulnerability and vulnerable groups will be essential to our critical analysis of the capability development of WWD, as will be the concept of actors. In Zambia, WWD were initially supported by the state following the country's independence in 1964. However, following the economic reforms from Structural Adjustment Programs in the 1980s, this source of support diminished or altogether disappeared. (Noyoo, 2010) Now, the few government agencies still tasked with the status of WWD are supplemented by a wide range of civil society actors, including donor countries, large NGO and INGO tasked with improving the status of WWD. (personal observations, 2010)

Have these previously mentioned actors really had a positive impact on the lives of women with disabilities in Zambia or are there other actors that need to be considered? Can the concepts of vulnerability and agency play a role in determining the quality of life of women with disabilities? This study will look at the situation of a sample of women with disabilities in Zambia to understand the concepts of 'vulnerability' and 'agency' as well as 'human development' through Amartya Sen's Capabilities Approach. This will be explored through the analysis of the life stories of 15 women with disabilities as well as through specific interviews with seven organizations working on the subject of disability and equality

² Vulnerable groups are social groups who experience limited resources and consequent high relative risk for morbidity and premature mortality. (Ruof, 2004)

in Zambia. Furthermore, the theoretical concepts of 'labeling' and 'actors' will be essential to our discussion.

The purpose of our research is to explore the interaction of these concepts in the context of the life of women with physical disabilities living in Lusaka, Zambia. Despite being labeled as a vulnerable group needing external assistance, and considering the various social and economic constraints they face and which may be exacerbated by their physical condition, we argue that women with physical disabilities in Zambia nevertheless express their own agency and develop their capabilities while interacting with their own social worlds. The concepts of capabilities, functionings, agency, and freedom are what we view as being essential in the achievement of a life that is valued. They are the ends that 'development' must aim for, they are what we will be searching for in the lives of WWD.

The main objective of the research is to critically explore what impact being a *woman* with a *physical disability* born, raised, and living in a *developing country* has on the development of her capabilities. The two subsequent objectives are:

1. Through a life histories approach, identify and analyze the processes that have led women to their current capability development level. This will be done using one-on-one interviews with women conducted in 2009 and 2010. These will be supplemented by discussions with key informants and observations.
2. To understand the role of social actors (organizations of all sorts including government, NGO, churches, families, and friends) and the arena, or entourage (be it the neighbourhood or other social spaces such as markets and schools where women go) in the development or hindering of capabilities. This is achieved through interviews with organizations, their clients, and informed community members as well as through the information provided during the life history interviews.

We will further explore the supports available to and constraints faced by the women in our sample. These affect both their ability to reach the functionings they target and the processes that lead to capability development. Although we initially posited that the roles played by government and civil society are essential to these processes, we will prove that actors closer to the day to day lives of WWD, such as their families and community, have a bigger impact. Moreover, we will argue that disability itself is not sufficient to explain the

social status of these individuals and that it is essential to include their social world and their individual characteristics, such as gender and their environment, into the question.

The following text will be divided into 6 further sections:

- Chapter 2 will provide the theoretical framework of our research, based in critical development and critical disability theory and furthered by the Capabilities Approach pioneered by Amartya Sen. Section 1 will explore current schools of thought on development, capabilities, poverty, global health, disability, stigma, vulnerability, and gender. Section 2 will provide the theoretical operationalization of our framework, taking a deeper look at the links between disabilities and the Capabilities Approach, the concept of agency, and the Actors Oriented Approach.
- Chapter 3 will outline the context of our research. Section 1 will provide a general overview of Zambia, its socio- and politico-economic history, its demographic and health profile, and the gender relations operating within its society. Section 2 will further explore the situation of disabilities and women with disabilities in Zambia. Finally, section 3 will describe our specific research context in the peri-urban regions of Zambia's capital, Lusaka.
- Chapter 4 will explain our methodological underpinnings as well as our data collection and data analysis tools.
- Chapter 5 will relate the results from our research. Section 1 will provide an overview of the women who were part of our case study. Section 2 will present the various actors who participated and were identified by our research. Section 3 will explore the four capabilities we chose to analyze.
- Chapter 6 will provide the analysis of our results and answer our research question.
- Chapter 7 will be our concluding remarks.

CHAPTER 2: THEORETICAL FRAMEWORK

2.1 Conceptual Approaches to Vulnerability and Disability in the Domain of International Development

This section will serve to detail our views on the development paradigm and the disability world, while exploring the concepts of global health and vulnerability. We will have a particular focus on women throughout. We find it particularly important to outline the progressive changes in development theory, policy, and practice, as this leads to a better understanding of how the context in which the women in our case study has changed over time. As Zambia is considered to be one of the poorest and least developed countries, currently benefiting from many international donor initiatives and a variety of development projects, understanding the overarching global paradigm is important. Moreover, as the women in our research group are often characterized as belonging to one or many various ‘vulnerable’ populations and ‘target’ groups, it is essential to understand how this discourse has come to pass and the benefits and consequences it can entail. Our aim with this section is to propose and highlight new and innovative methodologies with which to study vulnerable populations, such as human development and Amartya Sen and Martha Nussbaum’s Capabilities Approach.

2.1.1 The Development Paradigm – Towards New Perspectives?

Development: We use the term here to refer to processes of social and economic change which have been precipitated by economic growth, and/or specific policies and plans, whether at the level of the state, donor agencies or indigenous social movements. These can have either positive or negative effects on the people who experience them.

Development is a series of events and actions, as well as a particular discourse and ideological construct. We assume that these are inherently problematic; indeed, some aspects of development are actively destructive and disempowering.

(Gardner and Lewis, 1996)

With the increase in international assistance through aid programs, massive bilateral and multilateral loans, Structural Adjustment Programs (SAP), and Poverty Reduction Strategy Papers (PRSP), *development* is no longer seen as only a political and economic goal, but also as an object of study and a legitimate career path and profession. (Kothari, 2005) It is also an important tool for international relations and trade. The more vocal critics argue that “international aid is not designed to change the structure and dynamics of relations between North and South. On the contrary, it is fully integrated into the current

international financial architecture in terms of its goals and values—and its architects.” (Katz, 2004) In keeping with this critique, the expected results of decades of development projects - eradicating poverty and permitting all humans to live in dignity - are far from having been achieved. Taken over by neoliberal policies and principles, the core objectives of development are in crisis. (Kothari, 2005) They have been hijacked by the basic objectives of economic development and growth.

Our research participants – labeled as women, living in poverty, from an ‘underdeveloped’ country, part of the ‘marginalized’ population of persons with disabilities – should be a ‘perfect’ target group for development worker and academics. However, despite this, development programs have, overall, ignored them. These labels, and the images they evoke, are a result of the evolution of the concepts of development and international aid. Moreover, they have become important to different groups, at different times, for different reasons, and are being addressed by different actors – be they government, NGO, civil society, churches, families, multilateral organizations, corporations. This leads to an ever-increasing multiplicity of actors. The concept of labels, first advanced through the work of Erving Goffman on the subject of stigma, will be detailed later. To understand how we have come to this development paradigm laced with labels, and further understand the influence of this paradigm on the lives and livelihoods of women with disabilities, we will first explore the history of ‘development’ as we know it.

In the opening chapter of *Development Dictionary: A guide to knowledge as power* (2009), a critique based in post-development theory, Wolfgang Sachs tracks the history and various meanings of the term. It was first used in the 18th and 19th century in biology and the natural sciences to define “transformation that moves towards an *ever more perfect* form” (by the likes of Wolff and Darwin). In the 19th century, Durkheim, Engels, and Marx appropriated the term for the social sciences. For Durkheim, society evolves from a ‘primitive’ to a ‘modern’ form. (Gardner and Lewis, 1996) Marx had a similar argument, whereby he viewed society to evolve through changes in the mode of production “with the same necessary character of natural laws” (i.e. moving towards an ever more perfect form.) (quoted in Sachs, 2009:3) In this light, development was mostly linked to the improvement of technology, the economy, and infrastructure of a region or country. The late nineteenth and early twentieth century led to added meanings for the term development and closely linked it to the concept of colonialism. Colonialism, although primarily used for the economic development of metropolises, involved an aspect of moral obligation. The colonizers saw themselves as “rational agents of progress” while the colonized, or natives, were seen as

backwards and childish needing help to become civilized. (Gardner and Lewis, 1996) This moral obligation was further enshrined in 1939 when the British government changed its “Law of Development of the Colonies” into the “Law of Development *and Welfare* in the Colonies.” (Sachs, 2009:5, their emphasis) This change in semantics led to a paradigm shift, where the colonizer had a role in both developing a country economically and in caring for the natives. Sachs argues that semantically linking the “level of civilization to the level of production” led to our more recent conception of ‘development’. (Sachs, 2009:6)

The term ‘underdevelopment’ and its connotation of the poor, the miserable, the inadequate, the victims, and so on, was popularized by President Henry S. Truman’s inauguration speech on January 20, 1949. (Rist, 2001:116; Sachs, 2009; Servet, 2010) Point Four of his address reads:

“we must embark on a bold new program for making the benefits of our scientific advances and industrial progress available for the improvement and growth of underdeveloped areas. More than half the people of the world are living in conditions *approaching misery*. Their food is *inadequate*. They are *victims* of disease. Their economic life is *primitive and stagnant*. Their poverty is a *handicap* and a *threat* to both them and to more prosperous areas. For the first time in history, humanity possesses the knowledge and skill to *relieve the suffering* of these people. The United States is pre-eminent among nations in the development of industrial and scientific techniques. The material resources which we can afford to use for assistance of other peoples are limited. But our imponderable resources in technical knowledge are constantly growing and are inexhaustible.” (quoted in Rist, 2001, our emphasis)

This speech led to a shift in how we would come to view others and ourselves. No longer the ‘colonized’ and the ‘colonizer’, where one was viewed as being inherently stronger or weaker than the other, but the ‘developing’ and the ‘developed’ countries – all part of one spectrum of being and able to improve one’s self and ‘develop’ into a higher and more perfect state. (Rist, 2001)

The 1960s saw the rise of the Modernization Theory, which was heavily based in the evolutionary political economy theories described above and popularized by the work of W.W. Rostow. Modernization sees countries, or societies, on a linear development path, leading towards industrialization and urbanization in a world where secularism, universalism and profit are king. (Gardner and Lewis, 1996) Rostow identified five economic stages of development: “(1) the traditional society, (2) the preconditions for take-off, (3) the take-off, (4) the drive to maturity, and (5) the age of high mass-consumption.” (Rostow, 1960, quoted in Rist, 2001) However, the theory did not take long to show its weaknesses. The most

fundamental criticism was that, by ignoring individual country histories and political factors and putting them on a linear path of development, modernization fails to understand the real causes behind underdevelopment and poverty. Every country context is different. (Gardner and Lewis, 1996) Another criticism, closely linked to our research population seen as ‘the disabled’ or ‘women’, is that of homogeneity.

“Disastrously (for the poorest and for some minorities), modernization theory does not distinguish between different groups within societies, either because it assumes these to be homogenous (the ‘mass poor’) or because it believes that eventually the benefits of growth are enjoyed by all (...) (At the micro level) (h)eterogeneity exists not only between households, but also within them” (Gardner and Lewis, 1996:15)

Today, despite the many criticisms of modernization theory, one of the most widely understood definitions of development remains that of sustained economic development, which focuses on continued Gross Domestic Product (GDP) growth, levels of industrialization, and the primordial role of an open market in creating wealth and development. (Rist, 2001; Donnelly, 1999) It is assumed that greater affluence would lead to increased private incomes and a ‘trickle-down effect’. In the event the trickle-down did not occur, governments would simply step in to remedy the situation. (Stanton, 2007) To use Rist’s terminology, unfortunately, these ‘beliefs’ time and again proved to be unfounded, leading to highly concentrated and unequal growth. (Hicks and Streeten, 1979, quoted in Stanton, 2007) They ignore what Drèze and Sen have dubbed *unaimed opulence* where there is “maximization of economic growth without paying any direct attention to the transformation of greater opulence into better living conditions.” In this case, increasing GDP does not improve the lives of the many – it in fact leads to widespread poverty, illiteracy, ill health, child labor, crime, and starvation. According to their research, there is no inevitable connection between GDP and the quality of life without public action. (Stanton, 2007) It is no surprise then that several authors consider development as a fallacy and ‘sustainable development’ as an oxymoron. (Sachs, 2009; Esteva and Prakesh, 1998; Rist, 2008)

Despite this, growth-based development maintained its prominence and those who were left out or, worse, deprived through these policies started to find new ways of advocating for support. Salamon *et. al.* (2003) have coined it the *global associational revolution*. They cite the breakthroughs in information technology and increased literacy as a main factor, helping people realize that their circumstances are not immutable and that

they are not alone in the fight. Grassroots organizations, church groups, community-based programs, and even larger national and international non-governmental organizations have been able to sprout up and connect, awakening activism and environmental, gender, and ethnic consciousness. (Salamon et. al. 2003) Moreover, the dissatisfaction that has grown towards the market and state mechanisms has spurred individuals and organizations to action. (Salamon et. al., 2003) This has led to a veritable multiplication of actors on all levels and all stages – sometimes acting in concert, sometimes in opposition. As Cannon notes, NGO and civil society are ‘filling in gaps’ for the government, but may also be motivated more by profit than by service. (Cannon, 1996) The concept of civil society and grassroots actors are integral to our research and will be further developed below.

The focus on growth has led to neoliberal principles taking over development policy in the 1980s and ‘responsibility’ for development shifting from the international community to International Financial Institutions (such as the World Bank, the International Monetary Fund, and regional banks). Structural Adjustment Programs (SAP) - leading to privatization of state-owned assets, deep cuts to governmental social and health programs, and deregulation of markets -- were introduced in an attempt to stave off the Latin American and African debt crises. A ‘lost decade’ of development followed; the developing world was worse-off than it had been before intervention. (Hulme, 2007) Following this, a new form of development, *human development*, gained ascendancy. Although it had been argued for previously by the likes of Rawls, Sen, and Nussbaum, the release of the *Human Development Report* in 1990, under the direction of Mahub ul Haq working for the United Nations Development Program (UNDP), was the game changer. Its conceptual framework, based heavily in Amartya Sen’s Capabilities Approach to social welfare (described further below), created the Human Development Index (HDI). The HDI emphasizes the importance of ends (like decent quality of life) over means (like GDP). (Stanton, 2007) Now in its 21st edition, the Human Development Report has managed to popularize human development as a new understanding of wellbeing and to provide an alternative to GDP per capita as a means to measure development over time and across countries. (Stanton, 2007)

In the decade that followed the HDR, there was a plethora of international conferences focused on poverty, debt, and human rights. The conferences of 1995 were of particular relevance to our research: the World Summit on Social Development in Copenhagen -- where the world agreed that poverty reduction was the main goal of development -- and the Women’s Summit in Beijing -- where the goals of gender equality and women’s empowerment were reaffirmed. (Hulme, 2007) The decade culminated in the

creation of the Millennium Development Goals (MDG) in 2000, to be achieved by 2015. The eight goals are an amalgamation of other goals set during the many conference of the 1990s. (Hulme, 2007) They are:

1. Eradicating poverty and hunger
2. Achieving universal primary education
3. Promoting gender equality and empowering women
4. Reducing child mortality
5. Improving maternal health
6. Combating HIV/AIDS, malaria, and other major diseases
7. Ensuring environmental sustainability
8. Developing a global partnership for development (Sachs, 2005)

The MDG project took hold of the development agenda and the vast majority of projects undertaken today are done within this framework. Taken at face value, the MDGs seem to be an extension of the human development paradigm. However, upon further inspection, the goals continue to be a means to promote neoliberal economic development. (Saith, 2006) While the HDI does not include income poverty in its calculations, the first and most prominent goal of the MDG is GNP and the dollar-a-day income poverty line popularized by the World Bank. (Saith, 2006) This undermines the Human Development paradigm's definition of poverty not as a lack of income but as an inability to meet basic needs and capabilities. Saith paints a picture of the MDG as an exercise that has taken "one step forward and two steps back", where the main stance to eradicate *inequality* was watered down to the simple reduction of forms of *absolute poverty*. Saith continues: "the MDG exercise reduces the development issue to a ghettoized state, with a focus primarily on the developing economies. (...) It excludes all the poor and the excluded in the rich countries from the frame of reference. The issue of inequality is thus entirely suppressed." (Saith, 2006)

Despite this, as well as further blows to the neoliberal and growth-led development theory (such as the crash of the Asian Tigers in 1997 and the global financial crash of 2007 where unchecked market-based economics showed their failings), the development paradigm is still nebulous. Although human development is gaining in influence, the belief in growth-led development continues to taint the scene. Aristotle once said: "wealth is evidently not the good we are seeking; for it is merely useful and for the sake of something else." Nobel laureate Amartya Sen (1999) adds

"without ignoring the importance of economic growth, we must look well beyond it. (...) Freedom should be the principal end of development. (...) Development requires the removal of major sources of unfreedom: poverty as well as tyranny, poor economic opportunities as well as

systematic social deprivation, neglect of public facilities as well as intolerance or overactivity of repressive states.”

For the purpose of this paper, development is understood as an improvement in overall quality of life, including economic betterment, and the freedom to achieve whatever capability set one desires.

2.1.2 Poverty

Where there is no wealth, there is no poverty either.

- Tswana proverb (quoted in Rist, 2001:230)

What links our main research objective - understanding the capability development of women with disabilities in Zambia - with the paradigms of development and global health is the concept of poverty. As elucidated above, the eradication of poverty is at the core of all development work. Health, disability, poverty, and vulnerability have often been linked together when studying marginalized groups. How is poverty defined? How is it measured? Is there one grand theory on poverty and how to overcome it? What link does it have to women with disabilities in Zambia? Like that of development, the conceptualization of poverty has changed over time -- and is relative to each context. Poverty is currently viewed first and foremost as a *deprivation* of material goods. Elucidating how the development world has come to see poverty and the poor as vulnerable, destitute, and lacking control is essential to understanding why our group of women are perceived the way they are. As Laderchi *et al.* (2003:244) clarify, “how poverty is defined is extremely important as different definitions imply the use of different indicators for measurement” which can lead to different groups or individuals being identified as poor, as well as to the use of different types of programming.

Scholars have tried to measure poverty through a variety of indicators and terms, such as *absolute* and *relative* poverty. *Absolute* poverty is defined as being consistent over time and countries and only considers material needs for physiological efficiency. (Eide and Ingstad, 2011) The most popular measure for absolute poverty is income per capita, or the “dollar-a-day” terminology used by the World Bank. *Relative* poverty measures a poor standard of living in comparison with that of the rest of society. It is an index of income inequality and is generally measured by the Gini coefficient³. (Eide and Ingstad, 2011) However, similar to what has been explored with the development paradigm, the focus is

³ The Gini Income Inequality Coefficient measures the inequality among incomes within a country. A value of 0 is perfect equality, a value of 1 is maximum inequality.

solely on income and financial poverty. Overtime, many efforts have been made to find an all-encompassing definition.

In his book *The Stigma of Poverty*, Waxman details two opposing views on poverty and its causes: poverty as a manifestation of a particular 'subculture' versus poverty as a result situational factors. The cultural perspective sees the 'poorer' class as having patterns of behavior and values (or subculture) that are specific to them and different from those of the dominant society. It also argues that these behaviors are "transmitted inter-generationally through socialization" and are determinants of the status of the poor. (Waxman, 1983) In this model, changing the situation of the 'deviant' poor involves changing them directly— and only them. The situational perspective argues that the Poor's particular characteristics and coping mechanisms are not a result of internal factors and socialization to a subculture, but are a consequence of living in an adverse position in a restrictive social structure. (Waxman, 1983) To change poverty is not to change the Poor, but to change the social structure that makes them poor. Waxman concludes that neither perspective is correct. In fact, for Waxman, poverty has both internal properties, such as personal beliefs and abilities, and external properties, such as institutionalized discrimination and racism. Poverty is relational, dependent on both the person's personality and the social actors around them. This is similar to Sen's views on the factors affecting capability development (the self, the material access, and the environment) and the factors that influence the participation of women with disabilities in their community.

Gardner and Lewis (1996:25) define poverty as: "a state in which people are denied access to the material, social and emotional necessities of life. While there are 'basic needs' (water, sufficient calorific intake for survival, and shelter), many of these necessities are culturally determined. Poverty is first and foremost a social relationship, the result of inequality, marginalization and disempowerment. It occurs in the North as well as the South." According to Rist (2001), poverty is a social construct. Laderchi *et al.* support this view. For them, "different interpretations of reality translate into different poverty measures. These differences, in part, reflect different views of what constitutes a good society and good lives." (Laderchi et al., 2003:244) Rist (2001) details 'solutions' to poverty that have been popular in the past. They include philanthropic or charitable solutions— where donations are amassed based on compassion and a sense of religious duty —, political solutions— where the Poor are seen as a menace to law and order and sometimes even considered as a 'dangerous class'—, and economical solutions— where the Poor are forced to make themselves useful and economically productive to finance the state welfare they

receive. Rist advances that, following the new paradigm of the 'struggle against poverty', international organizations have found a fourth 'solution' – getting rich. This "injunction to get rich", as Rist (2001:231) calls it, simply removes poverty by the acquisition of wealth.

In 2000, The World Bank produced a three-part report titled *Voices of the Poor*. This publication became a reference work for many development workers, yet there are serious problems with its methodology and view of who the 'Poor' are. (Cornwall and Fujita, 2007) The Bank states that the purpose of the research was "to gather the views, experiences, and aspirations" of the Poor. Once The Bank heard their voices, projects and policies could be tailored to their laments. (Narayan et al, 2000:xv) It marked a milestone of The Bank moving towards participation and empowerment in its development jargon. Yet, many critics saw it as new cover to an old book of neo-liberal policies. (Pithouse, 2003) Throughout the text, 'us' and 'we' -- the rich elite, saviors, and educators -- are continuously juxtaposed to 'they' and 'them' -- the Poor, the destitute. The Poor are suffering, are in pain, and are crying out for change. (Narayan et al, 2000) Pithouse sees the book as a renewed attempt to 'other' the Poor and delegitimize their struggles against the broken system. Through this work, the Bank sees the Poor as a relatively homogenous group of people, who are "politically inert and largely responsible for their own circumstances" -- their struggle serves to legitimize the work of the Bank and other similar organizations in the development machine. (Pithouse, 2003:120) Furthermore, in all the comments and suggestions found in *Voices of the Poor*, there is no criticism of the ruling order. "The World Bank's book is a response to the crisis of legitimacy confronted by the transnational capitalist class. It seeks to turn the fractious, suffering, angry, desiring, resisting, accepting, self-destructing, self-creating, border crossing multitude into The Poor - lost lambs who need to be guided home by their shepherds." (Pithouse, 2003:142) In this context, the Poor are seen as powerless victims and passive recipients of aid programs. There is no participation, there is no agency. Despite many more inclusive definitions of poverty and the Poor, that of destitution and economic poverty still dominates. This is closely related to the way women with disabilities in Zambia are seen and are forced to live their lives.

We, however, take our definition from Sen. He defines poverty as a deprivation of basic capabilities, rather than merely as low income. Basic capabilities are "the ability to satisfy certain crucially important functionings up to certain minimally adequate levels." (Sen, 1993:41) Although lowness of income is an important factor, Sen argues that there are many other influences on capability deprivation. He further argues that this method, the Capabilities Approach (CA), permits an understanding of poverty in all societies and across

situations as the relationships between low income and low capability vary between countries, communities, and even between families and family members. The CA presents a somewhat more holistic approach to studying poverty.

2.1.3 Global Health and Population Health

“The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being”
- World Health Organization Constitution

Health and global health are an integral concept to our discussion on disabilities in the developing world. The causes and consequences of disabilities will be elaborated upon further below, but it can be clearly stated that disability and health have been linked both in the actual physical causes of disability and in the way people with disabilities are perceived. Moreover, when considering health and disabilities in the developing world, the sheer number of world conferences and organizations that work to ‘conquer’ ill health and disease is impressive. Health is integral to the ability to lead a full and fulfilling life and to achieve personal and social development. Without good health, day-to-day activities become difficult if not impossible, the ability to participate in society is limited, and integration within work and family life are often curtailed. We will first explore three theoretical definitions of health: economic, human rights, and the social determinants of health. This will be followed by an overview of recent global health initiatives and their impacts on the poor, women, and persons with disabilities.

2.1.3.1 Theoretical Perspectives on Health

The physical causes of disability are inextricably linked with health, health care and the health system. Moreover, disability has mostly been treated as a health issue. It is important to understand the health paradigm in which our research group finds itself to better grasp the conditions under which they have lived and continue to live.

Economic Perspective

The economic perspective on health has been prevailing at the international level for many centuries. Edwin Chadwick, a follower of Bentham’s utility concept, was among the first to articulate the concept of health as an economic driver in 1842. He promoted health as a utilitarian objective – disease was the begetter of poverty while poverty caused social ills, disorder and high taxes to support the poor. By promoting public health, poverty could

be eliminated. (Susser, 1993) The economic viewpoint highlights the utility of health to be able to produce more, leading to more prosperity and hence, more health (or the 'virtuous cycle'). This conception was regularized in the early 20th century by the all-powerful Rockefeller family and their various corporations and foundations. (Brown, 1976; Katz, 2004) Through their programs aimed at eliminating hookworm, yellow fever and malaria from areas where they had industries and thus leading to less sick and dying workers, the Rockefeller Foundation was able to define health as "the capacity to work" (Brown, 1976) and "a means to achieving(...) long-term economic growth." (Sachs, 2001) The fact that the Rockefeller Foundation's International Health Commission and the Rockefeller Sanitary Commission were the precursors to the World Health Organization further highlights how the economic conception of health dominated discourse for the majority of the past century – most recently with the release of the Sachs Report on Macroeconomics and Health.

This perspective does not discuss the causes of poor health, focusing instead on its economic consequences. Furthermore, it sees health resulting solely from the services received from health providers, and not, as indicated by a wide body of research, as a result of a multitude of intervention in other more important sectors (such as socioeconomics, political and cultural). (Katz, 2004) Overall, we can see how closely this perspective follows the 'development as economic growth' paradigm. Health, like poverty, is targeted because it hinders economic development, not because health and being healthy are themselves worthwhile objectives.

Human Rights Perspective

Many authors categorically reject the concept of health as a simple economic factor – it is a human right. In 1844, Frederick Engels reversed Chadwick's assertion and defined health as having a social and political value in its own right, devoid of the economic implications. (Susser, 1993) It took over a century for the right to be institutionalized. Article 25 of the Universal Declaration of Human rights reads: "everyone has the right to a standard of living adequate for the health and well-being of himself and his family". Article 12 of the International Covenant on Economic, Social and Cultural Rights went further, highlighting the obligations of the state towards its citizens in the provision of health. (Ruger, 2006; Susser, 1993) The creation of the WHO in 1948 further cemented the concept of health – defined as "a state of complete physical, mental, and social well-being" – as a human right. (Susser, 1993)

We will distance ourselves from the human rights definition and framework for a variety of reasons. The first counter-argument against viewing health as a human right is that it is simply inoperable. To assure health as a right is unfeasible; it would ignore a plethora of factors that cannot be controlled by society, such as the genetic makeup of a person as well as choices people make that lead them to be less healthy than they could be. (Ruger, 2006) Instead, the object of the right should be health care and equality of access or entitlement to health services. (Norman Daniels, quoted in Ruger, 2006) Here, the argument is that a right to live in conditions permitting the fullest health achievable by a person is what a *right* is for all.

Another counter-argument is that health as a human right would fall within the second generation of rights - economic, social and cultural rights - and that the overarching political practice has always been the promotion of the first generation of rights - civil and political. Simply said, when confronted with choice of which type of rights to fight for, health is not considered a priority within the current paradigm and framing it within this paradigm could detract from other more powerful arguments for health. (Evans and Ayers, 2006) A third argument against using the human rights view is that, currently, universal human rights exist with no actual ability to be enforced; there is no supranational mechanism capable of holding nations accountable for providing rights. (Shafir and Brysk, 2006) Moreover, due to the nature of international human rights treaties, the duty bearers are always the state, the same actors who are overall accused of violating these same human rights. (Stammers, 1999) Finally, the human rights framework can be argued to be a form of Western hegemony, a way to spread and impose cultural ideology around the world while eschewing local contexts, cultures, and decision making into what is considered important and essential in that society. (Stammers, 1999) Despite our belief in the value and potential of human rights overall, for the reasons described above, we will not be considering this framework as one from which to analyze the data collected for our research nor to draw conclusions.

Social Determinants of Health

In 2003, the WHO created the Commission on the Social Determinants of Health. Led by Michael Marmot, it highlighted yet again the causal link between poverty and poor health. Health is affected throughout a person's life through poor social and economic circumstances. The lower the person on the 'social ladder', the likelier they are to have a serious illness and premature death than those above them on this same ladder. (Marmot,

2003) The social determinants of health are “the conditions in which people are born, grow, live, work and age, including the health system.” (WHO, 2012) These are affected by structural drivers: social policies and programs, economic arrangements, and politics, to name a few. In 2008, the Commission on Social Determinants of Health reported three overarching recommendations on how to tackle ill health:

1. Improve daily living conditions.
 2. Tackle the inequitable distribution of power, money, and resources.
 3. Measure and understand the problem and assess the impact of action.
- (Marmot, 2003:26)

The argument is that health status is a consequence of much more than simply health services. If the health of a population suffers, it is because a large set of social arrangements needs to change. (Marmot, 2005) Poverty through material deprivation, a lack of quality medical care, unfair distribution of goods and services, and economic policies advantaging the rich instead of the poor are some of the main causes of overall poor health. (Marmot, 2005) Poverty is the single most important determinant of poor health, but poor health is in no way the main cause of poverty; projects promoting only certain specific medical interventions do not tackle the root causes, such as social exclusion, gendered power differentials, and unequal access. (Katz, 2004)

This framework argues that, although addressing existing diseases is urgent and should be a priority, the underlying social determinants of health must be addressed to improve population health in a sustainable way. (Marmot, 2005) Moreover, it addresses the fallacy of focusing *only* on the most disadvantaged, advocating instead for actions that are universal, on a gradient of scale and intensity proportionate to the level of disadvantage. (Marmot, 2005) Sen and Nussbaum’s capabilities approach served as a guiding principle behind the Social Determinants of Health perspective. Both note health and being healthy important not only as an innate functioning but also as a complex capability. In fact, Nussbaum has health as one of her ten essential capabilities. This framework will be further discussed in the theoretical application section.

2.1.3.2 The Global Health Paradigm

The idea of Health For All was advanced during the International Conference on Primary Health Care in Alma Ata in 1978. At this conference, the concepts of “Primary Health Care” and “Health for All” were outlined and agreed to by all countries present. Health would be possible for all people through the concept of Primary Health Care, which is: universally accessible, participatory, affordable, central to the country’s health system,

multifaceted (education, prevention, nutrition, safe water, basic sanitation, family planning, immunization, treatment) and integrated with all other relevant national sectors (agriculture, animal husbandry, food, industry, education, housing, public works, communications). (quoted in Maciocco, 2008:37)

However, only one year following Alma Ata and the agreement to its principles by all states present, a report on “selective primary health care” written by two researchers of the Rockefeller Foundation was published in the New England Journal of Medicine. (Maciocco, 2008:37) It argued that the objectives set out in Alma Ata were too costly and that selective disease interventions should be used in the meantime (such as vaccinations, promoting breast feeding, anti-malaria programs and oral rehydration). This new approach had the support of the World Bank and quickly replaced the principles of Health For All. It has been severely criticized as a return to top-down, vertical, medical-model type of health services where the population has no say in setting priorities and the reality on the ground is often disconnected from what is being promoted. (James, 2008) The consequences of the targeted interventions on specific illnesses versus basic primary health care for all were made more evident following the petrol crash in the 1970s and the resulting Structural Adjustment Programs (SAP) of the 1980s. UNICEF denounced the SAP as being “inhuman, unnecessary, inefficient and the cause of the worsening conditions of life and health.” (James, 2008)

In 2001, on the heels of the Millennium Development Goals, Jeffery Sachs and the UN Commission on Macroeconomics and Health published its report *Investing in Health*, also known as the Sachs Report. The report stated that the *lack of access* to health services by the world’s poor is the main reason that there is illness and poor health. The main tenet of the Sachs Report was that the major remaining health issues in developing countries can be remedied through a few targeted interventions on specific illnesses – the population would then be healthier, which would lead to increased productivity and economic growth. (Sachs, 2001) It continues to follow the path set out by the Rockefeller Foundation and the World Bank. The Sachs Report also advocated for increased aid coming from developed countries and reforms to the economic system of the developing countries to answer requirements set out by international bodies like the IMF and the WB.

Alison Katz was one of the most vocal opponents of the Sachs Report and the neoliberal policies to health advanced in the beginning of the 21st century. Katz, a proponent of the social justice and human rights-based approach to health, highlighted that the growing desire to utilize market systems when tackling health issues ignores the root

problems of ill health – poverty and inequality – and relies upon international aid and charity to target only a few diseases. “(The international health establishment’s) account of disease and death contains no actors, no causes, no interests and no power struggles” (Katz, 2008) Similar to Pithouse’s argument regarding the World Bank’s attempts at ‘tackling’ poverty, Katz argued that the big players in global health do not attack the underlying issues of oppression, struggle, and abuse from the elite. Conversely to what is ascertained by Sachs, Katz highlighted the long held knowledge by health and development workers “poor health is very far from being the single most important determinant of poverty”. (Katz, 2008) The Sach’s Report ignores already established concepts of poverty as multidimensional. Moreover, the vertical-type programs and interventions promulgated by the Sachs Report focusing only on a small group of key diseases will potentially help diminish the prevalence of these diseases but they will never address the overarching issues of poverty and inequality—something the Sachs Report purports to do.

It is in this general framework of development and global health that this study takes shape. On the whole, disability has been treated as a medical problem, requiring prevention, intervention, operations, and rehabilitation. When disability is addressed like health has been in the past by such actors as the Rockefellers or the World Bank – through targeted interventions aimed at illness reduction and treatment instead of by diminishing the poverty and inequality at the core of it – it leads to the same mercantilism of people’s health and well-being. Health – defined by the WHO as not only the absence of disease but also the fulfillment of social, psychological and physical health – must be seen as a capability that everyone must be permitted to attain and not simply an economic driver. (Waitzkin, 2003; Katz, 2004; Maciocco, 2008) The link between health and disability and the serious consequences related to using vertical silo models for intervention is clear. Despite the fact that it affects over 1/10th of the world population, and nearly 1/5th of the population of developing countries, disability is almost ignored by the neoliberal basic health care model. It is in this perspective that we address disability as a health, social, and economic development issue; with moral, equality, and human rights components.

2.1.4 Conceptual Models and Definitions of Disability

Disability is generally viewed to be a limitation in six domains of functions or actions: seeing, hearing, mobility, cognition, self-care, and communication. (WHO WRD, 2011) Our research focused on women whose main impairments were related to mobility. Disability is

diverse, and results from interactions between personal factors (gender, age, socioeconomic status, sexuality, ethnicity, to name a few), health conditions, and the environment. (WHO WRD, 2011) This definition will be further explored in the following sub-sections.

Many models have been developed to understand disability and to attempt to intervene upon it. This multiplication of visions, mandates, objectives, and purposes is linked to a multiplicity of actors intervening on the same situation but with often vastly different means and aims. (Long, 2001) Not only can this lead to a squandering of resources due to competition from different organizations and groups, but also to a weakening of the disability advocacy movement itself. This will be seen further in our analysis section. However, it can also be argued that the multiplicity of models is not inherently negative. In fact, it indicates the multifaceted nature of disability itself. The various models can bring a new understanding to disability in different contexts. (Mitra, 2006) Below are some of the main disability models. We argue that the best model with which to understand disability is through the Social Model, which is closely related to the Capabilities Approach.

2.1.4.1 Medical Model

The most prominent model is the medical model, which focuses on identifying and curing only the disease or illness that causes a physical condition intrinsic to the individual. Disability is seen as an impairment of the *normal* functioning of a *normal* person. (Dubois and Trani, 2009) In this model, there is always a *defect*; disability is seen as something wrong within the person, a derivation from normal functioning, and must be fixed to make that person as close to being 'whole' as possible. The model also implies that the power of action over the disability lies only in the hands of professionals who can provide rehabilitation and interventions – the agency of the person is not considered. (Dubois and Trani, 2009) Furthermore, there is no consideration of the fact that society and its structure may be creating the impasse to the full participation of this person. The model's objective is not to change norms and stigma but to find a cure and address the disability through medical experts, invasive procedures, and rehabilitation. (CSV, 2005)

This model was also a proponent for hospitalization and institutionalization. As PWD are seen as a 'burden' to the family, they are often placed in institutions that 'take care' of them. A main critique of the medical model is that while PWD may need medical assistance from time to time and research on the causes of some disabilities can lead to their prevention and eradication, it is naïve and simplistic to think that the medical system is the

place from which to fashion policy related to PWD. Particularly, PWD are themselves quite capable of acting on their lives and participating in society – institutionalization and the ‘sick’ role they have accompanying them are simply not acceptable. (Kaplan, 1999)

2.1.5.2 Charity Model

In this model, the PWD is seen as a tragic character, someone who will never be able to be part of normal society and who will always depend on the support of others to survive. It is linked to the religious model with respect to how PWD are ‘assisted’ – through handouts and pity. (Kaplan, 1999) This model lowers the person’s self-esteem, belittles them, and makes them objects of pity. Although the support offered by charities often palliates certain areas that are lacking in government support, it follows in the medical model’s classification of people, seeing their situation as a consequence of their inability to act versus as the lack of desire of society to be adaptable to all. (Kaplan, 1999) Others see PWD as needy, dependent, to be pitied and unable to live their own lives without the support and control of others. (Gill, 1999 quoted in CSV, 2005) In this perspective, they are not seen as ‘whole’ people with rights and capabilities, but something less; something dependent on others for survival. This model is further linked to the concepts of ‘vulnerability’, ‘victimization’, and ‘stigma’. These will be discussed further in following sections.

2.1.5.3 Religious/Moral Model

It has been argued that this model is less prevalent today, but it is in fact still quite present and particularly important to consider in the case of Zambia. (Kaplan, 1999) This model attributes supernatural significance to disability. Devlieger (1995) conducted research among the Songye of Zaire. Here, like in Zambia, the belief in sorcery, the power of ancestors, and the role of social taboos are important. When discussing the causes of disability or impairment, past transgressions of social taboos or problems in the family are first and foremost mentioned. This renders the disability not an individual condition, but a problem of the family. (Devlieger, 1995) Burck adds that often what is viewed as shameful is not the disability itself but the social conditions that are seen as having caused it. (1999) Devlieger argues that when these conditions cannot be blamed for the disability, God is the other explanation. (1995) Here, disability is seen as having a “religious or moral significance” where people develop a disability as a punishment for their sin or that of their family. (Gill, 1999 quoted in CSV, 2005) In a country where religion and other spiritual beliefs play a pivotal role, including the belief in the power of spirits and God to inflict pain as

a form of penance, this model has significant traction. Persons with disabilities and/or their families are either shamed due to a perceived lack of piety and/or become all the more religious to obtain absolution for whatever caused their plight. (Kaplan, 1999) In this case, the stigma related to the disability and its causes are internalized within the person, the community, and their shared beliefs, making it that much more difficult for PWD to improve their lives and be seen as equal.

2.1.5.4 Social Model

Recently, the general consensus in the disability movement has moved towards a social model of disability. (Loeb, 2008; WHO, International Classification, 2009; Elwan, 1999) This model is closely related to the Social Determinants of Health and the Human Development Paradigm in that it considers disability multifaceted and mostly dependent on societal consideration. The social model states that disability is a relative term dependent on cultural and societal constructs (Elwan, 1999). The World Health Organization (WHO) defines disabilities as “impairments, activity limitations and participation restrictions ... that can be encountered ... (while) executing a task or action (or) in life situations”. (WHO, International Classification, 2009) In recent years, disabilities are no longer viewed as purely physical problems but as a variety of interactions between the body of the person and societal, environmental and attitudinal barriers surrounding the person. (DPI, 2009) This definition shifts the focus from the person's disability to that of a disabling society where the status quo in norms, values, perception, infrastructure, and the sort impedes the full realization of a person's potential. The International Classification on Functionings, Disability, and Health is the development industry's attempt at creating an indicator based on the social model of disability.

2.1.5.5 WHO Classifications: DALY and ICF

Disability Adjusted Life Years (DALY)

Despite many strides being made by the disability movement in removing barriers and diminishing vulnerability, some of the most powerful advocates are still insisting on economically driven definitions and indicators. The WHO introduced the measure of the Disability Adjusted Life Years (DALY) when they created the *Global Burden of Disease* study in 1990. DALYs are used as a measure of the health of a population and quantify the burden of disease from premature mortality and from disability. (WHO WRD, 2011) They are calculated as the sum of years of life lost due to premature mortality (YLL) and the years of full health lost due to disability (YLD) caused by the disease or injury. The lesser amount of

DALY measured, the better off the society is considered to be. (WHO WRD, 2011) This indicator further promulgates the idea that to have a disability is to be lesser than others; you are unable to contribute fully to society and so you make that society weaker.

International Classification on Functioning, Disability, and Health (ICF)

The ICF is based in the social model and the medical model of disability. It was adopted on 22 May 2001 by all 191 WHO Member states through resolution WHA 54.21 as an international standard to “describe and measure health and disability.” (WHO International Classification, 2009) The objective of the ICF is to ‘mainstream’ the experience of disability and acknowledge that every human being can experience different levels of health and ability. Health is a continuum and disability is thus rightfully defined as “a universal human experience.” (WHO International Classification, 2009)

According to Mitra (2006), the ICF posits that disability starts with a medical condition that causes impairments (problems in body function or alterations in body structure, like paralysis or blindness), which can lead to activity limitations (difficulties in executing activities, like walking or eating) and participation restrictions (in any area of life, such as facing discrimination in employment or transportation). It considers disability “to be the result of a combination of individual, institutional, and societal factors that define the environment surrounding a person with impairment.” (Dubois and Trani, 2009) It uses two lists to evaluate the depth of the disability: a list of body functions and structure and a list of domains of activity and participation, expressed along a continuum of functioning to disability. In the ICF, *functioning* encompasses all body functions and structures, activities and participation whereas *disability* refers to impairments, activity limitations, and participation restrictions. (Welch, 2002:7) Overall, it focuses on two kinds of assessment factors to properly evaluate the disability: environmental (physical environment, social environment, and the impact of social attitudes) and personal (personality and characteristic of the individual). (Dubois and Trani, 2009) The ICF also distinguished between “a person’s capacities to perform actions and the actual performance of those actions in real life”, which is linked to the capability and functioning concept of Sen’s Capabilities Approach. (WHO WRD, 2011) The WHO and the WB are currently promoting this model, most clearly in the 2011 World Report on Disability and Health.

2.1.5.6 Disability Creation Process (DCP)

The DCP was first presented in the mid-1990s by a group of Canadian researchers part of the International Network on the Disability Creation Process (Réseau international du

processus de production du handicap) who were mandated by the WHO to review an older model on disability. (RIPPC, 2006) It is based on the anthropological model of human development and disability which asserts that the disability process is a consequence of the “dynamic and interactive process between personal (intrinsic) factors and environmental (extrinsic) factors.” (Levasseur et al., 2007) The DCP’s main contribution internationally has been the full recognition of environmental factors as a conceptual dimension in factors affecting a life and leading to disability. (RIPPH, 2006) The DCP was a fundamental model for the ICF and the INDCP has participated in the review of the ICF since its creation in 2001.

DCP is based on the interaction between individuals and their environment and it operationalizes social participation via the concepts of life habits (defined as daily activities and social roles valued by the person). (Levasseur et al., 2007) The DCP also considers capability, or the “intrinsic ability of an individual to accomplish a physical or mental activity regardless of the environment” as an essential operational component. Both the social participation and capability terms are closely linked to Sen’s Capabilities Approach, representing functionings and capabilities, respectively (this will be further explained in section 2.3.1). Although there are many similarities between the DCP and the ICF (such as their universal approach, their integration of environmental factors, and their focus on participation), Levasseur et al. (2007) provide a substantial list of conceptual differences between the two. A main one of interest to us is that the ICF still considers disability initially from a health condition problem, while the DCP considers the health condition as one of many personal factors that interact with the environment and life habits, which can then lead to disability. (Levasseur et al., 2007)

We see the DCP as closer to the Capabilities Approach than the ICF as it is focused on the concepts of rights, equality, and the particular importance of environmental factors in its analysis. The DCP’s understanding of disability as a *spectrum* and dependant on many external factors, such as context and society, further highlights this link. Furthermore, the DCP focuses on the concept of social participation and the ability of a person to participate in society. We take our definition of disability from the DCP and so posit then that Sen and Nussbaum’s Capabilities Approach can be used in a method of understanding and analyzing disability.

2.2 Challenges to and Caused by the Current Development Paradigm

2.2.1 Labeling, Discrimination, Stigma, and Victimization

Labeling, discrimination, stigma, and victimization are essential concepts to understand when studying the lives of the women in our sample as well as how they have been viewed and classified. Understanding how they have come to find themselves labeled and stigmatized for the simple fact of having a mobility restriction, of being economically poor, or of being a woman will help in grasping the complexity of the challenges they can face.

2.2.1.1 Labeling

We label others and ourselves to signal different aspects of our identities. (Moncrieffe and Eyben, 2007) Labels impose boundaries and define categories. They are a means to construct our social world; to define norms in relation to others who bear similar or different labels. In the world of international development, labels are used as a means to quantify and measure categories of people, which then permit the aid worker to define needs, justify interventions, and formulate solutions to perceived problems. Usually, we perceive labels as being objective; yet labeling can shift – or sustain – power relations in ways that trigger social dislocation and prejudice efforts to achieve greater equality. (Moncrieffe and Eyben, 2007)

Moncrieffe and Eyben (2007) also argue that the labeling process involves relationships of power. Moreover, people are named or categorized by themselves and others as a means to reflect frames in which they live – or how a certain problem is understood and how it is represented in policy debates and discourse. The motivations for labeling are diverse and the process leads to varied, and often unanticipated, outcomes. When the intent is good, it can lead to discord; when the intent is malevolent, it can lead to people using labels to claim political space; when there is no labeling, it can lead to omitting people from policies and programs, and even decide who is more or less of a priority. (Moncrieffe and Eyben, 2007)

According to Long (1989:232), “labeling legitimizes the diagnostic and therapeutic measures undertaken by public bodies. It also attempts to establish the parameters and superiority of the discourse of planned intervention itself”. Consequently, labeling and framing processes are complex and involve intricate relations of accountability that are both complementary and conflicting. We elaborated upon this previously when discussing the development paradigm and the creation of labels, such as: colonizer and colonized,

development worker and target population, the 'Poor', and so on. The label of 'the Poor' popularized by the World Bank report *The Voices of the Poor* is a perfect example of the consequences of labeling. Their model created a homogenous group of crying, pained, destitute people, ignoring every other aspects of who they are. As Cornwall and Fujita (2007:48) highlighted, this label created a narrative where the poor are "responsible for their own 'empowerment' (and) the inequities of existing social and economic relations that sustain poverty, vulnerability, insecurity, and alienation are brushed out of the frame." Every time a label is created, it brings with it certain plans of action as well as very defined perceptions on the people that are 'defined' by them.

2.2.1.2 Stigmatization

The frames created by labels often had negative connotations, as can be seen by the list above, and can lead to stigmatization. Bruce Link and Jo Phelan (2001) proposed a link between labeling and stigma through their stigmatization model. They highlight four specific conditions that must converge to lead to stigma: (1) individuals differentiate and label human variations, (2) prevailing cultural beliefs tie those labeled to adverse attributes, (3) labeled individuals are placed in distinguished groups that serve to establish a sense of disconnection between 'us' and 'them', and (4) labeled individuals experience "status loss and discrimination" that leads to unequal circumstances.

Erving Goffman (quoted in Rogel, 1997) defined stigma as being a severe social disapproval of or personal discontent with a person on the grounds of their unique characteristics distinguishing them from others in society. He identified three overarching categories:

physical stigma (physical handicaps, vision troubles, disfigurations),
stigma associated to the personality or the past of the individual (mental illness, drug addiction, alcoholism, criminal backgrounds, etc.), and
"tribal" stigma (race, religion or nationality). (Rogel, 1997)

According to Goffman, stigmas may be *visible* or *invisible*. A visible stigma, such as disabilities or skin color, leads to the person being 'discredited' by that stigma. The effect of the stigmatizing characteristic will depend on the *importunity* or *intrusion* it has on a situation. In this case, the stigmatized person feels the need to control social interactions that can highlight the visible stigma. A wheelchair is not disconcerting when all are seated at a table, but it becomes so when everyone else is standing. (Rogel, 1997) Invisible stigma, such as that caused by a delinquent past or homosexuality, renders the person

'discreditable' and needing to control access to information that could highlight their stigma. (Rogel, 1997)

Goffman highlights that the stigma or mark is seen by the general population as something residing *inside the person* rather than something others *affix to* the person. This means that, when evaluating and judging behaviors, the attention is drawn towards the person who is stigmatized -- they are the 'bad ones' -- instead of towards the ones who are producing the rejection. This makes stigma different than *discrimination*, where societal judgement is focused on those who are rejecting and excluding others -- those who do the discriminating -- rather than on the people who are the recipients of these behaviors. (Link and Phelan, 2001:367) Goffman (1963:3) further highlights that the study of stigma needs to be done in "a language of relationships, not attributes", meaning that an attribute that can be seen as negative in one context, or relationship, would not be seen as such in a different context. And so, someone who is using a wheelchair would be stigmatized in the context of a marketplace but would not be when participating in a wheelchair basketball game. The stigma is dependent on the context in which it is manifested; socio-cultural norms and beliefs are part and parcel of stigma.

Goffman has been criticized by disability rights authors for "lumping together all sources of stigma" which can lead to overgeneralization of stigma and ignoring the complexities of disability. (Wendell, 1996) Furthermore, he is seen as acknowledging yet not challenging stigma and the social constructs that lead to it. (Wendell, 1996) We recognize these particular limitations, however, we feel that his contributions to the understanding of stigma and its social construction are undeniable and can be used in conjunction with the social model of disability to understand societal and social responses to it. (Susman, 1994) Overall, for the purposes of our research, his writings are used as a basis for understanding stigma, its definitions, and how it comes to pass.

In the case of women with disabilities, and in particular those of our case study, the stigma they (may) face is both visible and invisible, related to physical and 'tribal' conditions. When discussing the misunderstanding related to stigma studied by persons not part of the stigmatized group, Fine and Ash (1988, quoted in Link and Phelan, 2001) identify five assumptions on persons with disabilities:

1. Disability is located solely in biology.
2. The problems of the disabled are due to disability-produced impairment.
3. The disabled person is a 'victim'.
4. Disability is central to the disabled person's self-concept, self-definition, social comparisons, and reference groups.
5. Having a disability is synonymous with needing help and social support.

These assumptions will be challenged by the discourses of the women we have interviewed. Unfortunately, as can be seen by the medical, charity, and religious models of disability, the concepts brought forth by Fine and Ash have been internalized and reproduced in the definitions of disabilities. By further enshrining them in policy and intervention, persons with disabilities continue to be stigmatized by society and are not considered as whole persons. This leads to ignoring their needs and desires, their skills, their abilities, and their struggles, and continues the stigmatization, vulnerability, and victimization that the programs purport to attack.

2.2.1.3 Victimization

The notions of 'victim' and 'victimization' are brought forward in the quote from Fine and Ash. In the vast majority of literature, 'victimization' is presented as being the consequence of criminal acts. (See Wolhuter et. al, 2009 and Best, 1997) What we are interested in is the societal exclusion and the construction of victims and victimhood. Dunn's article *Accounting for Victimization: Social Constructionist Perspectives* (2009) discusses four different types of victim creation.

accounting to self: victim self-definition through rationalizing a life situation as being victimizing

accounting to others: convincing others of your victimization through accomplishing your victim identity,

accounting by others: to tackle what is seen as a social problem, create the image of victims from those who are living that social problem; changing the perception of those affected from being blamed to being victims.

accounting for others: by creating social movements, activists seek social change to the situation; creation of new frames such as moving from stigmatized to oppressed, which leads to solidarity between the groups.

These four types of victim creation are important to our research group as the language of vulnerability and victimization is often used when claiming assistance and support. Often, severely marginalized groups will be seen as victims, either from outside actors or from themselves. This requires creating the identity of a 'victim', a process closely linked to labeling and stigma. (Dunn, 2008) To achieve this awareness, or this label creation, the person needs to rationalize the situation she is living in as something that is to be rejected. (Dunn, 2008) We argue that this rationalization can also be done by outside actors, which leads to the creation of victims, where the 'victims' may not yet know of their victimization. This is particularly important in the case of women with disabilities in

developing countries and their relationship with outside actors. Their victimhood will often instigate and inform intervention.

2.2.2 Vulnerability

Vulnerability – defined as being capable of being physically or emotionally damaged or, as being open to attack, is not fixed in time and, by definition, refers to a process. (De Chesney and Anderson, 2008) Victimization, then, is when that vulnerability turns to reality, when a person is damaged or attacked. In recent years, the notion of vulnerability has seen a surge in popularity in the development world. Grassroots activists and international organizations use it alike as a means to identify certain sub-populations that require increased attention and intervention. It has also garnered particular importance when discussing poverty and climate change. Vulnerability is defined in a variety of ways, depending on the field of particular interest. (De Chesney and Anderson, 2008) A few of the main types of vulnerability include:

2.2.2.1 Economic

The issue of economic vulnerability has been significantly discussed above, under the development and poverty sections. The bulk of definitions for vulnerability are centered on liberal economic principles. One definition by Calvo and Dercon (2007) sees vulnerability “*as the burden of the threat of future poverty*. As such, it relates both a) to the likelihood of future poverty episodes, and b) to the severity of poverty in such cases.” Similarly, Chaudhuri et al (2002) see vulnerability “within the framework of poverty eradication, as the ex-ante risk that a household will, if currently non-poor, fall below the poverty line, or if currently poor, will remain in poverty.”

2.2.2.2 Health

In health, vulnerability is considered in two forms -- 1) the vulnerability of the patients to the medical system; 2) the vulnerability of people to ill health. In the Common Rule for clinical medical research, vulnerable subjects include “children, prisoners, pregnant women, and persons who are handicapped, mentally disabled, economically disadvantaged, or educationally disadvantaged.”(quoted in Ruof, 2004) A more complete definition coming from the health world sees vulnerable people as “those at risk for poor physical, psychological, or social health.” (De Chesney and Anderson, 2008) The concept of *risk* needs to be included and means that there is a “*probability* that an individual could become ill within a given period of time.” (Aday, 1994) This means that everyone is at risk of some

form of ill health, but may be more or less at risk at different times. Aday identified a list of three factors that lead to vulnerability in health and which are similar to those of social vulnerability (below):

1. social status: personal characteristics (age, sex, race)
2. social capital: nature of social ties (family, friends, neighbors)
3. human capital: environment (schools, jobs, incomes, housing, violence)

2.2.2.3 Social

Cutter's (2003) definition of social vulnerability, while pertaining to environmental change hazards, has certain elements that we would include in our definition of vulnerability. It is "partially the product of social inequalities—those social factors that influence or shape the susceptibility of various groups to harm and that also govern their ability to respond. However, it also includes place inequalities—those characteristics of communities and the built environment, such as the level of urbanization, growth rates, and economic vitality, that contribute to the social vulnerability of places." Although best suited for vulnerability to climate changes and natural disasters, the concept of place inequalities can be well utilized when considering "vulnerable populations" as their housing, their region of dwelling (urban, rural) and the infrastructure surrounding them will influence their ability to achieve the life they wish.

2.2.2.4 How to Assess Vulnerability

Cutter (2003) also advances a group of indicators that should be considered when attempting to evaluate a person or a group's vulnerability. These include: socioeconomic status, gender, race and ethnicity, age, occupation, unemployment, rural or urban dwelling, residential property owner or renter, family structure, education, population growth, medical services, social dependence, and membership to a "social needs population". Finally, another important aspect to consider when discussing vulnerability is that it is not only the characteristics of the person and their immediate environment that must be looked at; macro-level considerations and their effects must be taken into account such as social structure, international terms of trade, and global political situations. Katz (2004) highlights these particular aspects in her critique of the Sachs Report.

Importantly, De Chesney and Anderson (2008) highlight that "to be a member of a vulnerable population does not necessarily mean one is vulnerable. In fact, many individuals within vulnerable populations would resist the notion they are vulnerable." We must be mindful that, just like disability, "anyone can be vulnerable at any given point in time as a result of life circumstances." (De Chesney and Anderson, 2008:3)

Although a useful concept when identifying power relations, targeting populations, and in developing policies and projects, we find that the term 'vulnerability' has fallen into overuse. Categorizing people as vulnerable simply because they possess certain characteristics (i.e. they are women, poor, in a developing country) without taking into account the specifics of their lives, their survival strategies, and their inherent skills is a common practice. It also often leads to further stigmatization when assuming, from the onset, that they are unable to help themselves. This can lead to the creation of victims where there were none and the perpetual victimization of 'others'. There is no consideration of 'agency', whereby a person or a group takes an active interest in their lives and outcomes. Agency will be further discussed in our Theoretical Operationalization section as it is an essential component and tool of our research analysis.

2.2.2.5 Vulnerability and Disability

The concept of vulnerability is easily extended and linked to that of disability. All of the models described previously, except the social and ICF models, focus on the assumed inherent vulnerability and, sometimes, complete inability of the person. It is believed that not only are they 'different' and unable to function like 'normal' human beings but they never will be able to do so without changing themselves or receiving the charity of others. Yet, the processes of 'othering' and categorizing disability are inherently flawed - disability would "best be understood as a dynamic and contextualized range". (Pothier and Devlin, 2006:4) What would be a manageable disability in North America, such as a limp caused by polio, is severely debilitating in Zambia where rehabilitation services and mobility aids are not available. Pothier and Devlin (2006:4) continue: "disability has no essential nature. Rather, depending on what is valued (perhaps overvalued) at certain sociopolitical conjunctures, specific personal characteristics are understood as defects and, as a result, persons are manufactured as disabled". Disability and the vulnerability it can entail are highly dependent on how society is organized, both physically and within socio-cultural expectations.

For our purposes, vulnerability is seen as the product of social inequalities and barriers that impact the ability of each person to fully achieve their potential and ensure their survival, safety and happiness. Furthermore, it can be described through the investigation of the various indicators advanced by Cutter. We would qualify our group of women as being perceived as vulnerable by many social actors around them, despite their own methods of survival and ability to overcome challenges. This will be discussed further in the analysis chapter.

2.2.3 Women, Gender, and Development

Women are portrayed in a large swatch of literature as inherently vulnerable. Living in and under the shadow of patriarchy and the dominance of males in society, women are almost always handed the “short end” of the stick. (Snow, 2007; Smith, 2003, Cornwall, 2003) By observing the gender relations of many of the previously detailed indicators on vulnerability, we can assert that women as a whole face severe inequality. This inequality can lead to their victimization and limit their ability to fully achieve a fulfilling life. Moreover, this assumed victimhood often translates to further victimization of women by other actors (such as the government, law makers, NGO, and their male counterparts) when it is surmised that they are unable to act on their own lives. (Marchand and Parpart, 1995; Cornwall, 2003) “Labeling individuals as ‘vulnerable’ risks viewing vulnerable individuals as ‘others’ worthy of pity, a view rarely appreciated” (Ruof, 2004) Marchand and Parpart (1995:228) add that women living in developing countries are further exposed to this ‘othering’, continuously incorporated in a view of being “backward pre-modern beings with no agenda of their own, tied to traditional ways of thinking and acting.” It is under these relationships of power and domination that the women in our sample must challenge the status quo. They are rarely seen as strong agents, important actors in their own lives and in the community surrounding them. Their ability to continuously develop new methods of adaptation, their resilience, and their strong drive to ensure their survival and that of their families are often disregarded.

The Gender and Development (GAD) approach is crucial to this issue. Gender and Development stems from a shift in thought regarding the lives of women. The term ‘Women in Development’ (WID) emerged in the 1970s from feminist lobby groups who argued that women in developing countries were not benefiting from the improvements to the status of women that emerged in the 1950s and 60s. As Rathberg (1990) describes, GAD focuses on the social constructions and power differentials that create the oppression of women and that validate the roles assigned to men and women. This framework focuses on why women are in the position they are in and advocates for their emancipation. Women are seen as agents of change and not as recipients of aid, where they can exercise their agency to achieve change in their environment. GAD also considers structural discrimination, such as class, health status, and religion that lead to divisions between the genders and within the genders – they are no longer homogenous groups. Overall, the GAD framework strives for long-term changes, re-examination of social structures, and loss of power of the entrenched elites (Rathberg, 1990). This framework is instrumental in advocating for equity between

genders. Through this, the real role and value of women as agents in their family and their society is highlighted; the important work they undertake both in procreation and production is recognized. It also helps in identifying if and where there are gender differentials and lack of recognition for the roles of women, their needs, and their inherent value.

The population of interest for this study falls well within this example. As women, this group is already seen as 'suffering' from its gender. When we add the extra 'burdens' of disability, ill health, risk of HIV, unemployment, poverty, and being citizens of a highly indebted and underdeveloped country like Zambia, the picture painted for these women is seen as bleak. Moreover, often, little attention is paid to the skills and abilities they possess and have been utilizing far before development actors became interested in their situation. Viewed through the lens of vulnerability, these women are often seen incapable of helping themselves and in need of the support and intervention of outside actors.

2.3 Theoretical Operationalization

This section will detail the main theories and frameworks we will be using to analyze the data collected from our research participants. They include the Capabilities Approach, the concept of agency, and the Actor's Oriented Approach.

2.3.1 Sen and Nussbaum's Capabilities Approach and Disability

How to work against poverty, vulnerability, and inequality? How to define those terms? The overarching neoliberal approaches to health and development have been argued against by an important number of left-leaning academics, not least of which is Amartya Sen. Sen's approach was developed over a variety of theses in welfare economics, including *Commodities and Capabilities* (1985), *Development as Capability Expansion* (1989), *The Quality of Life* (with Martha Nussbaum) (1993) and culminating in one of his most renowned works *Development as Freedom* (1999). (Mitra, 2006) For Sen, "development involves expanding the freedoms enjoyed by individuals and removing the sources of unfreedoms, such as poverty and poor economic opportunities." The method of evaluating unfreedoms, which is the Capabilities Approach (CA), focuses on "the capability set that a person has, that is, the substantive freedoms he or she enjoys to lead the kind of life he or she has reason to value", making this achievement, the freedom to lead one's life, the true form of development we should be aiming for. (Sen, 1999:8)

The capability set each person possesses determines what the person is capable of doing and being through the realization of functionings. (Dubois and Trani, 2009) The

potential to achieve these capabilities is determined by the individual's personal characteristics, the basket of goods they have access to, and the environment in which they find themselves. (Sen, 1999) Capabilities are understood as practical opportunities while functionings are the actual *achievements* of the individual, what they achieve through being or doing. (Mitra, 2006:235) When functionings are present but the capability to utilize these functionings is not, there is *capability deprivation* and a curtailment of freedom. Furthermore, the CA emphasizes the role of agency and choice in achieving one's capabilities. Sen uses the example of two men starving to explain this. One man is starving because he is fasting – by choice. The other is starving because he is unable to acquire enough food to feed himself – here there is no choice, only force. In both cases, the men are being insufficiently fed, and so are not achieving that functioning. However, the one man who is fasting is choosing to do so; he is exercising his agency and doing so purposefully. The one who is starving does not have the capability to feed himself and is so forced to starve. This example highlights the role that agency plays in achieving functionings and capabilities.

Martha Nussbaum, a political philosopher, further developed Sen's approach and created a list of 10 essential capabilities. This is where she distanced herself from Sen. It had been his intention to leave capabilities ill-defined so that they could be applied to different situations and circumstances, thus having a pluralistic use. (Sen, 2004) Sen continues to argue that fixing a list precludes the possibility of participation by society in choosing the capabilities that are most important to them. It also presupposes that the list would have to remain fixed. (Sen, 2004) For Nussbaum, the list is essential. She is a strong advocate of universality, including human rights, and found it important to define a particular group of inalienable human capabilities.

We side with Sen, in that capabilities should not be given a priority list as all capabilities are as valuable for leading a good life and no one capability should be defined as 'better' than any other. We believe that this distinction should be left to each individual and the society in which they live. However, for practical purposes, we have chosen from Nussbaum's essential capabilities list for our analysis of the capability development of women with disabilities. This will be detailed later in the second section of this chapter. Importantly, Nussbaum (2000) has focused much of her work on the condition of women. Power differentials between genders are what guide Nussbaum's work and she has stated that "unequal social and political circumstances give women unequal human capabilities." This particular focus lends further support to our use of the CA for our research as it

includes gender as an essential analysis component. Below is Nussbaum's list of inalienable human capabilities (Nussbaum quoted in Loutfi et al, 2001:55):

1. Life
2. Bodily Health
3. Bodily Integrity
4. Senses, Imagination, and Thought
5. Emotions
6. Practical Reason
7. Affiliation
8. Other Species
9. Play
10. Control Over One's Environment (both political and material)

She explains the list by advancing the idea of basic, internal, and combined capabilities.

Basic capabilities are the innate equipment of individuals' essential for realizing more complex capabilities. (Nussbaum, 2000:84) The capability to hear and the capability to love are seen as basic capabilities. *Internal capabilities*, such as speech, are seen as developed states of the person that provide sufficient conditions for the exercise of requisite functions. (Nussbaum, 2000:84) This is achieved through maturation and almost always requires support from the surrounding environment (be it through basic nutrition and growth or social interaction). Finally, the concept of *combined capabilities* considers the fact that although an internal capability may have been developed, the power to function in accordance with it may be lacking. A *combined capability* is defined as the internal capability *combined with* suitable external conditions for the exercise of the function. (Nussbaum in Loutfi et al, 2001:55) Nussbaum uses the example of sexual expression as a functioning that can be attained when a woman is not genitally mutilated (internal capability) and is in a relationship permitting this expression (combined capability). (Nussbaum in Loutfi et al, 2001:55) Capability, then, is not only the attainment of functionings but having an environment that permits the full expression of these functions.

Finally, Sen and Nussbaum's work stands out through the inclusion of the role of human beings as agents of their own well-being, and by considering agency important not only as an end in itself but as a means to achieving capabilities and freedoms. (Stanton, 2007) Nussbaum and Sen both argue that the appropriate goal is the *capability development* of persons and having the *ability to choose* which functions one wants to achieve. In the previous example, a woman whose genitalia is whole can choose to express herself sexually, thus achieving this capability, or choose to remain celibate. The objective

these authors argue for is the capability to achieve whichever functioning one *chooses*, and to be able to act upon this through their agency. (Nussbaum in Loutfi et al, 2001: 56)

The Capabilities Approach framework defined by Sen and further elaborated by Nussbaum is in our view the best methodology from which to understand the complexity of our research participants. Often cited in relation to poverty reduction, development projects, and human rights approaches, it has very recently been appropriated by the disability community as a means to both understand and define disability within the social context. The works of Welch (2002), Mitra (2006), and Dubois and Trani (2009) are a few examples. Mitra (2006) highlights that under the CA, “disability can be understood as a deprivation in terms of capabilities or functionings that result from the interaction of the individual’s (a) personal characteristics (age, impairment), b) basket of available goods (assets and income) and c) environment (social, economic, political, and cultural).” Dubois and Trani add that by providing an analysis of the sociopolitical context in which PWD live, the CA permits us to “explore the mechanisms through which oppression and exclusion ensue.” (Dubois and Trani, 2009:198) Consequently, the Capabilities Approach supersedes the definitional issues of what kind of disability a person has and goes straight to the source of the problem: how these characteristics (personal, economic and, environmental) impact each person’s abilities to achieve the capabilities they wish.

Moreover, the CA allows us to explore whether the physical impairment actually leads to disability. Disability can be considered deprivation at the level of capabilities or at the level of functioning. “At the functioning level, the focus is on what an individual values doing (or being), and on what the individual succeeds in doing/being. (...) A person is disabled (only) if she cannot do or be the things she values doing or being.” (Mitra, 2006) And so, when one adapts to the changes that come from the physical impairment, one may not be disabled at all. We base our analysis of the status of WWD on the definitions of capabilities, functionings and agency defined by the Capabilities Approach. More specifically, we will be looking at four capabilities identified by Nussbaum in her inalienable capabilities’ list: Bodily Health, Bodily Integrity, Affiliation, and Environment Control.

2.3.2 Agency

Vulnerability and victimization are two very important concepts to explore when considering the case of women with disabilities. However, as previously discussed, their assumed vulnerability does them a disservice when we ignore their own skills and survival

strategies. Their role as agents and actors in their own lives and their society is often ignored or forgotten. For Sen (1999:19), an agent is seen as “someone who acts and brings about change, and whose achievements can be judged in terms of her own values and objectives, whether or not we assess them in terms of some external criteria as well”. The ability to be an agent in one’s own life is seen as an essential freedom by Sen. The value to this is “significant in itself for the person’s overall freedom and important in fostering the person’s opportunity to have valuable outcomes”. (Sen, 1999:18)

Critical disability theory also addresses the issue of agency and victimhood. “Critical disability theory does not want to portray persons with disabilities as passive victims. While there are undoubtedly pervasive structures of inequality (...) there are also many and diverse agentic practices developed by the disabled to resist the exclusion and oppression. For every moment and instance of ‘power over’, there are moments and instances of ‘power to’.” (Pothier and Devlin, 13) Even when someone may consider himself or herself as a patient, or a person needing support, it does not preclude their status as agents or cancel out the responsibilities others have in recognizing them as such. (Sen, 1999:190)

Sen (1999:137) also argues that there is a “need to see people – even beneficiaries – as agents rather than as motionless patients. The objects of ‘targeting’ are active themselves.” The concept of agency underlies that of responsibility; it considers how one acts (or refuses to act) and how one chooses one action over another. (Sen, 1999) In this case, agency must be recognized as both a tool for self-emancipation and as an obligation to consider how our actions affect others. This concept will be essential in understanding WWD themselves as well as the various actors in their lives.

2.3.3 The Actors Oriented Approach

The Actors Oriented Approach is a tool to understand and navigate complex processes of social construction and reconstruction and has generally been used in the planning and evaluation of development projects and programs. It starts with the identification of particular issues or problematic situations by the actors themselves (which can range from policy-makers, researchers, local actors, and so on) that occur within a particular spatial, cultural, institutional, and power domain. (Long, 2001) The approach argues that each situation will inevitably be perceived and interpreted differently by each party that is involved, leading to a variety of arenas, conflicts, and strategic groups. The Actors Oriented Approach, as stated above, is interested in social events and, consequently, in cultural phenomena. (Long, 2001) It rejects the concept of cultural

homogeneity, arguing instead for 'cultural repertoires' (recombination of various cultural elements by each person to create their own distinct and ever changing cultural understanding), 'heterogeneity' (creation and co-existence of multiple social forms within the same arena, making culture living, changing and variable), and 'hybridity' (the end product of the mixing of various cultural repertoires following interaction between actors). Long describes the Actors Oriented Approach as one "locating individuals in the specific lifeworlds⁴" of their everyday life. The role of individuals in social change and cultural transformation is of particular interest and Long (2001:13) argues that it is thoroughly "unsatisfactory to base analysis (of development) on the concept of external determination" only, meaning that although outside forces (like the market or international bodies) impact the populations they target, these interventions are done within the existing lifeworld of a person and this lifeworld's existing structures. The concept of agency is closely related to that of the actor in the Actors Oriented Approach. Long (2001) argues that, given the access to information and resources people have, individuals and social groups are seen as 'knowledgeable' and 'capable' of solving and avoiding difficult situations as well as contributing to their own world. Conversely, they can also be 'active accomplices' to their own subordination and victimization, depending on the actions they take.

The Actors Oriented Approach also offers a different view on interventions and development projects. This is highly relevant to the study of women with disabilities who have been the subjects of intervention throughout their lives. Intervention is seen as a 'multiple reality' made up of differing cultural perceptions and social interests, and with continuous social and political struggles that happen between the various social actors that are involved. (Long and Van der Ploeg, 1989) For Long, the Actors Oriented Approach also focuses attention on the role played by those undergoing the intervention, through the strategies they devise and the types of interactions that develop between themselves and the intervening parties. They are not passive receivers but actors within the programs, influencing the purpose, directions, methods, and outcomes. For the purposes of our research, it will be used to explore the roles of women themselves in their development as well as that of other groups, such as NGO, government, church and family, which are involved in their lives.

⁴ *Lifeworld* being a concept first advanced by sociologist Edmund Husserl as a grand theatre of objects variously arranged in space and time relative to the perceiving subjects. It is already and always there, and is the ground for all shared human experience. (Husserl, 1936:142)

2.3.4 Research Question and Objectives

The theoretical concepts of vulnerability, labeling, capabilities, agency, and actors have been discussed above. The purpose of our research resides in exploring the interaction of these concepts in the context of the life of women with physical disabilities in Lusaka, Zambia. Despite being labeled as a vulnerable group needing external assistance, and considering the various social and economic constraints they face and which may be exacerbated by their physical condition, we argue that these women with physical disabilities nevertheless express their own agency by developing specific capabilities while interacting with their own social worlds. What are the support and constraints faced by the women in our sample to reaching the functionings they target? What are the processes that lead to capability development, or lack thereof, for the women in our sample?

The first hypothesis is that government and civil society play an essential role in providing the women with the tools and conditions to utilize their own agency and develop the capabilities and functionings they find important. The second hypothesis is that the disability itself is not sufficient to explain the social status of the individuals in our research; it is essential to include their social world and their individual characteristics, such as gender, disability, and environment.

The main objective of the research is to critically explore what impact being a *woman with a physical disability* born, raised, and living in a *developing country* has on the development of a her capabilities. The two subsequent objectives are:

1. Through a life histories approach, identify and analyze the processes that have led women to their current capability development level. This will be done using one-on-one interviews with women conducted in 2009 and 2010, as well as discussions with key informants and observations.
2. To understand the role of social actors (organizations of all sorts including government, NGO, churches, and families and friends) and the arena, or entourage (be it the neighborhood or other social spaces such as markets and schools where women go) in the development or hindering of capabilities of these women. This is achieved through interviews with organizations, their clients, and informed community members as well as through the information provided during the life history interviews.

CHAPTER 3: CONTEXT

The following chapter will provide the contextual information of our research: an overview of the country of Zambia in general (including recent politico-economic history), a demographic and health profile, and an exploration of gender relations. We will then further develop the concepts of disabilities and women in the particular Zambian context, including statistical data, existing laws and programs, and important actors. Finally, we will explore the particular details of our case study, including the peri-urban settlements in which our target population lived and in which we worked.

3.1 Zambia: Politics and People

This first section will explore the larger context of Zambia in an effort to understand the historical, political, and cultural underpinnings that affect the lives of the women in our case study. We will also study the health situation as well as Zambia's particular gender relations.

3.1.1 General Background

Zambia is a landlocked republic in the centre of Southern Africa with a population of just over 13 million people. (CSO, 2012) It borders with Zimbabwe, Botswana, Namibia, Angola, the Democratic Republic of Congo, Tanzania, Malawi and Mozambique – it also hosts over 120 000 refugees from these countries. (UN Data, 2009) Notwithstanding this complex neighborhood, Zambia has avoided significant inner turmoil and conflict. This has often been attributed to the fact that, with a total of over 73 different ethnic groups (mostly from Bantu origins, the main groups include the Bemba, Nyanja, Tonga and Lozi) and 85 languages and dialects, no one group has been able to dominate the main wealth-producing areas. (Byrne, 1994) The country is mostly Christian, with an important minority of Muslims, Hindus and animists. Its capital, Lusaka, is the scene for our research. It is the largest city in Zambia, with a population of about 1.7 million people, or over 10% of the country, many of whom live in peri-urban settlements. (CSO, 2012)

3.1.2 Political and Economic History

The region came under the influence of Britain in the 18th century with the arrival of the South African Company and became the protectorate of Northern Rhodesia in the late 19th century. (Towen, 1996) In the 1920s, Zambia's copper mines were opened in what is now the Copperbelt region; this led to massive influx of migrants from rural areas to the new mining centers. (Towen, 1996) The country achieved independence in 1964 under the rule

of President Kenneth Kaunda and, in 1972, fearing challenges to its power, Kaunda's United National Independence Party (UNIP) declared Zambia a one-party state. (Phiri, 2006; Noyoo, 2010) It would return to a multiparty system in only 1991, following mass protests. (Phiri, 2006)

During the initial multi-party era, Zambia saw a period of economic growth, with a mixed economy and heavy public investment in human development (such as roads, houses, schools, and hospitals). (Noyoo, 2010) In fact, at independence, Zambia was thought to be one of the richest countries on the continent due to its mineral wealth, particularly in copper. (Byrne, 1994; Noyoo, 2010) However, in 1974, copper prices fell dramatically while oil prices rose. Adding the burden of expenditures of government-financed programming, the country had to finance its debt with loans from the IMF. (Towne, 1996) In 1984, Zambia implemented its first Structural Adjustment Program (SAP). (Towne, 1996) This SAP led to, amongst other things, reductions in government expenditures, including food subsidies and health care. (Noyoo, 2010) These cuts significantly impacted the poor, the marginalized, and those vulnerable to acquiring disabilities related to malnutrition and other diseases. The consequences of the SAPs could already be seen in the early 1990s, when cost sharing schemes were developed for health and education, eliminating access to health services for many of the poorest. (Byrne, 1994) Furthermore, this directly affected persons with disabilities as the subsidies they previously received for mobility aids, rehabilitation, food, and quotas to access employment were removed.

In 1991, Frederic Chiluba ousted Kaunda and Zambia returned to a multiparty system. (Noyoo, 2010) At this time, Zambia was close to bankruptcy, with a total external debt of US \$7 billion owed to the World Bank, Paris Club⁵, and Non-Paris Club bilateral donors, as well as private banks. (Towne, 1996) Immediately, Chiluba embarked on a no-holds-barred implementation of the SAP. Although the government did succeed in fully liberalizing the economy, as required by international donors and neo-liberal purists, it was done on the backs of the poor and led to increased rates of absolute poverty. (Phiri, 2006; Towne, 1996) Public assets were unbundled and sold off, the Zambian Kwacha was devalued by 120%, prices and interest rates were freed, trade and foreign exchange

⁵ The Paris Club is an informal group of financial organizations from some of the biggest world economies that work in war funding, debt restructuring, debt relief, and debt cancellation for debtor countries. Its members include Australia, Austria, Belgium, Canada, Denmark, Finland, France, Germany, Ireland, Italy, Japan, Netherlands, Norway, Russian Federation, Spain, Sweden, Switzerland, United Kingdom, and United States of America. Non-Paris Club members are non-permanent members that have participated in some financing schemes. They include Abu Dhabi, Argentina, Brazil, Korea, Israel, Kuwait, Mexico, Morocco, New Zealand, Portugal, South Africa, Trinidad and Tobago, and Turkey. (Paris Club, 2012)

controls were liberalized, and living standards fell drastically; malnutrition affected nearly 50% of those under 15 and 30% of adults. (Noyoo, 2010) The manufacturing and agricultural sectors were devastated through liberalization -- the two sectors in which our research participants most often worked. Health reforms led to the introduction of higher user fees as well as a decline in the provision of services. (Phiri, 2006) This, combined with severe droughts and food shortages, meant that, by the end of the millennium, more Zambians were living in absolute poverty than in 1991. In 2000, the country had an external debt of over US \$6 billion and was classified as a Highly Indebted Poor Country (HIPC). This qualified Zambia for the debt relief. Donors promised to pardon US \$3.8 billion of debt if various economic and political benchmarks were met over the next years. (Noyoo, 2010)

Chiluba's tenure was rampant with political abuses, fund diversions, tribalism, nepotism, and cronyism. (Phiri, 2006; Noyoo, 2010) Following a hotly contested election in 2001, Levy Mwanawasa won the presidency. His time in office was defined by his battle against corruption. Within months of his election, he established the Task Force on Economic Plunder that targeted Chiluba and other leaders. (Simon et. al., 2008) Chiluba was tried for corruption in Zambia and in a parallel process initiated by the United Kingdom, due to the fact some of the money had been sent to UK banks. He was acquitted in Zambia but convicted in the UK and ordered to repay US \$46 million of public money he had misappropriated during his time in office. (Simon et. al., 2008; Noyoo, 2010) The Chiluba period is important as it highlights large-scale and high-level corruption, which had massive negative repercussions on the people of Zambia. In a country hampered by poverty and foreign trade woes, these actions were disastrous to donor confidence and, more importantly, removed funding from programs in need.

Mwanawasa pursued many of the same economic policies undertaken by Chiluba. (Simon et. al., 2008) During Mwanawasa's tenure, Zambia achieved the benchmarks for HIPC debt relief; relief started on April 15, 2005 when Canada cancelled Zambia's debt to it. (Simon et. al., 2008) In 2006, global market prices for copper prices started to rise, thus further aiding Zambia's economy. (Simon et. al., 2008) The 2000s also saw renewed interest in Zambia by China. It has since become an important investor in privatized public enterprises and the mining and infrastructure sectors. Two other presidents succeeded Mwanawasa since his 2008 death while still in office. These marked the third and fourth successive peaceful transfers of power in Zambia's democratic history since 1991. Time will tell how the Zambian economy will fare during the global economic crisis. However, the Central Statistical Office reported that the economy grew 6.6% in 2011 and inflation

remained at 6.4% in March of 2012. (CSO, 2012) In 2011, the country's foreign debt was of US \$1.9 billion, or 10.7% of GDP, and two-thirds of the country still lived below the absolute poverty line of US \$1.25/day. (UN Data, 2012)

3.1.3 Urbanization

With over 13 million inhabitants on a land of 750 000 km², Zambia has a nation-wide population density of 17 persons/km² and an urban population of about 36%. (WHO Statistics, 2011) This makes it one of the most urbanized countries in the region. It is important to note that the majority of Africans living in urban centers occupy informal settlements, or peri-urban settlements. This type of urbanization is a relic stemming from colonial policies. (Towen, 1996) Previously, permanent formal urban settlements were reserved for European settlers. Migrant policies allowed for the hire of African men in the cities for term contract. Once the contract was over, they were no longer legally allowed to live in the urban centers and would then settle on the outskirts of town – and often rejoin their wives and families who had migrated to the outskirts. (Fallavier and Mulenga, 2005)

Following independence, Africans were formally allowed to live in the urban centers but found that these were unable to accommodate the increased demand. And so, the wave of migrant workers attracted to the economic strength and promise of a better life in urban centers were siphoned into the already overcrowded informal settlements. (Fallavier and Mulenga, 2005) Women migrated for mainly social reasons, such as to join husbands or family members working in towns, or to escape abusive marriages. For the women who migrated independently, they faced more difficulties than the men in their search for employment, housing, and support due to social norms limiting their ability to seek employment outside of the home. (World Bank, ZSCGA, 2004) The rapid and intense migration that followed independence has also led to some acute social problems as population growth has not been matched by investments in education, health, sanitation, and infrastructure. (Byrne, 1994) In fact, although 60% of the Zambian population now has access to improved drinking water (on par with the sub-Saharan Africa regional average of 61%) and 49% has access to improved sanitation (above the 34% regional average), access to these services has in fact decreased in urban areas since 1990, going from 89% to 87% and 62% to 59%, respectively. (WHO Statistics, 2011) This indicates the deterioration of infrastructure as well as the continued overcrowding of these cities.

3.1.4 Economic, Socio-Demographic, and Health Profile

Table 1 – General Development Indicators

Indicator	Zambia	SSA Region	World
Average income (GNI/capita in US \$) (2011) ¹	1,254	1,966	10,082
Annual GDP Growth Rate from 1999-2009 (%)	2.4	2.5	1.2
Literacy (% of population) (2008) ¹	70.90	63	81
HDI* (2011) ¹	0.430 (164th of 183)	0.682	0.463
Gini** ¹ (2005)	50.7	-	-

*The HDI is a composite development indicator for human development and includes health, schooling, and income. 1 is the highest indicator possible. (UNDP, 2011)

** The Gini Income Inequality Coefficient measures the inequality among incomes within a country. A value of 0 is perfect equality, a value of 1 is maximum inequality. The UN does not calculate regional or global values for the Gini.

1 - Source: World Human Development Report (2011)

Table 2 – Burden of Disease Indicators

Indicator	Zambia	SSA Region	World
Life expectancy (2009) ¹	Overall: 48 Female: 50 Male: 46	Overall: 54 Female: 56 Male: 52	Overall: 68 Female: 71 Male: 66
HALE* (2007) ²	40	45	61
DALY** (2004) ³	62500		
HIV rates, 15-49 years (2010) ⁴	13.5%	4.7%	0.8%
HIV rates, 15-24 years (2009) ³	Female: 8.9 Male: 4.2		
IMR / U5 Mortality*** Rate (2009) ¹	Overall: 86 / 141 Female: 77 / 127 Male: 96 / 155	Overall: 80 / 127 Female: 74 / 121 Male: 85 / 133	Overall: 42 / 60 Female: 41 / 59 Male: 44 / 60
MMR**** (2008) ²	470 [250 – 680]	620 [460-910]	260 [200-380]
Top causes of death (2008) ³	HIV/AIDS Lower respiratory infections Perinatal conditions Diarrhoeal diseases Malaria		
Disability prevalence (2008) ⁵	14.8%	15.3%	15.6% - 19.4%

* HALE: Healthy Adjusted Life Expectancy, which is an index combining mortality and health to determine the amount of expected years of healthy life.

** DALY: Disability Adjusted Life Years, which is a measure of overall disease burden in a country, measured through the years lost from ill-health, disability, or early death per 100,000 people. They are the sum of years lost to premature mortality (YLL) and years lost to disability (YLD). The DALY data for Zambia is extremely unreliable and has been extrapolated from data collected on child mortality. It can be assumed that it suffers from gross under-reporting.

*** Infant mortality rate (under the age of 1) and Under 5 years of age Mortality Rate, measured per 1000 live births

****Maternal Mortality Rate, ratio of number of maternal deaths per 100,000 live births

- 1 - WHO Statistics (2011) [Zambia: Health Profile](#)
- 2 - World Bank (2011) [Human Development Report](#)
- 3 - WHO (2009) [Global Burden of Disease - Death and DALY Country Estimates](#)
- 4 - WHO (2012) [Data on the HIV Epidemic](#)
- 5 - WHO and World Bank (2011) [World Report on Disability](#)

As one of the most highly indebted poor countries (HIPC), Zambia suffers from extreme poverty (according to the World Bank, 68% of the population is under the national poverty line). Moreover, it is also a relatively inequitable country, with a Gini of 51 (or 130th out of 152 reporting countries), and is considered to be one of the least developed countries in the world, coming in at 164th out of 183 countries. (UNDP, 2011) It also finds itself below the regional average of sub-Saharan Africa and of the low development countries group, with an HDI of 0.430 versus 0.463 and 0.439, respectively. That being said, Zambia's HDI has been steadily, if slowly, improving over the years. The HIV rate has seemed to plateau in recent years but still remains crippling at 13.5% in adults 15 - 49 years of age, the sixth highest prevalence rate in the world (compared to the world average of 0.8%). (WHO Statistics, 2011) In 2008, there was 1.1 million people living with HIV, including nearly 100 000 children under the age of 15, and around 55 000 people died of AIDS each year. (UNAIDS, 2008) Due to increased government presence in prevention and treatment, there has been improved access to anti-retroviral medication, with nearly 64% of those infected having access to the drugs.

The average life expectancy is now of 48 years (47 for men, 50 for women), a significant increase from 42 in 2000. (WHO Statistics, 2011) Although a positive improvement, it is still second only to Malawi, with the lowest life expectancy of 47, and a far cry of the world average of 68 years. Healthy life expectancy was measured at 40 years in 2007, close to the regional average of 45 but still quite far from the global average of 61. The median age is of 17 and nearly half (46%) of its population is 14 years old or younger (WHO Statistics, 2011). The scourge of HIV, which generally affects those in the reproductive age and has been doing so for decades, is the main reason behind this current epidemiological profile. Another important factor is the very high fertility rate, coming in at 5.8 children per women in 2008 (down from 6.5 in 1990) and an adolescent fertility rate of 146.8 girls becoming pregnant per 1000 girls.

3.1.5 Health System and Social Programming

One important aspect to consider when evaluating the health profile of a country is the strength of its health system. In the early years following independence, Zambia was a

rich country that invested heavily in social programs, including its health sector. In the 1960s and 70s, people were able to access high quality health care, education, and social welfare services. (Noyoo, 2010) Moreover, the mining sector, which was the main source of income for the country, invested heavily in social services for its employees, providing them and their families with free health care. (Noyoo, 2010) In fact, some of the women in our research received their treatment and rehabilitation services from these mining companies. However, when the economy crashed, SAPs were introduced and funding to social services was severely cut, the consequence of which can still be seen in Zambia's profile today.

Zambia has a human resource crisis with only 649 doctors in the country, or 0.6 per 10 000 people. Moreover, there are only 7.1 nurses, 0.1 dentists, and 0.1 pharmacists per 10 000 people. (WHO Statistics, 2011) Due to the poor working conditions and low wages, regional, European, and North American competitors are successfully recruiting Zambian-trained health professionals. The government spends less than 6% of its GDP on health. When we consider that the total per capita expenditure is \$80 at PPP (\$49 of which comes from the government), compared the US \$899 PPP⁶ average worldwide, the lacuna in health and health services funding is staggering. (WHO Statistics, 2011)

It is important to note that women are especially affected by the health and development situation in the country. Maternal mortality rates are of 470 per 100 000 live births and, as mentioned, female fertility is high at of 5.8 children per woman. In addition, women are often the sole providers of health care for children, family members, and the community. They are exposed to increased health risks and have significantly less free time than men. (Byrne, 1994) Furthermore, their vulnerability to infection by HIV is an important concern as their subordinate position in society severely limits their control over their own sexuality and their ability to negotiate for safer sex. (HRW, 2007)

Another challenge is related to materials and funding. Very little funding is directed towards programming for persons with disabilities. With issues such as a lack of major infrastructure, severe poverty, and an HIV pandemic, disability is pushed aside. Moreover, Zambia has suffered corruption at the hands of its political leaders, important human rights abuses (mostly of women and children), and has generally failed to invest in social and health programs. (Noyoo, 2010) In 2009, the Zambian Anti-Corruption Commission unearthed a US \$7 million embezzlement scam in the country's Ministry of Health. This led the Global Fund to Fight AIDS, Tuberculosis, and Malaria to suspend US \$137 million in funding in August of 2009 until the situation was rectified. Much bilateral aid was also

⁶ Purchasing Power Parity.

suspended. (Usher, 2010) It is in such a climate that persons with disabilities find themselves fighting for support and access to health and employment.

3.1.6 Gender Relations

Table 3 – Gender Inequality Indicators (all data from the UNDP Human Development Report. For 2011, unless otherwise indicated)

Indicator	Zambia	SSA Region	World
Gender Inequality Index	Rate: 0.627 Rank: 131	0.61	0.492
Adolescent fertility rate (per 1000 girls)	146.8	119.7	58.1
Seats in national parliament (% female)	14	19.8	17.7
Population with at least a secondary education (%) (2010)	female: 25.7 male: 44.2	female: 22.2 male: 34.9	female: 50.8 male: 61.7
Labor force participation (%) (2009)	female: 59.5 male: 79.2	female: 62.9 male: 81.2	female: 51.5 male: 78.0
Contraceptive prevalence (% married women 15-49) (2005-2009)	41	24.3	61.6
Total fertility rate (child per woman)	6.3	4.8	2.4

The particular situation of women in this context is important to consider as they are not only subject to the ills of poverty, but also to those associated with their gender. As is the case generally for Zambia, there is very little research providing proper accounts of gender relations and cultural norms. Byrne's 1994 report on the Gender Profile of Zambia for the Irish Department of Foreign Affairs highlighted that little was known on the situation of women in peri-urban zones (of particular interest to our research), nor on women's political participation or about violence against women and children. Furthermore, gender disaggregated data was very limited. (Byrne, 1994) Some new research is starting to appear, mostly within the context of the MDG and reporting on the progress of these specific eight objectives.

Although improvements have been seen over time, many indicators make it appear that women are second-class citizens in Zambia. The situation is generally worse for women in rural regions versus those in urban areas. (UN Data, 2009; Zambia DHS, 2007) Regarding education, although nearly the same amount of girls are registered into school as boys for grade one (with a ratio of 0.95), this significantly decreases over time (to 0.83 for secondary education and 0.74 for tertiary education). (MDG Progress Report, 2008) On a positive note, the ratio of girls to boys enrolled in school has been progressively increasing

since 1990. Political participation is limited; only 15% of parliament seats are held by women. In 2006, 100 women stood for election versus 605 men. There are currently 22 MPs who are women out of 157 seats, and only 5 out of 21 cabinet members are female. Women in leadership roles are also rare, with only 19% of legislator or manager positions being held by women. (UN Data, 2009) Overall, women can expect to earn a little over one third (34%) of male salaries for equal work despite the fact they provide up to 70% of agricultural labor and spend nearly twice as much more time working than men (7 hour days versus their 12-13 hour days). (MDG Progress Report, 2008; World Bank, 2004) In 1993, Beatrice Liatto-Katundu, head of the Department of Development Studies at the University of Zambia in Lusaka, noted in her article on the Women's Lobby of Zambia and gender relations that "it can be asserted that women are absent in the public sphere because they are tied to the hoe, to the pot, to the laundry basket, and to the nappies." This assertion seems to remain true to this day; women are still expected to fulfill these social expected roles that limit their ability to develop other capabilities and functionings outside of homemaker and caretaker.

Domestic and sexual violence is common, property rights are not enforced, literacy rates are significantly lower than those of men, access to markets and economic means is limited, and political participation is also limited (Human Rights Watch, 2007; Nosek, 2001; Smith, 2004). In 2001-2002 more than half of ever-married women surveyed reported being beaten or abused by their husbands. (DHS, 2000) There are no specific laws against domestic violence, as it falls within the general assault statutes, and no laws prohibiting marital rape. (HRW, 2007) In the 2007 Demographic and Health Survey (DHS), domestic violence (with the women suffering the abuse) was reported as being acceptable by over 60% of women and 50% of men for at least one reason (such as infidelity, arguing with the husband, neglecting the children, refusing to have sex, cooking bad food or serving food late). As well, almost half of women (47%) over 15 years of age reported experiencing physical violence and around 21% reported sexual violence occurring at some point in their lives (DHS, 2007).

The Human Rights Watch report on gender violence and HIV in Zambia details the social conditioning that women go through during their childhood, adolescence, and particularly pre-wedding to be submissive and obey their future husbands. This leads to many women feeling that they cannot make any decision without their husband's approval (such as receiving HIV tests, treatment or other health related activities) and also feel that they must remain in their marriage no matter what. (HRW, 2007) When women do want to push back against the abuse, often divorce is not an option. Cultural norms are strongly

against divorce and when divorce is granted, the woman and her family are generally left destitute as they must repay the bridal price. (Touwen, 1994) There is a *Matrimonial Causes Act* that discusses settlements upon divorce but it only applies to marriages made under the marriage statute. As most people in Zambia marry according to customary laws, this cannot apply to them. (HRW, 2007) The Zambian Minister of Gender and Women in Development reported to UN Commission on the Status of Women that, despite the government's commitment to issues surrounding women and their empowerment, important challenges still persist. These include "the feminization of poverty and HIV/AIDS pandemic, limited (understanding) of gender-based violence (as) a violation of human rights, limited (mainstreaming) of gender in ministries (...) and weak accountability mechanisms for gender mainstreaming at all levels." (Government of Zambia, 2008)

The Zambia constitution guarantees every person their fundamental rights and freedoms, irrespective of race, color, creed, sex, place of origin, or political opinion. Moreover, women are guaranteed the right to vote and discrimination through law or administrative regulation is also prohibited. (Byrne, 1994) However, the Constitution also recognizes customary law as a preliminary method to conflict resolution. Although statutory law prevails in principal, in practice, when customary law is applied, it is followed without further appeal. This creates a power differential between men and women in the private sphere, which then leads to gender-based inequalities in the public sphere. (WB, 2004) Customary law is based on clan affiliation and patriarchal systems. Women's rights concerning marriage, divorce, property, and succession are relatively nonexistent. (Byrne, 1994)

These difficulties are significant for WWD as their access and participation is even more limited. They face barriers to accessing reproductive health and motherhood services (as PWD are seen as non-sexual), difficulty participating in the local markets and creating revenue, and problems of mobility within their community. They also have limited access to local services (such as health centers, social services, community gatherings, etc.). Systemic disrespect of their basic human rights, constant abuse, neglect, and sexual and physical violence at the hands of not only their partners but also caregivers and the general community are all significant concerns. (Groce, 2004; Elwan, 1999; Smith, 2004)

What lacks in the research is information regarding the active roles of women in their day-to-day lives. Although they face many challenges, women find ways to overcome. While men are generally seen as the breadwinners and control the money they earn without sharing it equally with their wives, women find different ways to acquire funds and goods.

(Touwen, 1994) While employment in the formal sector is difficult to access, women are ever-present in the informal sectors, mostly in beer (or cachasu) brewing and selling, markets, piece work, domestic work, and even begging and prostitution. (Touwen, 1994) The World Bank (2004:7) also highlights that women have dominated the coping strategies that have been developed in the recent past, including food for work. These various strategies often go undocumented as they are not considered on the same level as formal work. However, it is part of the women's coping mechanisms and shows their agency. Other highly productive and important roles, like being heads of households and support systems for their extended family, are also often ignored. These will be further detailed through the results of our research, highlighting the agency self motivation of WWD.

3.2 Disabilities and Women in Zambia

The current situation of women with physical disabilities in Zambia is characterized with chronic poverty and vulnerability, financial insecurity, negligence by loved ones and the public, a sentiment of dislike and mistrust towards 'able bodied' people, and a general sense needing to fight for survival. Many of these aspects can be found within the overall female population in Zambia, but these are exacerbated by WWD. It must be highlighted that not all is bleak in this community and there are a number of relatively successful WWD.

3.2.1 General Overview of Living Conditions

It is important to note from the onset that there is very limited research done on disabilities in the Zambian context, or in the Southern African context for that matter. When looking for gender disaggregated data and particular information on women with disabilities, there is almost none to be found. There are a few reports from the World Bank, the World Health Organization, some NGO and governmental bilateral donors, but their breadth and scope are limited. Moreover, the statistics reported by the Zambian government and UN organizations tend to vary widely, highlighting the need for increased research and harmonized methodologies. It is only last year, in 2011, with the publication of the first World Report on Disability, that there was a large scale effort to evaluate and report on the conditions of persons with disabilities. (WB, 2011) In an effort to better report on disabilities, the Zambian census underwent many changes in the past twenty years to ensure that it better represents all types of disability. Following changes in wording and providing a spectrum of severity, the prevalence of disability jumped from 0.9% in 1990 to 14.5% prevalence in 2006. (Zambia Statistics, 1990 and 2006) However, in part due to the social

stigma associated to disability, underreporting is still assumed. Depending on the definition used, it is estimated that there are between 300,000 to 2 million persons living with a disability in Zambia. (STARZ, 2010)

As disability was not included in the 2007 DHS and the data for the 2010 census is still unavailable, the most recent report on the condition women with disabilities in Zambia comes from SINTEF Health Research, the largest independent health research organization in Scandinavia. Conducted in 2005-2006 by Arne H. Eide and M. E. Loeb, this research was done in collaboration with the Zambian Federation of Disability Organizations (ZAFOD), the Institute for Economic and Social Research (INESOR) of the University of Zambia, and the Central Statistics Office (CSO) of Zambia. Unfortunately, the research is not on women with disabilities, but on persons with disabilities in general. There is very limited gendered data.

The study found that around 42% of PWD had a physical disability, 47% had sensory impairments, and 11% reported intellectual, learning and emotional disorders. Over half of respondents indicated the disability occurred before the age of five – harkening to the severe challenge to health seen by mothers and infants in the country. Among children five years and older, 24% with a disability never attended school, compared to 9% of those without a disability. If they did attend, however, they tended to succeed at the same levels as those without a disability (80% reached grade nine). During the survey, 55% of persons with disabilities versus 42% of persons without disabilities were not working. The lack of education or employment increases with the severity of disability reported. However, 59% of persons with disabilities within the potentially economically active group (15 - 65) reported having some skills. This is likely linked to the type of education and vocational⁷ training that is generally offered to PWD.

It was found that over 60% of PWD reported having had access to health services and traditional healers. The quality of care was not evaluated. A very small proportion (13%) claimed to be using assistive devices, such as crutches, calipers, and wheelchairs. Furthermore, only 4% claimed that provision and maintenance of these devices were done through the government. Two thirds claimed to pay for it themselves or through their families while the rest could not afford to maintain their devices. Important lacunae were identified with regards to access to vocational training, welfare services, education, assistance device services and counseling. Emotional and economic supports were the two forms of

⁷ Vocational training is generally to provide practical skills for employment in non-academic, generally manual, employment. In our context, it is generally targeted towards specific trades, artistry, agriculture, industry, or trade.

assistance most often mentioned by the respondents. Importantly, social exclusion was often mentioned as a difficulty, particularly in relation to having the inability to participate in traditional ceremonies, making important decisions in one's life, and not being married nor having children. Shortcomings with regards to accessibility to public transportation, workplaces, and banks were also highlighted.

Overall, the report claims that, nationally, households with at least one family member with a disability are slightly worse off than those without a family member with a disability, but not significantly so. This can be somewhat confusing when considered within the larger context of international research. It is important to note that when presenting this particular data, the report was lacking age disaggregated data and information regarding whether the person with a disability was the main breadwinner or a ward of the family. This information is of particular concern when discussing the concepts of vulnerability, independence, and agency of the person. Although, on the whole, the Zambian families interviewed may be at similar socio-economic levels irrespective of the presence of a family member with a disability, it is likely that this data would be different depending on the role of the PWD within the family. Finally, there is a clear need for data focusing on the quality of life and the life situation of the person with a disability *in particular*. This research focused on the financial and social impact disability has on a family unit, but not on the individuals themselves.

3.2.2 Legal Instruments and Government Programming for PWD and Women

3.2.2.1 International Conventions and Legal Instruments

The past few decades have seen many advances in the legal instruments for PWD and women. In 1979, the *Convention on the Elimination of All Forms of Discrimination against Women* (CEDAW) was adopted by the United Nations General Assembly and open for signature and ratification. Although there is no specific mention of disabilities in this convention, it focuses on discrimination against women as well as the respect of legal, reproductive, and overall human rights. (UN, 1979) Zambia signed and ratified this convention by 1985. In 1996, the Zambian government passed the *Persons with Disabilities Act*. This act assured the establishment of an Agency charged with the welfare of PWD, and a variety of rights and services that would be guaranteed by the Zambian government. (Government of Zambia, 1996). There is, however, no specific mention of women or girls in this act. The Zambia constitution guarantees every person their fundamental rights and freedoms, irrespective of race, color, creed, sex, place of origin, or political opinion. It does

not, however, make any mention of persons with disabilities. Lobby groups for persons with disabilities participated in the Constitutional Review exercise that occurred from 2007 to 2012 in Zambia. Through these efforts, the rights of persons with disabilities are enshrined in articles 48 and 53 of the draft Constitution of 2012's Bill of Rights. (NCC, 2012)

In 2003, the African Union brought forth the *Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa*. This protocol served to guarantee women their pre-existing human rights through a legally binding document. It also highlighted other timely subjects, such as the end of harmful practices and the protection of women in armed conflict. Significantly, it mentioned WWD, including Article 23 that "ensured the protection of women with disabilities (... and) ensure the right of women with disabilities to freedom from violence" (African Union, 2003). Zambia has signed and ratified this protocol.

In 2008, the *International Convention on the Rights of Persons with Disabilities* (also known as CRPD), agreed upon and signed at the United Nations, came into force for all signatories. It outlines the civil, cultural, political, social, and economic rights of PWD, thus specifying these rights and "clarifying existing international law regarding disability." (WHO WRD, 2011:9) The CRPD was accompanied by an Optional Protocol that set out complaints and inquiry procedures for citizens of ratifying countries. These procedures are lodged with the treaty's monitoring committee and can lead to tangible consequences for non-compliant countries. (WHO WRD, 2011) Persons with disabilities are now internationally recognized as "subjects with rights who are capable of enforcing those rights" and not as "objects of charity and protection." (UN, 2006) Article 6 of the Convention focuses entirely on WWD and the important role states must play to ensure their full rights and freedoms. Zambia signed the convention in May 2008 and ratified it on February 1st, 2010. Although it signed to Optional Protocol in September 2008, it has yet to ratify it. Change is slow to come within the government, and all the more so at the level of society. Certainly, administrative difficulties as well as limited motivation to implement this Convention in light of other pressing matters can serve as one explanation. (personal communications)

The existence of these national and international legal obligations regarding women and persons with disabilities are important as they show a change in societal views regarding these two groups. Although we do not take the human rights perspective as one of our main theoretical concepts, it has influenced many aspects of the disability advocacy movements, as well as helped propel the creation of programs and organizations to answer protect and enforce these rights. These are discussed below.

3.2.2.2 International Programs

A list of the various international programs enacted over the past four decades in relation to disabilities and women is provided in Annex 1. It is important to note that there has been a steady increase in attention to the case of persons with disabilities since the 1980s, with the creation of the International Year of Disabled Persons in 1981 to the Convention on the Rights of Persons with Disabilities in 2008 and the first World Report on Disabilities in 2011. These programs did face many challenges, such as lack of buy-in and lack of resources for implementation and promotion, which can be seen by the need of follow-up the African Decade of Persons with Disabilities of 1999-2009 with a second one, as the first did not achieve its desired goals. However, their existence does hint towards continued international interest in disability and gender.

3.2.2.3 Government programs

Policy initiatives are mostly coming from outside sources and international actors, such as CARE, SIDA, NORAD, and FINNIDA and include micro-finance initiative, community-based rehabilitation schemes, and advocacy work. There are some national organizations for PWD (roughly 30 nation-wide), but they are not sufficiently effective. (Phiri, 2008) This is most likely due to a lack of coordination as well as limited resources being distributed. Some prevention of illness-induced disabilities has been accomplished through immunization efforts, but Zambia still falls short of universal coverage. In fact, its immunization rates have decreased in the past 10 years. (WHO, Statistics, 2011)

The policies from the Poverty Reduction Strategy Paper (PRSP) are also crucial, but have yet to be evaluated. The Zambian PRSP was produced in December 2006 and is for the period of 2006-2010. Disability has a prominent place in the PRSP with an entire section dedicated to outlining needs and possible interventions to improve the inclusion of persons with disabilities in development work. (IMF, 2007) The vision of the PRSP vis-à-vis disabilities is to ensure that PWD “enjoy equal opportunities that are generally available in society and are necessary for the fundamental elements of living and development by 2030” which will be done through full participation, equality and empowerment of PWD. (IMF, 2007)

Disability was mentioned in Zambia’s *Fifth National Development Plan 2006-2010* (FNDP) in its section on Disability and Development - this was a first for National Development Plans. The FNDP highlighted that although there is the Persons with Disabilities Act, its violations are widespread and very rarely recognized due to the

ignorance of most stakeholders. (GoZ, 2006) It also describes particular areas of focus for the government, including accelerating the attainment of the rights and needs of PWD, increased communication through accessible means, increased spending, development of mainstreaming policies, reviewing of legislation, and establishing and strengthening institutions and systems. (GoZ, 2006) The *Sixth National Development Plan* (SNDP) was launched in 2011. Unfortunately, although the SNDP made disability a “cross-cutting issue”, there appears to be a significant cut in disability-specific programming. Over the next five years, the SNDP is only allocating ZMK 69.1 billion (roughly US \$13 million) to disability, from a budget of ZMK 53,560 billion (roughly US \$10 billion), or 0.13% of the budget. (GoZ, 2011) It is however similar to the percentage allocated to disability programming in the FNDP. There are three government-level organizations that operate towards the welfare and well-being of persons with disabilities in Zambia: the Ministry of Community Development and Social Services (MCDSS), as well as the Zambian Agency for Persons with Disabilities (ZAPD) and the National Trust for the Disabled (NTD) (the last two falling under the jurisdiction of MCDSS). Another government agency of some importance in the National Aids Council (NAC) as it has started to include disability in its programming.

With regards to women, there is a *National Gender Policy* that was first discussed in the *Fourth National Development Plan* in 1989, in the Women and Development chapter. The national gender policy also takes into account the issues and concerns contained in strategic documents such as the *Convention on the Elimination of all forms of Discrimination Against Women* (1979); the *Beijing Declaration and Platform for Action* (1995); the SADC *Declaration on Gender and Development* (1997); and the *Millennium Declaration and Development Goals* (2000). (Lupunga, 2007:4) It has however been severely criticized as being both ineffective and suffering from the institutionalized gender inequalities within government itself. (CRPD, 2004)

The government addresses gender through a variety of levels: national (with the Gender in Development Division under the Cabinet Office and the Minister of Gender and Development), sectoral (through gender focal points in the line ministries), provincial (through gender coordinating points), and district (through district gender focal points). (CRPD, 2004) However, it is important to note that all efforts done through the government are woeful when considering that only 0.04% of the national budget is directed to the GIDD. (HRW, 2007)

3.2.2.4 Civil Society

International

Important bilateral organizations present in the country and working on disability issues include: JICA, SIDA, NORAD, FINNIDA, DFID, and Christian missions from the United States, Finland, Sweden, Denmark, Germany, Ireland, and the United Kingdom. (Loeb, 2006) Only two multilateral organizations are active in supporting disability programs: the International Labor Organization (ILO) and the European Union (EU). There are also some important contributions provided by larger organizations, including international and local actors, such as: Action on Disability and Development (ADD), Leonard Cheshire Homes International, Sight Savers International Zambia, Norwegian Federation of the Disabled, and various churches. (Loeb, 2006)

National

The main NGOs working on issues of disability active in Lusaka include ZAFOD, ZNADWO, Zambian National Association of Physically Handicapped (ZNAPH), and Disacare (a skills training and wheelchair building association). There are many more national organizations that deal with specific disabilities, such as the Zambian National Federation of the Blind (ZNAFB), Zambia Deaf Vision, and the Foundation of Blind Women in Zambia. An exhaustive list is currently unavailable on the websites of umbrella organizations, ZAPD, or MDCSS. There is also a very large amount of international NGO and UN programs that are involved in Zambia but that are not specifically tailored to disabilities.

An important observation noted during a conference organized with the National Aids Council highlights one of the main impediments facing the civil society movement surrounding disabilities. The report highlighted particular difficulties faced by DPOs, including the lack of knowledge and skills within DPOs to address issues of HIV among their membership, as well as lack of resources for developing HIV programs and evidence-based advocacy campaigns. It was also suggested that DPOs were poorly coordinated, and did not share information, work collaboratively nor undertake joint planning. (STARZ, 2010)

3.2.3 Further Challenges

Despite these initiatives, many challenges remain to addressing the issue of disability in the Zambian context. We have already detailed the significant hurdles faced from the social structure, the economic conditions, and the gendered power differentials.

Although the Zambian government officially guarantees health services and rehabilitation for all persons with disabilities, access to these facilities is extremely difficult and under-funding is commonplace. (Phiri, 2008) The Zambian census indicated that education levels of PWD were extremely low and over 80% of PWD had achieved only primary education or none at all. As well, employment is an issue as only 55% report to work and over 80% of that work is done in the informal and agricultural sectors. (ibid) The government is unable or unwilling to implement its own legislation and mandates due to lack of funds and interest. Discrimination is rampant and PWD are more often than not viewed as pitiful, a burden, and even a curse upon the family. (ibid) Most importantly, the ravages of the HIV epidemic are causing marked increases in disability rates. As well, HIV is devastating the workforce, wreaking havoc upon the economy and consuming most resources allocated to health interventions, which have significant impacts on the lives of persons with disabilities dependant on social supports.

The impact of HIV/AIDS is important to consider when looking at disabilities in Zambia. In most countries, the number of PWD is increasing due to population growth and increased life expectancy, thus increasing age-related disabilities. In Zambia however, aging is not a significant contributing factor. With an HIV prevalence of 13.5% in adults 15-49 years old, its life expectancy is 48 years (males and females) and its Healthy Life Expectancy is 35 years (males and females). (WHO, Zambia, 2009) Persons with disabilities are disproportionately vulnerable to HIV infection in Zambia as information and intervention programs rarely target them. In fact, it has been highlighted that PWD were “rarely considered as a vulnerable group (by the National Aids Council) because it was incorrectly assumed they were not sexually active, or exposed to sexual violence and substance abuse.” (STARZ, 2009) This infantilization and dehumanization of PWD is likely to increase their risk and this risk may be exacerbated among women due to what was highlighted earlier regarding their socioeconomic status in the Zambian context.

Furthermore, HIV can be considered as a cause of disability when we explore the physical, mental and social consequences associated to it. Article 1 of the Convention on the Rights of Persons with Disabilities states that “persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (UN, 2006) When applying this definition to the physical consequences of HIV/AIDS (depressed immune system, high sensitivity to opportunistic diseases, Kaposi sarcoma and dementia, among others), they are clear forms of disability.

(UNAIDS, 2008) Moreover, the disabling effects of societal exclusion and lack of participation linked to the stigma of HIV/AIDS must be considered within the social model of disability. These types of disabilities are more prominent in poor regions, as there is less treatment available and increased marginalization through lack of information.

3.3 Research Context

The field research was conducted over two periods: July to September 2009 and June to September 2010. It was done in partnership and within the context of a project with the Shared World Initiative (SWI), a student program from the University of Ottawa that has been working in Lusaka since 2008. Its projects are community-based, multidisciplinary in nature, and utilizing a participatory action model. My participation was two-fold:

Project coordinator in charge of the logistics of a training program for the Koseni Women's Club.

Conducting research on the lives of women with disabilities who survive through begging. (This would also serve as my field research for my master's thesis.)

The goal of this project was to build Koseni's capacity to ensure a sustainable organization for women with disabilities and to break the 'beggar's mentality' that constrained them. As a relatively young group, mentorship was requested to develop certain areas such as democracy, teamwork, and business skills and to develop a general understanding of the functioning of the local and international civil society world. The main objectives of the project were:

1. The promotion of financial, social, and political independence of the organization.
2. The rehabilitation of the physical and psychological environment of the women.
3. The development of a mentality of teamwork and democracy within the organization.
4. The creation of important partnerships with other local and international organizations (Lupwa Lwabumi Trust (LLT); Ubuntu Association of Zambia; Zambia Disability HIV/AIDS Human Rights Program (ZAMDHARP); Ethiopian Women with Disabilities National Association (EWDNA); SWI).
5. The creation of an environment prone to advocacy and education on human rights.

In 2009, the project was composed of a series of workshops. They were:

1. Visioning Workshop (July 13th to 17th, 2009. Given by SWI, EWDNA, and Ubuntu)

Focused on identifying the vision, strengths and weaknesses of the association as well as discussing certain strategies to achieve their goals. Accomplished through lecturing, group discussions, role-playing, interactive activities, and question periods.

2. Teamwork and Team-building (August 5th to 7th, 2009. Given by LLT)

Built upon the work done in the first workshop but was done in the vernacular.

Permitted more participation from the women as well as a culturally appropriate intervention to work on serious organization problems.

3. Business Skills and Management (August 18th to 21st, 2009. Given by LLT)

Main focus was on building the association's confidence in their own income generating potential and addressing any outstanding issues in their lives that are affecting their businesses.

Also provided an introduction to some hard skills, such as budgeting and bookkeeping.

4. Human Rights, Disability, HIV/AIDS and advocacy (September 2009. Given by ZAMDHARP)

Organized as a result of identifying the lack of knowledge on human rights and HIV and AIDS for persons with disabilities.

In 2010, the project was mostly focused on a return to the field to confirm interview data, but also to organize a conference to unite as many organizations working on the women and disability issue as possible. The goals of this event were to identify the best practices of service delivery for women with disabilities and the challenges to their implementation as well as to create a forum of open discussion between actors in the disability world. Community-based organizations (CBO), non-governmental organizations (NGO), government agencies, and concerned women with disabilities will be participating at this meeting. Our role was the logistics, coordination, and reporting on the conference. We recruited the Director of a local organization that lies on the outskirts of the disability community, the Bwafwano Home Based Care Community Center, to lead the meeting.

The project was in Lusaka, the capital and economic centre of Zambia, as well as certain outlying peri-urban settlements. As one of the most highly urbanized countries in sub-Saharan Africa, Zambia's small population is concentrated in urban centers, and roughly one-third of its urban population lives in Lusaka. (UNHABITAT, 2007) The hope of a better life through employment opportunities, improved access to social services, and a diversified economy has led to an annual population growth of 6% for Lusaka, or twice the national average. (UNHABITAT, 2009) Faced with great difficulties in integrating within their rural communities due to cultural, physical, and gender barriers, many women with disabilities hope to find a better situation in the capital. However, what they find is more of the same, as well as increased risks vis-à-vis personal security, a lack of supporting family bonds, and food insecurity, to name a few. Most migrants end up living in informal settlements, named compounds in Zambia, with inadequate shelter, social services, and sanitation. (UNHABITAT, 2009) These areas are where the majority of our research participants live and is also where our research took place.

The downtown core of Lusaka is where the main transportation and trading hubs are located, as well as the local markets. The majority of the women interviewed lived in the Western section of Lusaka, in the high-density areas. The Eastern side of the city is reserved for middle to upper class Zambians and foreigners. It is also where the majority of the large organizations working on disabilities are located, with the exception of the Ministry of Community Development and Social Services (MCDSS) and the National Trust for the Disabled (NTD). They are located within the downtown limits. The women in our sample mostly lived in high-density areas. They include: Lilanda, Matero, Garden, Kanyama, Chibolya, Misisi, Kabwata South, Chazanga, and Habitat. Two women lived in medium density housing areas: Northmead and Chelston. The training in 2009 was conducted in Chazanga. As of 2009, Koseni had access to a building in Chibolya to use as their club office. This box describes our first impressions upon entering Chibolya, one of the most under resourced and volatile peri-urban settlements of our research:

Entering Chibolya

Chibolya is said to be the most dangerous of all the compounds in Lusaka. The locals nickname it “Baghdad” due to the high levels of violence. There is also competition from John Laing and Misisi, all situated in proximity to each other. The first time I went in, one of the women from Koseni and her husband, both with physical disabilities, accompanied me. However, their presence seemed to give me protection. I must admit that although nervous, I didn’t feel very threatened while walking around. The compound did seem a little bit more rundown than what I am used to in Chazanga, although Chazanga itself is not considered to be one of the best or most developed places in town – not by a long shot.

Upon entering, the paved road immediately turns into a dirt road with massive potholes, littered with garbage. What is different here than in other neighborhoods is that pigs are sold here. It is the first time I’ve seen pigs in market. They were roaming around the coal selling area. As we walked through the neighborhood, people were clearly surprised to see that I was walking with two persons with disabilities, and by the fact that I was entering their community. Yet, nothing was said out loud -- at least not in a language I could understand. The smell from the pigs was quite imposing and the smell of marijuana was also very present. I’ve been told it is assumed that whenever a *mzungu* (white person) enters Chibolya, it is only to purchase drugs, most often marijuana but other types as well. Apparently some people offered to sell to me while we were walking. You could also see a lot of youth and men clearly affected by both drugs and drink as we walked along, also similar to what I’ve seen in other compounds.

The walk to the office was quite long and we met some other members of the organization along the way: a member of the executive and a member of the general membership who had just given birth to a baby. This one was very excited to see me and came running out to give me a hug. I was surprised to see a lot of friendly greetings from friends of the women, many wanting to be greeted by a *mzungu*.

After a long while, we arrived at their offices. Quite a lovely building built by CARE International, situated right beside the police station of Chibolya. The building and grounds were well kept with a security guard at the gate. However, the building was not accessible. For those in wheelchairs, they either had to be wheeled up the stairs or they would get off their wheelchairs, crawl up the stairs and use crutches to get to the meeting room. Alternatively, someone would bring up the wheelchair as well.

We often had meetings outside, sitting on the ground. I am not sure if that is because we, the mzungus, initiated it, but a few times when there were already some women when we arrived, they were seated outside. I've been told that sitting outside is an indication of the level a person holds in society or, in this case, of the organizations using the facilities. Being inside indicates a higher level of importance; outside is more "common". It must also be noted that the fact the women were in wheelchairs definitely impacted their ability to access the building and may have guided them to stay outside themselves.

Some women indicated their fear of going to Chibolya and that the location of the organization's offices hindered their participation because of the need to travel deep within the community. This was compounded by the distance factor where, although many women lived somewhat near (in Misisi, John Laing, Chibolya) others lived quite far and needed to take 2-3 minibuses to make it to Chibolya and then walk for about 20 minutes. I would normally access it by taxi. This location also affected the organization's functioning as it is flooded during the rains – access is impossible for the women who are already limited in their mobility.

- Field notes, 2010

CHAPTER 4: METHODOLOGY AND ANALYTICAL FRAMEWORK

Our research methodology combined exploratory research and case studies of women with physical disabilities. We had intended to include an aspect of Participatory Action Research (PAR) by having the women help design and guide our research, but this proved impractical once in the field. As discussed previously, our research was done concomitantly with the creation and implementation of a development project between the Shared World Initiative and the Koseni Women's Club. While the study of this North-South partnership and of the development of relationships between the two different organizations would have been fascinating studies within a PAR framework, they were not what we had set out to do. In the end, our research objective, to explore the processes leading to capability development for our research participants, did not permit for the use of PAR.

That being said, our involvement with SWI was very useful. It provided access to a pool of potential research participants, a variety of key informants that guided us quickly through the arenas in the disability world, a structure permitting continued contact with participants after the research period, and the ability to return to field and easily reconstitute data. On the other hand, the affiliation with SWI did cause some confusion regarding which role we were playing: project manager or academic researcher. At times, this impacted the type of discussions and information provided during interviews, as the focus would steer towards SWI. Overall, we strongly believe the proximity and trust that we were able to develop with our research participants through our collaboration with SWI was worth the complications we faced. In one case where we interviewed a woman who had not been a participant in the training program or involved with Koseni, the quality of the data was very limited and little to no sensitive information was shared.

Whenever possible, the interviews were carried out at the women's homes or those of their friends. When an interpreter was required to translate from Bemba or Nyanja to English, they were recruited from within the group of Koseni women. Although this may go against the typical methodology of choosing interpreters from outside the community of the participants so as to avoid fear of disclosure, this was done following consultation with the women. They said they preferred to have someone they knew to be there with them as it would make them more comfortable, they would not be afraid to be judged, and because these women already knew their stories. (personal communication, 2009) The benefit of this change in approach was underlined on one particular occasion. When none of the women were available to assist with translation, we recruited a university student who was not known to the participant. The data collected was very limited for two reasons: lack of

comfort with the interpreter and lack of knowledge of the woman's life which then diminished the ability to prompt for or clarify information.

Below, we detail the different information we sought to gather for our research, the tools and methods we used for the data collection, the information we wished to elucidate from the data gathered, and the tools and methods used to disentangle this information and analyze it within the frameworks of the Capabilities Approach and the Actor's Oriented Approach.

4.1 Data Collection

We sought to collect data on the lives of women with disabilities, particularly relating to their agency, their capability development, their interpersonal relations, and their connections with outside actors. We also gathered information on some of the key players involved in the disabilities movement from the NGO and government spheres. This was carried out throughout two research periods: in 2009 and 2010.

2009:

This research was undertaken for approximately eight weeks, through participation in training exercises, organization meetings, and discussions on the margins. Three distinct tools were utilized for the research: life histories, semi-directed interviews, and observation. The interviews had an initial list of set questions. However, any unexpected topics that seemed potentially significant were also probed and then incorporated into subsequent interviews. Thus, all the interviews covered the same basic questions but the later interviews included additional ones that emerged as significant throughout the course of the research. This flexibility was useful to gather more in-depth information from our participants, but it also means that there are discrepancies between interviews conducted at the beginning and the end of our research. This is true for both the women and the organizations.

Interviews with the women ranged from two to five hours in length, averaging about three hours, and from one to three hours with organization representatives. They were audio-recorded, unless this was refused by the participant, and transcribed. The life histories were conducted with fifteen women with disabilities: ten were members of the Koseni Women's Club, two were directors of the Ethiopian Women with Disabilities National Association, one woman was a member of an NGO (Ubuntu), one woman was a client of an NGO (Ubuntu) who developed a disability later in life through the effects of arthritis, and one

woman was a successful filmmaker, renowned through Zambia and Southern Africa. We included the two Ethiopian women because they provided general information related to their personal experience with their disabilities and the difficulties they faced. As they were leaders of a large and successful NGO for WWD in Ethiopia, they were also examples of women with disabilities who had overcome many challenges and managed to create important change in their community. As our research is not attempting to draw country-specific conclusions or comparisons, we feel it was acceptable to use their interviews in our analysis.

We conducted semi-directed interviews with NGO and government employees. They focused on identifying what (if any) role PWD play in the priorities, programming, management, and services of organizations as well as general questions on opinions and perspectives on WWD and their role, rights, and abilities in Zambia. Nine organizations were interviewed: six were NGO and CBO focused on advocating for rights and services for PWD and WWD, two were government organizations that provided general oversight of services to PWD as well as coordination of NGO while the other provided microfinance, and one NGO was a large international NGO that has been involved in services in Zambia for nearly two decades, but has no specific programming for PWD.

Observation was done during the community-based rehabilitation project with the Koseni Women's Club, Lupwa Lwabumi Trust, EWDNA, and SWI. By participating in the organization and delivery of the various workshops, we were able to observe interactions between the women and: persons without disabilities, local community workers, international development workers, the general community, and other women with disabilities. These observations included, but were not limited to: the women's personalities and demeanor; the women's interactions with their peers, the organizations they worked with, and the environment; and societal attitudes and reactions to persons with disabilities. Observation was difficult in the sense that interpretation of what we witnessed often proved challenging. As time went by and we better understood the context, the language, the cultural underpinnings, and so on, our observations became richer. The return to the field the following year greatly helped with this.

2010:

We chose to return to the field (from June to August 2010) for four main reasons: (1) complete our data, (2) implement the next phase of the Shared World Initiative's project with the Koseni Women's Club, (3) assist the women who participated in our research to have

unprecedented access to the government agencies responsible for them, and (4) organize a conference uniting a variety of organizations working on disability and women.

Based on our preliminary analysis of the data collected in 2009, gaps and misunderstandings in our interviews as well as additional questions to be asked to the research participants were identified. We reinterviewed ten of the initial fifteen women who had participated in the research in 2009. Although we were not able to re-interview everyone, the interviews we did manage proved to be invaluable to answer initial hypotheses as well as clarifying information that had been misunderstood. Moreover, they provided an opportunity to explore potential impacts of the project undertaken with the Shared World Initiative in 2009 as perceived and lived by the women who took part in the training.

The project was designed and led by the SWI in collaboration with the Koseni Women's Club. It included creating partnerships between Koseni and local organizations that provided training in poultry keeping and organic agriculture, producing and submitting a project proposal for government funding, and opening a bank account. The objectives of this project were partially a result of the information collected during the first field research with regards to what women were looking for in terms of income generating activities and support.

The third and fourth objectives were achieved with the organization of the conference *Dialogue and Cooperation: New Perspectives on Service Delivery for Women with Disabilities*. It united sixteen NGO, CBO and government organizations. To prepare for the conference, we first held a meeting with all the women from the Koseni Women's Club present our initial findings and have them confirm or repudiate our conclusions. Then, two representatives of Koseni attended the conference and presented their stories in their own voice, in front of many actors ranging from grassroots to government. The women re-appropriated the data gathered during the research to express themselves and achieve an objective. The story they told convinced the government to fund their application for a poultry and farming venture with a grant of ZMK 100 million (roughly US \$10 thousand).

The conference also allowed us to act on a conclusion from the previous data collection in 2009: the disability movement in Zambia is highly disconnected and even tends to work against itself. The conference provided a forum in which these organizations could come together and discuss their methods, challenges, and possible steps forward. Data collection was undertaken through observation of the interactions between organizations

and with the facilitator. It was also accomplished by collecting information regarding the organizations, their mandates, and their objectives.

4.2 Data Analysis

This section describes how the information collected was analyzed to provide the information required to answer our research question. It will first explain the capabilities we chose and the analytical concepts necessary to the analysis. It will then detail the steps and tools, such as life timelines and flowcharts, to conduct the analysis.

Table 4 – Summary of Data Collection and Analysis Tools

<u>Research Question/Hypothesis /Objective</u>	<u>Data Collection Tools</u>	<u>Analytical Framework</u>	<u>Analytical Tools</u>
What are the supports and constraints to reach targeted functionings	- Life history interviews - Targeted interviews with actors - Observation	Capabilities Approach	- Capabilities flowchart through discourse analysis from the women and organizations
What are the processes leading to capability development	- Life history interviews	Capabilities Approach	- Capabilities flowchart through discourse analysis from the women and organizations - Life timelines and comparison between different women
Who are the essential actors	- Life history interviews - Targeted interviews with actors - Observation	Actors Oriented Approach	- Life timelines - Discourse analysis and comparison separated by theme into tables
Do WWD have agency	- Life history interviews - Targeted interviews with actors	- Capabilities Approach - Actors Oriented Approach	- Life timelines - Discourse analysis and comparison separated by theme into tables

4.2.1 Theoretical Tools and Concepts

Inherent to the capabilities framework is the importance of *agency*, understood as the ability to act and bring about change in one's life and environment, both by the person and the actors who surround them. The analysis of the four previous capabilities will include an appreciation of the actions undertaken by the actors as well as the propensity for agency.

The Actors Oriented Approach, which is a theoretical approach based on the concept that of individuals and social groups are knowledgeable and capable of acting on their own lives and environment, will also be used to understand the role of these *actors*. An inherent difficulty with fully referring to the Actors Oriented Approach is the need for in-depth and long-term observation and analysis of interactions between the different actors and their social worlds. This is beyond the scope of this research and we will only be using the approach in an attempt to inform our study on the general conflicts the women faced with actors in their lives (parents, teachers, husbands, friends, employers, etc.), in various arenas (home, school, work, street, market, etc.).

The concepts of *conflict*, *arena*, and *strategic group* will also be key to describing the social environment in which the events occurred, and in which the women live. The concept of *arena* is easily translatable to that of social worlds. Here, the arena is seen as a place of concrete confrontation between social actors interacting on common issues. This place can be a development project, the leadership of an organization, a cooperative, and so on. (Olivier de Sardan and Bierschenk, 1997) In these arenas, where social interactions occur, leading to the development and achievement of capabilities, conflicts are omnipresent. *Conflicts* exist and permeate any and all societies. Conflicts are in part the expression of opposing objective interests, linked to different social positions (and) the effect of personal strategies, more or less linked to networks and organized in the form of alliances. (Olivier de Sardan and Bierschenk, 1997)

These networks and alliances used to overcome conflicts work through a maze of strategic groups. *Strategic groups* are composed of actors who defend shared interests in the appropriation of resources, in particular by means of social and political action. Depending on the contexts or circumstances, each social actor is potentially a member of different strategic groups, depending on their repertoire of roles. There are no rigid boundaries between strategic groups, meaning that one person can be part of many different groups, just like they constitute their own individual group. (Olivier de Sardan and Bierschenk, 1997)

4.2.2 Analysis of the Capabilities

4.2.2.1 Definition of Each Capability

By focusing on capabilities (understood as practical opportunities for a person to achieve whatever functioning they desire), we are focusing on the freedom to be what one

wants to be and to live in an environment that provides the tools, skills, and opportunities necessary to achieve these capabilities. Our research attempts to identify some key characteristics of the women themselves, their social worlds, and the key events in their lives that have lead to the achievement, or not, of capabilities. The breadth of capabilities, as identified by Sen (1999), makes it impossible for us to explore *all* capabilities. Moreover, the scope of the paper only permits a limited analysis. The list of capabilities we are using is not exhaustive, nor do we advocate that they are the main capabilities that need to be considered. We have based our focus to an adaptation of four capabilities from Nussbaum's (2000) list of essential capabilities. In no way are they the only important capabilities, but we deem them to be of particular relevance to the condition of women with disabilities living in poverty in Zambia. The data for each capability will be associated to sub-categories linked to this capability. These are described below. However, when certain subcategories overlapped between capabilities or were not particularly relevant to our research, we excluded them from our analysis. Also, we combined the control over one's environment and the senses capabilities from Nussbaum's list into the Environment Control capability as we believed their indicators were similar and complimentary, thus streamlining the analysis. The list original list and the excluded sub-categories can be found in Annex 3.

The capabilities we chose are: Bodily Health, Bodily Integrity, Affiliation, and Environment Control. All definitions of the capabilities are taken from Nussbaum (2000:78-80), while the subcategories are adapted from her list through our own interpretations of the capabilities. The analysis will be done through a discourse analysis of the life histories of each woman, by identifying information that relates to specific subcategories of each capability (these are described within each capability definition below) It will then be placed in a capabilities flow chart to further explore the processes, supports, and constraints leading to this capability's development. The capabilities flowchart is described in schematic format below.

1. Bodily Health

To have achieved the Bodily Health capability means to be able to have good health, including reproductive health; to be adequately nourished; and to have adequate shelter. The BH capability can be achieved through: access to health services; education on health and protection (HIV, malaria, etc.); access to family planning and the ability to have this respected; the ability to produce, purchase and consume food; and the ability to provide oneself with adequate shelter that is safe from environmental, societal, and other risks.

The three specific sub-categories for discourse analysis are: (1) physical health and freedom from disease, (2) the ability to have shelter, and (3) the ability to nourish oneself.

2. Bodily Integrity

To have achieved the Bodily Integrity capability means to be able to move freely from place to place; to have one's bodily boundaries treated as sovereign (i.e. being able to be secure against assault, including sexual assault, child sexual abuse, and domestic violence); and to have opportunities for sexual satisfaction and for choice in matters of reproduction. The capability can be achieved through: having mobility aids, accessible buildings, and rehabilitation if required; having a life absent of abuse, assault, injury caused by others or by avoidable factors; and having a life absent of rape, unwanted pregnancies, forced sterilization, mutilation, cleansing, and so on.

The three specific categories for discourse analysis are: (1) mobility and accessibility; (2) absence of abuse (physical, sexual, emotional); and (3) reproductive rights (wanted pregnancies and planning, ability to reproduce, sexual satisfaction)

3. Affiliation

The Affiliation capability has both an internal and an external component. To achieve the *internal* component is to be able to live with and toward others; to recognize and show concern for other human beings, engaging in various forms of social interaction; to be able to imagine the situation of another and to have compassion for that situation; and to have the capability for both justice and friendship. To achieve the *external* component is to have the social bases of self-respect and non-humiliation; to be able to be treated as a dignified being whose worth is equal to that of others. Concerted participation from the surrounding environment and actors is necessary for both of these components to be achieved. In the first case, there needs to be institutions that constitute and nourish such forms of affiliation and that protect the freedom of assembly and speech. In the second case, it entails, at a minimum, protections against discrimination on the basis of race, sex, sexual orientation, religion, caste, ethnicity, or national origin.

The five specific categories for discourse analysis are: (1) living in an inclusive environment; (2) being recognized as an equal by one's peers (independent of gender, social classes, disability or health status); (3) having been taught self-respect since childhood; (4) having the ability to create strong and positive family ties; and (5) having the ability to marry without coercion or derision.

4. Environment Control

The Environment Control capability has three components: educational, political, and material. We have combined Nussbaum's fourth capability (the senses, imagination, and thought capability) to this one as we found many of the concepts similar and dependent upon the other. To achieve the educational component is to be informed by an adequate education (including but not limited to literacy and basic mathematical and scientific knowledge) and to be able to express oneself using imagination and thought. To achieve the political component is to be able to participate effectively in political choices that govern one's life and to have the right of political participation, and protection of free speech and association. To achieve the material component is to be able to hold property, both land and movable goods (not just formally but in terms of real opportunity) and to having property rights on an equal basis with others; to have the right to seek employment on an equal basis with others; and to have the freedom from unwarranted search and seizure.

The six specific sub-categories for discourse analysis are: (1) to have access to education; (2) to be able to assemble and participate in the community; (3) to be heard in politics; (4) to have one's rights recognized; (5) to be able to hold property (movable and immovable); and (6) to be able to access employment.

4.2.2.2 Analyzing the Processes Leading WWD to Capability Development

The overall discourse analysis surrounding capabilities led to an overview of the agency of women throughout their lives, as well as other actors, and a perspective on how they achieved, or did not achieve, these essential capabilities. Key events were then regrouped under the four capabilities. Finally, through the capabilities flowchart, we compared the data gathered from all women to draw similarities and differences between them as well as the actors involved in the events. This was done to better identify the mechanisms that make these women able or unable to activate their agency in order to develop the capabilities necessary for their survival, to improve their well being, and to achieve the functionings they desire.

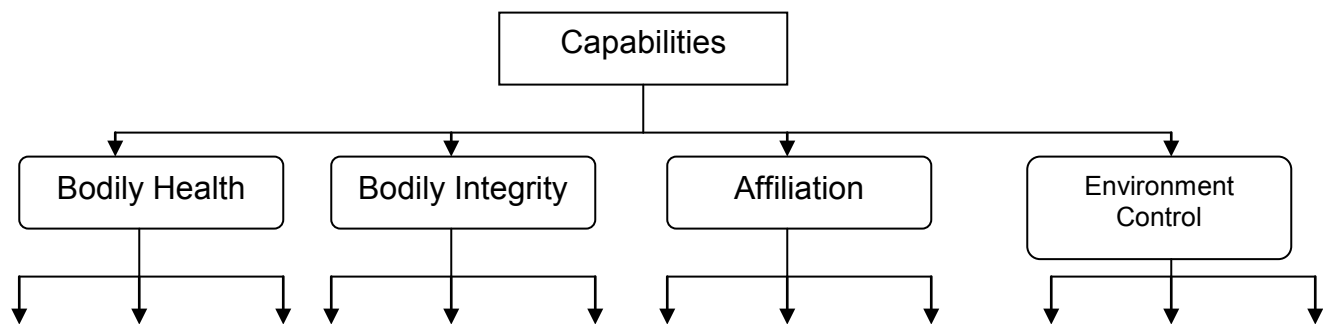


Figure 1 – Capabilities Flowchart

4.2.3 Using a Life History Approach

Another step of our analysis involved identifying key periods in the lives of our participants (such as the onset of disability, conflicts with family, education, and romantic relationships) to then elucidated capability development (or lack thereof). Furthermore, the roles of the women themselves and that of other actors (family, teachers, employers, government, service providers) during these moments permitted us to explore the agency demonstrated by these actors. This analysis was done through a life history approach, using the life events and social worlds of the women throughout their lives to identify patterns and profiles. Moreover, we triangulated this data with information collected from interviews with government agencies and local and international organizations working on the issues of women and disability. This was done through an analysis of the mandates, objectives, challenges, and aspirations of the organizations.

In order to answer our research question regarding the support and constraints faced by the women in our sample to reach the functionings they target and the processes that lead to their capability development, we took a multi-step approach. First, we analyzed the life story interviews of the women and identified the key events in their lives, the specific social worlds (or arenas) in which they participate, and the conflicts *within* these arenas and *between* the strategic groups with which the women interact. This was done using a life timeline (described below).

Timelines: Used to identify key events in the women’s lives (as they have identified them, and where we see a need to identify them) as well as highlight the social worlds in which they lived during this time.

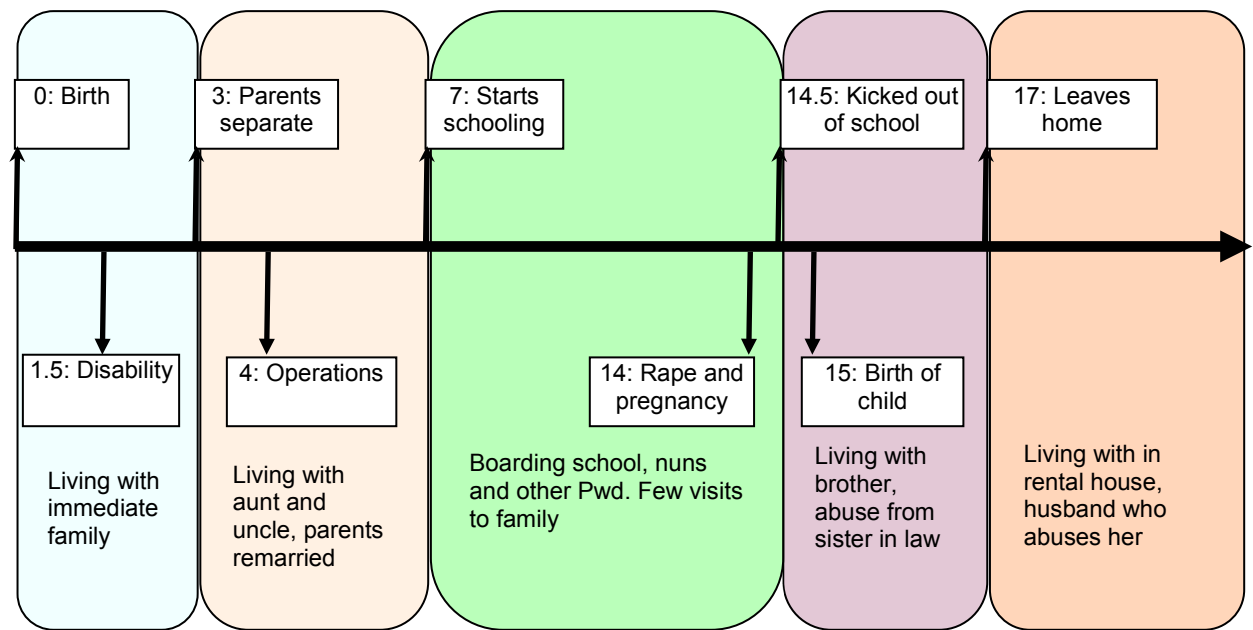


Figure 2 – Life History Timeline

The colored sections describe different environments, or arenas; the white boxes are conflicts, or moments of change, as well as personal characteristics; various events include details of actors involved.

Finally, we analyzed the interviews a second time, identifying language that related to the four capabilities we are exploring: bodily health, bodily integrity, affiliation, and environmental control. This allowed us to study capability development as well as the roles of various actors in this development through the words of the women themselves. This information was further supported by the data acquired from interviews with organizations on how they perceived their roles as actors in the capability development of women with disabilities. This was done with a capabilities flowchart.

CHAPTER 5: RESULTS

The role of actors falls within a spectrum of assisting to hindering. Actors can be considered any person or organization that come into contact with the life world of the women. They can work in conflict or in synergy, or anywhere in between. The main actors identified by women included their family, the men with whom they had relationships, the government, non-governmental organizations, churches, schools, nuns, their children, and friends. They will be discussed in the next section. A full exploration of capability development will follow in the third section of the analysis chapter. Factors that have influenced the women's capability development include environmental (their place of residence, the type of housing, the type of school, the political situation...), access to materials (employment, family finances, business start-up, loans), their personality and drive, and actors (including themselves through their agency).

5.1: Overview of the Women

My life...

I was born in 1965 to a father who was a miner and a mother who was a housewife. I contracted polio when I was 5, which led to my disability. When I was young, I was just ok. I went to school, finished high school and studied tailoring and designing in college. I started working right after school and I was supporting myself and helping my family.

I married twice while I was working, but both men would beat me regularly, sometimes until I fainted. I left them both. When the company I worked at was privatized, I lost my employment and had to find contract work. When that ended, there was nothing for me.

I started doing the barter system and invested in piggery, but my family, the ones who were supposed to help me, stole from me and ruined my business. There was no one else there to support me.

In 1997, I became pregnant but my third husband left me because I was disabled. His family told him I was nothing and that he needed to find an able bodied woman. My brothers didn't want to help me. Neither did my sisters. No one but the church offered help. So, I moved to Lusaka to start a new life, but I couldn't find employment. I had to feed my child and myself. I found myself in the streets.

In Lusaka, I met a man and he married me. But he mistreated me as well and wouldn't help support the family. All the responsibilities fell to me. Finally, I left him and now I am alone with my children.

I survived through begging for 8 years. I stopped last year after joining Koseni and going through workshops. But I am still in a very difficult situation. I haven't stopped begging because I don't need to, but because I don't want to anymore. I can't.

My friends have all been through similar things. Most have been beaten, robbed, betrayed by those they trusted. Some have been raped; some have been infected with HIV by men that don't care for them. Some have had children die from malnutrition because they can't afford food. Many are ignored by their families and left alone. And all because they are disabled and they are women.

- Ethel, Lusaka, 2010

Ethel's story is not unique. Violence towards women is common in Zambia, with nearly half of women reporting to have suffered domestic violence at some point in their lives and more than one-third reporting to have been abused at least once in the previous year. (DHS, 2007) The majority of women with physical disabilities in Zambia share similar life paths, sometimes better, but sometimes far worse. They are labeled, stigmatized and marginalized by the triple burden of their disability, their gender and, very often, their HIV status. Their disabilities often limit their ability to undertake socially expected roles, such as fetching water and food, cleaning the house, and rearing the children. This leads them to being seen as less than a 'whole' woman.

The risk of exposure to HIV is high for these women; it is very difficult to encounter a woman who has not been affected or infected by the disease. Their disability is accompanied with many preconceived notions, such as that they cannot be sexually active and so are viable to be used by HIV positive men looking for a cure to the disease through the 'virgin cure' myth. Others believe they are 'doing them a favor' by sleeping with them because no man would want them. Once they become pregnant or infected with the HIV virus, they are very often discarded.

These women are severely socially marginalized and, more often than not, left to fend for themselves. This reality was seen and discussed frequently with the women interviewed for the research and through observation (such as the reactions of 'able bodied' people to the women). Interestingly, it would seem that people with disabilities tend to harbor as much prejudice to able-bodied people due to past interactions and even schooling that has isolated them from the rest of the population. These mutual preconceptions severely affect the ability to cooperate and develop together.

5.1.1 Overview of the Research Participants

Fifteen women were interviewed. All had some form of physical disability, all were women, and all were African. Although only two-thirds were born and raised in urban or semi-urban areas (five were from rural areas), now they all found themselves in the capitals of their respective countries, be it Lusaka, Zambia or Addis Ababa, Ethiopia. As they were

identified through their linkages with organizations working with WWD (either large NGO or their own club) there is a bias towards those who have managed to access support systems, having enough mobility and personal independence to do so. All reported having been discriminated against due to their disability, some significantly more than others. Some highlighted discrimination based on their gender, either directly or indirectly through the wording they used.

The majority of disabilities were caused by polio while the remainder was a consequence of injury, medical malpractice, war, chronic illnesses, and malaria. All women had accessed Western-style medicine, although over half also used traditional medicines (six of them as a first remedy). Many of them face troubles regarding their mobility aids as they are unable to afford replacements when they break. They are then relegated to wheelchairs despite having relatively good mobility. The all had received some education, but did not necessarily finish schooling. The majority had been or were still married, had biological or adopted children, had begged at some point in time to survive and provide for their families, had undertaken vocational training, and had never worked in formal employment. There are obviously exceptions to each of these characteristics.

The profiles of our research participants can be found in Annex 2. They are grouped by capability development level, a categorization that will be further explored in the discussion section. Below is a table with general socio-demographic data.

Table 5 – Socio-Demographic Overview of Research Participants

Indicator	Subgroup	No.	Names
Age			
	30-35	1	Totela
	36-40	6	Meseret, Michelo, Mutinta, Tawona, Afi, Mary
	41-45	7	Eleni, Natasha, Catherine, Bupe, Ethel, Lusungu, Nataizya
	46-50		-
	50-55		-
	55-60	1	Malaika
Nationality			
	Zambian	13	Tawona, Totela, Catherine, Natasha, Ethel, Afi, Michelo, Lusungu, Bupe, Nataizya, Mutinta, Mary, Malaika
	Ethiopian	2	Eleni, Meseret
Cause of disability			
	Polio	8	Eleni, Tawona, Totela, Ethel, Afi, Michelo, Lusungu, Bupe

Indicator	Subgroup	No.	Names
	Injury	3	Malaika, Bupe, Mary
	Chronic Illness	2	Malaika, Bupe
	Medical Malpractice	3	Catherine, Natasha, Afi
	War	1	Meseret
	Arthritis	1	Nataizya
	Cerebral Malaria	1	Mutinta
Education			
	Incomplete grade school	5	Malaika, Lusungu, Mutinta, Afi, Mary
	Grade School	2	Nataizya, Tawona
	Incomplete High School	2	Natasha, Totela
	High School	6	Meseret, Eleni, Catherine, Ethel, Michelo, Bupe
	College	4	Meseret, Eleni, Bupe, Catherine
Employment (at time of research)			
	Begging	9	Tawona, Totela, Ethel, Afi, Michelo, Lusungu, Malaika, Mutinta, Mary
	Informal trading / self-employed	10	Totela, Catherine, Natasha, Ethel, Afi, Michelo, Lusungu, Malaika, Mutinta, Bupe
	Formal Employment	4	Meseret, Eleni, Catherine, Natasha
Marriage			
	Never Married	4	Meseret, Eleni, Catherine, Bupe
	One Marriage	6	Tawona, Natasha, Michelo, Malaika, Mutinta, Nataizya
	Many Marriages	5	Totela, Ethel, Afi, Lusungu, Mary
	Single	9	Meseret, Eleni, Catherine, Bupe, Catherine, Ethel, Afi, Lusungu
Children			
	No children	3	Eleni, Catherine, Bupe
	Biological Children	10	Tawona, Totela, Natasha, Ethel, Afi, Michelo, Lusungu, Mutinta, Nataizya, Mary
	Adopted Children	6	Meseret, Totela, Ethel, Afi, Lusungu, Malaika
Capability Development Level (within sample group)			
	Low	4	Tawona, Afi, Malaika, and Mary
	Medium	6	Totela, Ethel, Michelo, Lusungu, Mutinta, and Nataizya
	High	5	Meseret, Eleni, Catherine, Natasha, and Bupe

5.2 Actors

Your role...

What we need is help to access markets for the products we make and we need capital to start our businesses. We need loans, not grants. We need to change the mentality of

handouts and learn about financial responsibility. We need to be financially empowered. We need to employ PWD that are skilled and encourage others to be trained. We need a voice in the parliament and we need political representation that has a human face. We need land. This empowers us all, it permits us to be secure, to make food, and to build our own houses.

We need education for our children and for ourselves. We need accessible infrastructure. We need our rights to be recognized and advocated for. We need laws to be applied and not implied. We need YOU to talk to chiefs and headman to assist us with land. They can also give protection and help us by sensitizing others. We need workshops and advocacy campaigns for men and for the able bodied to know our rights.

We need parents of children with disabilities to be sensitized and to take care of those children just like the others. This will also help reduce discrimination because they are accepting the children and society can also see them as being equal. We need you to create a parents' support program to help parents accept their children's disabilities.

We need you to advocate for us to be equal and we need you to change traditional values. We need people to connect with us and know that we are human, we are just like you; we are the same. We need you to understand who we are, what we are living through, what our needs are and how you can best work with us.

We need you to work with us and with each other.

- Composite from different women, presented at conference, Lusaka, 2010

This is part of a speech that was addressed to government and NGO assembled at the *Dialogue and Cooperation: New Perspectives on Service Delivery for Women with Disabilities* conference organized by us in 2010, a strategizing conference for organizations working on disabilities and women. The speech was a composite of all the interviews conducted the previous year to establish a clearer portrait of the lives of the women we had interviewed. It was also a request for assistance from women with disabilities to the organizations that purport to assist them.

Before going to the field, particular types of actors were identified by us as being important in the world of women with disabilities. These included grassroots organizations, NGO, disabled persons' organizations (DPO), and government; they were the only kinds of outside actors that we interviewed over the course of the field research. However, once the women's interviews were analyzed, it became clear that the most significant actors in the lives of women were not those that we had expected. God, their family (immediate and extended), friends, and religious groups (churches, sisters, missionaries, Muslims) were most often mentioned by the women when we asked "Who helped you in your life? Who was there to support you?" Interestingly, "just myself" was mentioned a few times as well.

The government and other civil society bodies were rarely mentioned and, generally, only after the women were prompted by us during the interview. The lack of interviews with these types of actors (family, friends, and religious groups) is a gap in this research. Future research targeting these actors could provide important insight on their perceptions of the lives of women with disabilities as well as their roles and responsibilities in their capability development.

5.2.1 Actors Identified by the Researcher

Below is a list of actors as originally defined in the research proposal located in the Lusaka area. They were identified through key informants⁸ and research participants; most of them participated in the *Dialogue and Cooperation* conference. One of the objectives of the conference was to create a conceptual map of organizations in the area working on disability issues, while identifying mandates and overlap, discussing successes and challenges, and potentially creating a network of DPOs. The overall objective was to find ways around the competition and fragmentation existing in the movement. The conference attracted the participation of sixteen organizations working in Lusaka. Many other groups working on disability and gender issues (both large and small) were invited but were unable to attend.

Table 6 – List of Organizations Interacted with Over the Course of the Research

Categorized by type, participation in interviews, and participation at the Dialogue and Cooperation Conference.

<u>Type</u>	<u>Name</u>	<u>Interviewed</u>		<u>Participated in conference</u>	
		Yes	No	Yes	No
Government	Ministry of Community Development and Social Services (MCDSS)		•	•	
	National Trust for the Disabled (NTD)	•		•	
	Zambian Agency for Persons with Disabilities (ZAPD)	•		•	

⁸ Key informants were people that we worked with in the SWI placement and who themselves worked in the disability movement. They were very knowledgeable on who the important actors were, the history of the disability movement, and challenges faced by persons with disabilities, among other information.

<u>Type</u>	<u>Name</u>	<u>Interviewed</u>		<u>Participated in conference</u>	
		Yes	No	Yes	No
International NGO	CARE International	•			•
NGO	Disability Initiative Foundation (DIF)	•		•	
	Deaf Women's Network of Zambia		•	•	
	Ethiopian Women with Disabilities National Association (EWDNA)	•			•
	Foundation of Blind Women in Zambia (part of ZNCLB)		•	•	
	Zambian Disability HIV/AIDS Human Rights Program (ZAMDHARP)	•			•
	Zambian Federation of Disability Organizations (ZAFOD)	•		•	
	Zambian National Association of Disabled Women (ZNADWO)	•		•	
	Zambia National Federation of the Blind (ZNAFB)		•	•	
Grassroots	Bwafwano Community Home-Based Care Center		•	•	
	Disabled Entrepreneurs Association of Zambia (DEAZ)		•	•	
	Koseni Women's Club		•	•	
	Lusaka Urban Disabled Entrepreneurs Project (LUDISEP)		•	•	
	National Christian Organization for Disability (NCODI)		•	•	

<u>Type</u>	<u>Name</u>	<u>Interviewed</u>		<u>Participated in conference</u>	
		Yes	No	Yes	No
	Wise Youths in Action Disabled Organization of Zambia		•	•	
	Ubuntu Association	•		•	

Overall, representatives from nine of the above organizations were interviewed in the course of the research and data was gathered on a further ten organizations through their participation at the conference. There were extra groups that were discussed during interviews with the women, organizations, and informants but they were not contacted directly during the field research.

5.2.2 Actors Identified by the Women

Overall, the women mentioned their friends and religious communities (churches, donations from Muslims and mosques, Christian organizations, God) nearly twice as often as the government or NGOs when asked who played an important role and supported them in their lives. Even when asked directly about the government or NGOs specifically, many said they had never received their help or that it was so little that they could not count on them.

Some women did mention that the government used to be very helpful during the First Republic following independence, under Kenneth Kaunda. During that time, the government had many socialist policies that allotted free rehabilitation services, mobility aids, education for PWD, and hiring quotas for jobs that were reserved for PWD. “Kaunda gave the first priorities to the disabled. If a disabled goes to any company, they have to see the qualifications. If the qualifications are not enough, still they have to find something for them to start working there so that they can earn some money at the end of the day and feed their own family,” said one woman. Another added “all services were covered by the government, the government gave free braces and crutches until 1992 (the end of the First Republic under Kaunda). Now we have to pay for everything.” The consensus from the women is that PWD were better off when the government was active in supporting them. During that time, they could access education, were more mobile, were able to provide for themselves and their families, and felt as if they participated more in society.

The main actors mentioned by the women were, by order of importance⁹:

- **Friends:** Generally other WWD but included benefactors and the community.
- **Religious actors:** Generally meant a church that helped them in a particularly difficult time, but includes the missionaries at boarding school, God, and Muslims who donate on Fridays and sometimes paid their rental and school fees.
- **Family:** From their family writ large, to one parent, to a specific sibling or uncle, to their children.
- **NGO:** Generally their own organization, but also a few large national and international NGO (donation of money and mobility aids).
- **Shared World Initiative (specifically):** Following the work done with the women on the group, SWI was present in their mind as it was mentioned specifically, separate from the general grouping of 'NGO'. SWI helped them stop begging and provided training the women had identified as essential.
- **Government:** Mostly the Ministry of Community Development and Social Affairs and the Zambian Agency for Persons with Disabilities who provided some small grants and food staples from time to time.
- **Themselves:** Interestingly, women saw themselves as actors in both a positive and negative light. Some said that their own personality, strengths, and abilities are what they relied on while others said that unfortunately they could only count on themselves, as no one was willing to help them.

Although it comes up last in the list of actors, the role of the women themselves as agents in their lives is very important. The decisions they make, how they deal with challenges, their drive and motivation, their hopes and dreams; all of these influence their life paths and social worlds, and are a manifestation of their agency. As a general rule, the women did not feel as if they had received much support in their lives. Excluding a few exceptions, such as Catherine and Bupe, the women's views were that they generally faced the difficulties of life alone while they should have been supported. To them, the government has the responsibility to assist them in their rehabilitation, education, and employment as well as in the protection of their rights. When they would discuss the disability movement – meaning grassroots organizations, outspoken individuals, and large NGO – the view was overall negative. According to them, there is too much division, selfishness, and

⁹ As the information was generally volunteered by the women and sometimes prompted by us during the interviews (but not always), this list is not statistically accurate. However, we are listing who the women tended to mention the most often and see as most useful in their lives.

backstabbing. People are only working for themselves and do not try to help the entire group as a whole.

5.2.3 Detailed Description of Actors who Took Part in the Research

5.2.3.1 International Organization

International organizations were not a focus while doing the field research. They had not been identified as a priority in the lead up to the field and were, overall, much harder to contact. However, the international community's contributions were noted in the grey literature and detailed in the context section of this research. Considering the significant role they can play, such as directly lobbying the government for change and providing nation-wide programs, they would be an important actor to include in future research.

In the case of the one international organization we did interview, CARE International, the main problems identified in addressing the case of disabilities was the lack of donor interest in the issue and the fact that most of their funding is tied. "Donors know what they want to invest in, NGOs do proposals directed at what the donors want to fund and unsolicited proposals rarely happen, there needs to be an interest in the subject. Unfortunately, disability is not (interesting). Finally, there is very little untied aid so organizations can't choose projects easily. (...) The funding is hindered by competing demands," said our informant. As disability is not currently an 'exciting' subject for many donors, the organization had no experience with it. This reality adds weight to the argument that able-bodied people are seen as a better 'investment' for development programs. It would seem that, within the existing context of viewing PWD as less able than others to participate in daily life, those who are 'able' are more likely to be targeted by programming because they will be able to assist in economic development of the country. (personal observations)

International organizations can be important collaborators for WWD. CARE seemed to be quite effective, with a long history in the country, deep political ties, many successful projects, with a generally positive outlook on the potential for the country. Its funding was relatively sustainable and its relationship with the government apparatus was safeguarded by the memorandum of understanding (MOU) signed by both parties. International organizations have certain strengths national and local organizations may not have, such as: some independence from the government owing to the fact that they are an external actor, more significant and secure funding, international recognition, and years of experience in different contexts. However, they must still defer to the objectives of their own

donors, face their own organizational issues, and must also compete for funding. Finally, as was highlighted by our informant, issues like disability can be difficult to integrate into their mandates unless they themselves are specifically disability focused. This returns to the concept of development as having economic growth as the sole final objective. (Katz, 2004) If persons with disabilities are not seen as being a good investment, they will not receive funding.

5.2.3.2 Government

The government departments we interacted with (MCDSS, ZAPD, and NTD) were found significantly wanting. Underfunded and stagnant, they openly admitted to not achieving their mandates. “(We) do not focus on rights, we do not look at conventions. We are government, it is very difficult for government to govern itself,” said one informant at ZAPD. NTD added that despite the great need for their services, their program has been scaled down many times and has now become a pilot project that services only a few districts, instead of achieving its national mandate. Issues of accountability are also a concern: “accountability is to the government, as it is the donor” said NTD. The concept of accountability to their service recipients, the PWD, was only considered once prompted by the researcher.

Overall, the government bodies face severe lack of political will. This critique came from many NGOs as well the women interviewed. Although many projects have been accepted, such as the creation of disability desks in all ministries (to ensure that issues related to disability can be included and addressed across the board), the signing of the CRPD, and the creation of a social welfare system to support the most destitute, these have not been very successfully implemented. As funding is unpredictable, some organizations try to find income generating activities to be independent. “We want to become an independent national lending institution where the board of trustees can come up with their own ideas and run independently, without government influence,” indicated NTD. They added that implementation of regulations, such as the CRPD, are not a priority and are “too expensive.” ZAPD lamented that “we need incentives to do it. We cannot even do the baseline survey that is required to have an understanding of the situation in our country. (We) will not ratify the convention until (we) receive (outside) funding.” They added that they were aware that many of their constituents were severely dissatisfied with the government and that their failure to implement change was not only due to being under-funded. “We’ve always been talking of lacking resources as why we can’t do things, but I think it’s because we weren’t as action oriented as we are now.”

The quantity of persons with disabilities working at the government level is quite small. At NTD, there were no PWD working within the management structure, while there were only three persons with disabilities out of twenty employees working for ZAPD. Informants have attributed this to the lack of education and training that PWD have since the jobs are at a management level and are open to the public. “It is not really an objective to have (PWD) be part of the management, (it is) not a written policy,” said NTD. In the case of disability desk officers, ZAPD mentioned that “many of the officers do not even understand their mandate. They are supposed to be manned by PWD, but generally they are not.” Challenging the concept of ‘nothing about us without us’¹⁰ the informant at ZAPD highlighted the fact that it is important to consider the qualifications of those working in the main agencies versus only pandering to persons with disabilities. “It’s not about a disabled person working with the disabled that will make the service ok. It’s that someone has to be capable and qualified to work with them that matters. We as disabled come from families and our families are not disabled. To think that it has to be only us working is exaggerated.”

Finally, with regards to women with disabilities, “there is a slow change ... we are seeing a situation where women know their rights and can speak up ... discrimination is slowly dying down, but the pace is slow. Women still need more support, more sensitization about their situation, and more mainstreaming.” ZAPD added that over the past 35 years, there have been many attempts to improve the status of women with disabilities, such as the international Women’s Year in 1995. “Now, women are legally recognized as equals but they still have a lot of problem. In Zambian society, the man is first. (...) In general, PWD suffer discrimination and all forms of negligence. If women in general are still fighting to be equal to men, you can now begin to understand the gravity of the problem – that they are really on the bottom end of everything.” Some efforts have been made, but they fall short. NTD highlighted that they now allocate 75% of their funds to women because it was noted that women tend to be best at handling finances and ensuring that money goes towards worthwhile purchases and investment. ZAPD discussed both a fund created specifically for women that will be administered by the First Lady and a social welfare currently being created. However, these are for all people living in poverty, not women with disabilities specifically.

The informant at ZAPD argued that the main intervention needed for women would be education and skills training but that the creation of opportunities to participate (such as

¹⁰ A slogan chanted by the disability movement that no decision or action targeting them should be done without their participation.

political seats reserved for women, positive discrimination in the workforce, strict policies towards increasing the presence of women and women with disabilities into society) are not useful. “We should empower women with skills, no use thinking that we should provide opportunities without first of all translating what we want to provide them with. Should have a deliberate policy to empower and then to help them move on in society.”

5.2.3.3 Coordinating Bodies

The Zambian Federation of Disability Organizations (ZAFOD) was created 1990 as a response to donor outcry with regards to identification and coordination of disability actors on the ground. Its vision is “facilitating the unification, capacity building and efficient networking of Disability Organizations in Zambia as instruments of positive change in the lives of persons with disabilities and in their communities.” (ZAFOD document, No date) Its mandate is twofold: (1) coordinate the activities of DPO in the country and (2) advocate for the rights of persons with disabilities. In 1996, the Disability Act enshrined it into law as the registering body of all DPO, which are then recommended to ZAPD for registration.

However, conflict between these two organizations is highly apparent. According to ZAPD:

“(ZAFOD) is the (coordinating) arm of civil society. We are government and we are aware that sometimes our approach and/or operations can be biased to the government of the day. (...) But at the same time we cannot take on the government like civil society can when we aren’t happy with what government is doing. (So) we have allowed them to operate not necessarily in coordinating but in advocating. (...) If DPOs choose to be under ZAFOD, that is ok but we feel we are above all those, including ZAFOD”

The role of ZAFOD is viewed with ambivalence by the government agencies: on the one hand, ZAFOD is beneficial as it adds checks and balances to the actions of the political party in power, yet, on the other hand, it is not viewed as being as important as government and should not aspire to.

Over the years, ZAFOD added more roles and responsibilities to its mandate. These include: awareness raising, government lobbying, human rights advocacy, research, and microfinance through rotating funds. Both civil society actors and government have accused them of duplication of efforts as well as taking over the roles of its purported affiliates. Their critics assert that, as the coordinating body, the main purpose of ZAFOD should remain the coordination of activities, high-level advocacy, and awareness-raising. Its target population is supposed to be the DPO, not PWD. In the mean time, many other national coordinating organizations were created due in part to the dissatisfaction with ZAFOD.

- Zambia National Association for the Physically Handicapped (ZNAPH)

- Zambia National Association for Disabled Women (ZNADWO)
- Zambia National Federation of the Blind (ZANFOB)

ZAFOD does however recognize the challenges posed by these divisions: “The multiplicity of DPO has made the movement very weak, (there is) little funding to support everyone. (...) The DPO movement has mostly concentrated on employment provisions for the few. Those who cannot access the small cake do not feel like they are belonging. As a result the movement has gotten weaker and weaker. We are not strong.”

One such association that has its focus on women is ZNADWO, the Zambian National Association for Disabled Women. Established 1990 with help from Finnish organizations, it has branches throughout Zambia. Its purpose is human rights and advocacy, as well as capacity building and microfinance. At the time of research, it had roughly 2500 members. ZNADWO’s mandate is to represent all women with disabilities at a national level, to advocate for their rights and to help achieve social welfare. However, according to many different actors in the disability movement and the women interviewed, ZNADWO is not achieving its mandate. Colleagues in other NGO have attributed this to poor management, lack of resources (following divestment by their donors), and a stagnant management structure – where their Executive Director (who is also the founder) and had been in the same position for nearly 20 years. Over the course ZNADWO’s existence, few concrete changes have occurred in the lives of WWD. We view its inability to act as a resource for WWD and their families as another shortfall for the capability development of women.

ZNADWO is affiliated to ZAFOD but is an independent entity. This is often lamented by ZAFOD as they consider themselves the only true coordinating body. ZAPD is of similar opinion: “what is the difference (between ZNADWO and) other associations that have wings for women?” (ZAPD) The counter argument from ZNADWO is that by joining ZAFOD as one of its wings, it would lose its independence and its ability to be a strong voice for women with disabilities. The sentiment is echoed by one of the women interviewed. Says Tawona: “The men, mainly they defend themselves and they put themselves on top, every time. They don’t want a woman to participate. No wonder women like to be alone, like us in Koseni. If we were combined with men, some will come to destroy (us). So it is better women do things on their own.”

An example from a fellow organization from Ethiopia lends credence to this argument. Before the creation of the Ethiopian Women with Disabilities National Association (EWDNA) there was no organization in Ethiopia that focused on women with disabilities, only women's wings in the various organizations. The founders of EWDNA argued that: "women are discouraged much more than men. They are hidden at homes – in Ethiopia, women don't even go out to beg – and there are no women leaders in disability organizations. There are wings, but no leaders and no voices for women. (...) No one (even) knows about the different 'wings' for WWD in associations because they are not promoted." By being contained as a wing of an organization that is controlled by men, the specific problems women face are not addressed. At the time of research, EWDNA had existed for seven years and, in that time, had managed to attract over US\$1 million in financing from international organizations, build a large membership base with over 700 women, and achieve important advocacy objectives in its country. This was done through a methodology focused on the empowerment of their clients and by continuously networking and creating links with local and international actors. Their structure and success could be a source of inspiration for other women's organizations.

The failures of coordinating bodies in managing organizations, providing for their membership and listening to needs were often cited as reasons for the fragmentation and multiplicity of actors. We observed that, just as ZNADWO exists because of the inability of other actors to properly advocate for women with disabilities, its own inefficiency is one of the main reasons given by the women of Koseni, and many other women and women's groups, when asked about why they needed to start their own organization. Those who are supposed to be there to assist them are not. This is related to the concept of conflict, arenas, and cultural repertoires described by Long (2001). As the different organizations have different ways of interpreting and addressing the same issue they are all facing, conflict can arise and lead to either compromise and understanding, or separation.

5.2.3.4 Advocacy

There are a few advocacy-focused organizations in Zambia. By advocacy-focused, we mean organizations whose mandate is mainly to lobby the government and society for concrete changes in the situation of women and women with disabilities. We interacted with one in particular: the Disability Initiative Foundation (DIF), created in 1998 as an organization whose sole mandate is high-level advocacy and policy change. All members are volunteers who have high levels of education (often masters, diplomas, etc) and are professionals. They have had some important successes, such as participating in the

Constitution Review Committee and in the Fifth National Development Plan Committee. They also collaborate with ZAFOD to bring the government to court when there are abuses with regards to the rights of PWD. They attribute much of their success to the fact that they work in coordination with as many organizations as possible and that they seek out the support of able-bodied people as well. “(You must) work with both PWD and mainstream, when talking about inclusion you can’t only talk about yourself. You have to work 50/50 with able bodied. Alone is a thing of the past, who are we complaining to?” said an informant. The organization believes that “it is easier to work with professionals, they don’t want to reap from the organizations, receive money, food, transport...” They say that because their volunteers and workers are already meeting their basic needs and receiving a salary from their professional careers, there is apparently less need to receive financial support and more ability to focus on the objectives at hand.

That being said, the issue of fragmentation in the disability movement was noted by DIF as well.

“The problem (between organizations is that) (w)e block those who have knowledge because we treat this like a business. There is competition between NGO, it is huge. They are stabbing each other in the back. (There are) so many NGO! There is duplication of workers, we need to work in unison, to have a unified voice. (Otherwise) we can destroy the confidence that groups have in us. We need to consult one another. We need to have a network.”

5.2.3.5 Grassroots

Ubuntu is an organization based in the peri-urban area of Chazanga, in the north of Lusaka. Created in 2006 following research done by the universities of Ottawa and Massachusetts (a needs assessment of PWD in Chazanga), it currently operates in a few districts around Lusaka. Its mandate is to identify PWD, mostly children and women, assess their needs, and link them to service providers. Mainly, it was created as a means to palliate the higher burden of HIV in the PWD community and help them access the same resources as ‘able bodied’. It is different from many organizations in the sense that it is not itself a service provider; it does not replicate existing services but links people to what exists.

Largely owing to the charity mentality still employed by many actors working on disabilities in Zambia, Ubuntu’s structure has been poorly understood by their client base and has even led to problems between the two.

“Our biggest problem (is that) PWD have been on the receiving end. They want to be given things and not work for something, not bring in something in return. The perception is that we are a donor organization and have things to give. (This is a) very wrong perception. This has

sometimes brought a lot of suspicion and talk. They wonder why they are not benefiting, not getting mealie meal, etc. (But) this is not the mandate or programming.”

This echoes the previous comments concerning the ‘charity mentality’ and shows that it can be pervasive on both sides – the organizations and the clients. As many organizations have noted, and we observed, this expectation by clients to be supported leads to discontent and fragmentation when some think that they are not benefiting from funding. These types of issues add to the multiplication of actors. Clients are dissatisfied, thinking that the organizations are corrupt and keep funding from themselves, and so they create their own organizations to access funding.

There are many other problems that we observed within Ubuntu, and many that Ubuntu itself recognizes. Firstly, the organization itself is in serious need of support: materials, training, capacity building, and funding. Training and capacity building in general for everyone is necessary, from the secretariat to community mobilizers and the board. Moreover, there are a lot of management problems at the heart of the organization, charges of corruption and incompetence, and a general lack of understanding of the mandate. Over the years, this cost Ubuntu its main funding organizations, leaving management to search for other donors (often unsuccessfully) and to increase cooperation with other local organizations. The director died in 2010, which led to more difficulties for the organization as much of the knowledge and contacts were centralized. The other administrative staff have persevered and tried to maintain the organization. Their operational status is currently unknown.

5.2.3.6 Women

The women in our sample were discussed in the section above, but it is critical we mention them again as an actor in their own right. From the discourse of the women and the organizations, the role the women play in their own lives and the lives of others assuring survival and capability development is essential. The agency of the women will be demonstrated further below in the Capabilities section.

5.2.4 Challenges and Opportunities

5.2.4.1 Challenges

Following the one-on-one interviews with various organizations as well as the conference on women and disability, we were able to identify certain patterns in the disability movement. Challenges faced by the organizations in their work were identified at

four levels: (1) the client base, (2) the organization itself, (3) the organization networks, and (4) the society.

At the client base, organizations reported having a lack of knowledge about their target populations, the needs of these populations, and the challenges faced by them. Also, issues related to HIV/AIDS were a major concern, particularly regarding the need to create programs relevant and accessible to all different disabilities. A third major challenge was the need for increased advocacy towards the family and community of their client base. Finally, a fourth was the need to include clients in the work of the organizations.

At the organization level, many issues were identified. First and foremost was the lack of skills and knowledge of employees. All organizations identified the need to capacity build employees and the organization itself. Another concomitant challenge was accessing funds. The organizations noted that there is limited funding available for disability issues and, due to the fragmentation and multiplication of actors, funds are all the more difficult to access. Many organizations noted that another challenge was the limited participation of persons with disabilities and women in particular in the management of the organizations. PWD and WWD did not tend to be hired by the larger NGO and CBO - this was reserved for the management of small grassroots organizations like Koseni. However, this lack of participation also made it harder for clients to identify, and sometimes even trust, employees of the organizations. Finally, HIV/AIDS was identified as an important issue affecting the workforce. The high rates of infection in the population led to many employees being sick or dying from HIV, which caused more absenteeism and turnover in the organization and, ultimately, a lack of institutional knowledge.

At the disability network level, organizations stated that there was a general lack of knowledge about the various organizations on the ground. This then led to an inability to properly coordinate service provision and avoid overlap in programming. There was also a desire to share best practices and learn from others through collaboration. However, the main impasse was the divisions and fragmentation faced within the movement. Most organizations highlighted that the mistrust and competition between themselves and other actors were a huge challenge.

At the society level, all organizations agreed that there was a lack of political will to address disability issues. When there was programming, the funding was too limited to effect real change. Moreover, some organizations highlighted a general lack of coordination across all levels - from government, to NGO, grassroots organizations, churches, schools, and society as a whole. This was furthered by the negative views still held by society with

regards to persons with disabilities and women. There is not enough education or advocacy done at the societal level to eliminate the discrimination and prejudices present on the ground, which leads to the marginalization and victimization of PWD.

The fragmentation issue was mentioned as a particularly difficult challenge at all levels, ranging from competition between organizations to between individuals.

“We have a problem with PWD themselves. The educated versus the non-educated is an issue. There is some element of not trying to pull each other up, help each other. The few well-settled want to be champions of many things but with limited focus. The division and separation makes life very difficult because there aren't more than 20-30 people making noise at the policy level. Those that are doing it are doing it for themselves and not for the general disability movement, or the benefit of all disabled” (personal communication, 2009)

They add that this fragmentation is caused by the Zambian mindset itself. Since disability is seen in a negative light, those who pull through prefer to ‘outshine’ others. This could be linked to the lack of resources and opportunities in the country. As poverty increases, many traditional support systems have fallen to the wayside. Moreover, long term planning is nearly impossible when one is surviving from day to day. When someone succeeds in building a better life for themselves, there is a fear that it is precarious.

During the conference, the organizations also identified a long list of particularly challenging areas for women with disabilities. What is mentioned covers the vast majority of needs for high capability development and indicates the depth of difficulty faced by this marginalized group:

- Economic empowerment
- Poverty
- Accessibility (infrastructure and mobility aids)
- Political will to implement change
- Financing for disability organizations
- Population sensitization
- Charity mentality
- Employment
- Parents not educating their children
- Sexual exploitation
- Access to education (all ages)
- Health services
- Legal protection
- Equality in marriage
- HIV
- Overall inequality
- Recreation (sports, arts, culture)
- Participation in society
- Transportation
- Social security and welfare

5.2.4.2 Opportunities

There are some important tools and methods that have succeeded in helping very marginalized people in Zambia, such as microfinance for women, education programs, advocacy towards society as a whole, and the work of NGO dealing with gender abuses and/or HIV/AIDS. (Lewis, 2004; Human Rights Watch, 2007) By focusing on the best practices of these NGO, newly emerging associations, such as the Koseni Women's Club, could succeed in developing a successful framework for service delivery and action. As well, possibilities such as South-South and North-South partnerships, such as one with the Ethiopian National Association for Women with Disabilities or the Shared World Initiative, could guide new organizations and assist in the capability development of women with disabilities.

At the end of the conference, the organizations identified a list of opportunities:

- Come together and speak with one voice
- Collaborate and advocate for favorable policies
- Avoid replication of our interventions
- Lobby for increased access to education for women with disabilities
- Sensitize communities to enroll children into school early
- Promote information sharing

5.3 Capabilities

Our challenges...

In the past, we had free education and health, access to employment, good housing, and support for our families, but now we have nothing. Organizations are supposed to be there for us and fight for us, but we are not seeing change.

Today, we have no employment, we are left to do piece work or depend on our families. If you don't have a family that is there for you, you have to do dangerous things like beg on the streets, stay with bad men, steal, and even traffic drugs. This is not how we want to live. This is not all that we can do.

Our biggest problem is accommodations. Where most of us stay, things are not accessible. We have to go up steps, we have to crawl in the dirt to go to the common toilets. We have no employment but we still need to pay our rentals. Some are ZMK 250 thousand a month for two small rooms. We need to pay for food, school fees, and clothes... We cannot save money and we cannot provide a future for our children. If we die, our children are left with nothing and no place to stay. This is our biggest concern.

We are sometimes picked up and given land in settlements, but then we are left with nothing. The government wants us to go out and start farming, but they are putting us in dangerous conditions. We are put in mud houses with grass roofs that can catch fire and burn our things and ourselves. How are we supposed to leave if we can't use our legs or we can't see?

We can die because we can't access health. We can't walk to the clinics and if we get there, we can't afford the cost of getting through the door. People say we can't have HIV because they don't believe we have sexual relations. We are discriminated against.

We have had to fight for recognition. In March 2009, the government promised to give everyone who had registered with ZMK5 million so we could stop begging. That money never came so we went all the way to State House and protested. All we received was ZMK1 million, and many of us received nothing. Promises are made but we rarely see them accomplished.

We had to form our own organization because no one was able to help us. We want to affiliate with groups like ZAPD, ZAFOD, and Paralympics, but the fees are unaffordable.

- Composite from different women, presented at conference, Lusaka, 2010

This box highlights what women with disabilities see as lacking in their lives to be able to live in better conditions (particularly relating to health, housing, and the future of their children), to be able to fully develop their capabilities, and to achieve their goals in life. This section will explore the capability development of the women we interviewed, focusing on the three groups previously identified (high capability development, medium capability development, low capability development) and the roles of actors in this development. We will apply the concepts of capabilities and agency to disentangle our data using four particular capabilities. Their choice was informed by the discourse of the women and the organization themselves, highlighting that issues of health, of abuse, of accessibility, of employment (among many others) were particularly difficult. This list is in no way exhaustive, nor do we advocate for the creation of a list of 'inaliable' human capabilities. We remain strongly behind Sen's argument for relativism. However, to be able to operationalize the concept of capabilities within the limited scope of a master's thesis, we had to tighten our focus. These four capabilities were fact chosen from Nussbaum's (2000) list of essential capabilities.

1. Bodily health,
2. Bodily integrity,
3. Affiliation, and
4. Environment control.

While we are treating these capabilities separately for the simplicity of analysis, they are quite obviously closely linked and often overlap. They will be brought back together in the conclusion. It is through the exploration of these capabilities and the level of development for each woman that we were able to separate them into three development groups: low, medium, and high capability development.

The interviews with the women permitted us to understand where they are from, what they have gone through and where they are going. Through the analysis of these interviews as well as those with various organizations working on the issue of women with disabilities, certain 'triggers' were identified as potential causes to differing capability development between women. These were suggested either explicitly by the women and the organizations or implicitly through the discourse and undertones of their interviews. The triggers, or key moments, occur within the specific life worlds of each woman and include personal characteristics, access to specific resources and opportunities, and interactions (or conflicts) with other actors. They include:

- Access to education,
- Institutionalization,
- Relationship with parents,
- Acceptance by family,
- Degree or visibility of disability,
- Financial status of the family,
- Time of disability onset (before or after the socialist government),
- Age at disability,
- Age at first pregnancy,
- Age at first marriage,
- Existing support system,
- Presence of abuse (physical, sexual, emotional, economic),
- Self respect, and
- Motivation/drive.

This will be further shown through a study of each of the four capabilities, showcasing the differences between the women who have or have not had these triggers in their lives.

5.3.1 CAPABILITY 1: Bodily Health

To have achieved the Bodily Health capability means to be able to have good health; to be adequately nourished; and to have adequate shelter. Our analysis will be done by identifying information provided by the women that relates to three specific sub-categories: (1) physical health and freedom of disease, (2) the ability to have shelter, and (3) the ability to nourish oneself.

5.3.1.1 Physical Health and Freedom of disease

Table 6 – Cause of Disability

CAUSE OF DISABILITY		
Injury	3	Malaika, Bupe, Mary
Polio	8	Eleni, Tawona, Totela, Ethel, Afi, Michelo, Lusungu, Bupe
Chronic illness(es)	2	Malaika, Bupe
Arthritis	1	Nataizya
Cerebral Malaria	1	Mutinta
Medical malpractice	3	Catherine, Natasha, Afi
War	1	Meseret
<i>Seen as a curse</i>	4	<i>Eleni, Catherine, Michelo, Mary</i>

The majority of the disabilities were due to preventable illnesses (polio being the main one) as well as medical malpractice, injuries, and war. As the women's disabilities were mostly caused by preventable illnesses, the ability to be free from disease and to have physical health was limited by the environment in which they lived, the services that they could access, and the knowledge about health that their parents had (among other factors). In the cases of polio and malaria, this is particularly flagrant, while as in the case of injury and war, the lack of safe conditions in which to live and play were a factor. The age of the women is also a factor as the polio epidemic was in full swing in the 60s and 70s while the vaccine was not widespread in Zambia until 1985. (UNICEF, 2012) All women have received some form of treatment or rehabilitation at some point in their lives following the event that led to their disability. For some, it was helpful, for others, it was not. Despite rehabilitation, all women reported having trouble with their physical health in relation to their disability (such as broken mobility aids which led to improper usage and wounds, secondary injuries due to extra wear on joints, pressure sores from being seated for long periods of time, accidents due to limited mobility, and so on).

As the women aged, other health concerns became apparent, HIV and AIDS being paramount. In the group interviewed, there are two women who have a confirmed HIV infection. The first, Afi, was found extremely emaciated and sick from AIDS when we returned for the second field research; despite renewed treatment, she died two months later. She had apparently contracted the virus from her boyfriend who was aware of his status but did not disclose it to her. She started to take the antiretroviral (ARV) medication but ended up stopping after facing too much discrimination at the clinics. Even health professionals would say to her "how can you, a disabled woman, have HIV? That is not

possible. Why did you not take pity on yourself?” Once she stopped visiting the clinic, her ARV treatment stopped and her health declined dramatically. The second, Mary, discovered two months prior to our meeting again in 2010 that not only was she pregnant with her fifth child, a child she did not want, but that she had contracted HIV from her husband. Her husband of 11 years abused alcohol and was involved in many extramarital affairs. According to Mary, he would only use her for food, shelter, and sex when he decided. “He is the kind of man who is unworried, said Mary. Even my begging, he doesn’t care. He is just a man who doesn’t care for life, for providing for the family. He doesn’t care.” He refused to know his status and continues to expose other women to the virus. The status of the other women in our sample is unknown. ZAFOD reports that the HIV rates in the disability community are significantly higher due to a lack of accessible information, attitudinal barriers by lovers and caregivers, and cultural beliefs. Moreover, women with disabilities are often not taught and initiated into womanhood because of the belief that they will never marry. This lack of education renders them more vulnerable to infection by HIV and other sexually transmitted infections.

Overall, their disability has been a limitation with regards to accessing health services and being healthy. “The problems which we have, some people they don’t consider us like people. Like in hospitals, when you go to the clinic they don’t give you a place to sit, you can just stand like that. Now if you stand there for two hours we can collapse or fall down,” said Tawona.

5.3.1.2 Ability to Have Shelter

Table 7 – Living Conditions During Childhood

<u>LIVING CONDITIONS DURING CHILDHOOD</u>		
Rural	4	Meseret (Bale Goba), Eleni (Horata), Tawona (Mpika), Natasha (Muyombe village, Northern Province)
Semi-rural	3	Totela (Northern Province?), Lusungu (Mwinilunga), Mutinta (Kasama)
Urban	8	Catherine (Solwezi), Ethel (Chingola), Afi (Ndola), Michelo (Lusaka), Malaika (Kitwe), Nataizya (Lusaka), Bupe (Ndola), Mary (Lusaka, Ndola)

Table 8 – Dwelling and Migration

DWELLING AND MIGRATION		
Never moved	1	Nataizya
Technical orphan (abandoned by parents, lived with family members)	2	Tawona (later in life), Malaika
Educational migrant	7	Meseret, Eleni, Catherine, Ethel, Michelo, Lusungu, Mutinta
Medical migrant	7	Meseret, Eleni, Natasha, Ethel, Afi, Mutinta, Mary
Economic migrant	9	Meseret, Eleni, Tawona, Catherine, Natasha, Ethel, Afi, Mutinta, Bupe
Moved because of abuse/rejection	3	Ethel, Afi, Mary
Lived on the streets	3	Afi, Malaika, Mary

The lives of many of these women have been very mobile. Of fifteen women, all but one have moved multiple times due to their disability (for treatment, school, or other reasons), economic factors, or both. The majority of these women were born during the Zambian copper boom of the 1950s-60s. At this time, many rural people started migrating to urban centers near the mines for work. Often, treatment for disabilities was not available in the rural and semi-rural areas and some of the more specialized medical operations were only available in Lusaka or abroad. As a consequence, many women had to travel long distances to receive operations and rehabilitation as children and some were separated from their families for over a year or more during their treatment. Many of the women had to move to receive education since, at that time, PWD were generally sent to specialized institutions or boarding schools. They were not integrated into the community. Later in life, the majority had to move (from one to many times) to gain access to finances, be it because they were trading commodities, chasing jobs or moving to Lusaka in the hopes for a better life.

Sometimes, either due to rejection from their family or the inability of their immediate family to care for them, the women had to find other places to live. In the case of Lusungu, following her parents' divorce, she went to live with her aunt from the age of 3 (when she contracted polio) until her aunt's death nine years later, when she was 12. Only then did her father collect her and take care of her until she left school at the age of 19. Those who left abusive relationships or whose support systems died were left with challenges regarding shelter. They had to stay with family or with friends until they could find other places to live. Otherwise, they found themselves sleeping in the streets or in bus stations, or moving from

house to house. Such was Ethel's case: "When I left my first husband, I went to live with my friend Annie. When I left my second husband, I took all my belongings and I went to other friends' house until I found my own house and I had to move again."

As adults and heads of households, obtaining shelter and being able to afford the rental prices is extremely difficult. Discrimination based on their disability and their perceived inability to afford rentals is flagrant. According to Mutinta "when looking for housing, landlords look at disability and think we can't manage. They will pick an able family instead. We need to send someone else for us when looking for lodging." The sense of insecurity is extreme, with the vast majority (13 out of 15) of the women citing "owning my own house" as one of their biggest dreams. The cost of shelter in Lusaka is exorbitant – an average of ZMK250 thousand per month, or US\$720 per year, for the women interviewed – for a two-room house. When considering the average Zambian annual per capita GNP is US \$1,200 and that the earning power of these women is generally significantly lower, these costs are crushing. Rentals tend to be the main financial burden for the women and the reason they cite for begging in the streets. Says Michelo: "Now month end is here, the landlord will come to get his money. So what will I do? I have to force myself to go in the streets to pay my landlord so my children don't have to spend a night outside. If I had my own accommodations, I think things would be ok." This inability to own a house is not exclusive to WWD or PWD; in the peri-urban areas, the vast majority of people rent.

The way many of these women are able to survive is through their begging, but also through support from outside actors. For Michelo and Afi, it was support of an uncle or a brother. For Tawona and Mary, it was Muslims who would pay their rentals through the *zakat*, a religious duty to donate to the poor. ZAPD and other organizations have also come to assist the women. All too often this is not helping them be self-sufficient, but makes them rely on donations for as long as they are available. Natasha's example is an exception. Some years ago, she heard about Habitat for Humanity housing projects and applied. She was selected and started a home tailoring project to pay for the expense; she was able to pay for the house and buy food with the money she made. These houses are offered to destitute families with the understanding that they participate in the building of their houses, and future houses in the community. They also must be involved in the community throughout their tenancy there.

Living conditions are difficult and often impermanent in Lusaka. By living in the capital, rentals go up sharply and often. The cost fluctuations are difficult to keep up with, which makes ownership that much more of a dream. Clearly, housing is not only an issue

for women with disabilities. Through our observations on the ground, it is clear that housing is an issue for all who live in poverty.

5.3.1.3 Ability to Feed Oneself

Overall, malnutrition is a serious problem. The main food staple in Zambia is *nshima*, which is a porridge made of powdered maize and water; it contains few nutrients. It is accompanied by various relishes made from ground nuts and leafy vegetables. Sometimes, there is protein in the form of small dried fish; rarely, as chicken or beef stew. In their youth, many of the women were under nourished, which may have compounded their stunted growth. “As a child, I would never see breakfast or lunch, even if had to walk to school and clean for everyone. I would eat unripe mangoes I would get from climbing trees and I would barter for bread,” says Catherine. Now, as adults, some go to bed with hunger, preferring to feed their children first and feed themselves only when they can. Says Lusungu: “Sometimes if I don’t have enough food, I can just tell the family that ‘no, you cook and eat, myself no problem’. And the children they try to ask me ‘why mom, why are you sleeping with hunger?’ ‘Ah, no problem, I say. Nothing wrong. You just eat.’” This food insecurity is another important driver for begging and increased vulnerability. Says Tawona: “(I started begging) because I saw that there was no option, my husband was drinking very much so became hungry. The children would cry with hunger and my third child even died from hunger.” Nearly half of the women have had children die of malnutrition or preventable diseases.

Whenever possible, the women have relied on the assistance of MCDSS, their churches, and international organizations for donations of mealie meal and food packages. Family members or friends have also assisted some of the women when in dire need of food. Michelo mentions her family and God as being a source of support. “My family has been very important, like my elder brother, you’ll find that he will buy me a bag of mealie meal when I have no way of getting it. Thank God!”

5.3.1.4 Conclusion

Essential needs for survival are food, shelter, and health. As shown by the interviews from the women and organizations, even these basic needs have been very hard to meet. The capability of bodily health requires support from birth, all the way through adulthood, until death. This challenge is compounded by poverty and lack of access. The women who had good support systems from their families as well as friends generally reported limited difficulties in achieving the functionings related to this capability. Moreover, those who

reported having limited support overall still tended to receive assistance with this capability. It could be concluded that as this is essential to the basic functioning of life, even those who disregarded women with disabilities when looking at somewhat more complex capabilities (such as employment or education) could not eschew them this.

That being said, when the women were faced with the challenge of achieving these capabilities and were without support, or even hindered in their efforts, they found alternative methods. Either through foraging for food, begging as a means of capital generation, or other impermanent solutions, they used their own agency and skills to ensure the development of these capabilities for themselves and their dependants.

5.3.2 CAPABILITY 2: Bodily Integrity

To have achieved the Bodily Integrity capability means to be able to move freely from place to place; to have one's bodily boundaries treated as sovereign, i.e. being able to be secure against assault, including sexual assault, child sexual abuse, and domestic violence; to have opportunities for sexual satisfaction and for choice in matters of reproduction. Our analysis will be done by identifying information provided by the women that relates to three specific sub-categories: (1) mobility and accessibility; (2) absence of abuse (physical, sexual, emotional); and (3) reproductive rights and freedoms (wanted pregnancies and planning, ability to reproduce, sexual satisfaction).

5.3.2.1 Physical Rehabilitation, Mobility, and Accessibility

Table 9 – Medical Treatment and Rehabilitation

<u>MEDICAL TREATMENT AND REHABILITATION</u>		
Traditional initially and Western subsequently	6	Eleni, Natasha, Afi, Lusungu, Malaika, Mutinta
Western initially and traditional subsequently	3	Catherine, Michelo, Mary
Western only	6	Meseret, Tawona, Totela, Ethel, Nataizya, Bupe
Rehabilitation services	12	Meseret, Tawona, Totela, Catherine, Ethel, Afi, Michelo, Malaika, Mutinta, Nataizya, Bupe, Mary

It is striking that the majority of disabilities were caused by easily preventable diseases but, due to lack of resource or lack of knowledge at the time, helpful intervention did not happen. There does not seem to be a link between where the persons lived (rural or urban settings) and the use of traditional or western treatment. That being said, the majority of women were given Western-type medication from the onset of their disabilities which

were often complemented with traditional remedies. Traditional medicine¹¹, argues Bupe, is used mostly because of the parents' background. "It is because of how the parents grew up or where they grew up, and their educational background (that matters). That plays a great role in what kind of medication they access. You will find that if the parents never even went to school, it means all they knew was something traditional." There are many instances of the women undergoing traditional treatment with very negative consequences. In the case of Mary, a traditional healer held her for over two years because her family could not repay the debt for the treatment.

Mobility aids and rehabilitation services were provided gratis during Kaunda's tenure as president, before the arrival of the Structural Adjustment Programs. "The government gave braces and crutches for free, up until 1992, says Natasha. All services were covered. Now, I have to pay for it." Once the socialist policies were abolished and the reforms imposed, medical support was cut and PWD had to cover the cost of their aids. The cost of repair or replacement of mobility aids is prohibitive: one pair of calipers can cost between ZMK350 thousand to 500 thousand, or US\$70-100. Many of the women who are unable to repair broken calipers remain in their wheelchairs instead of walking around. This limits their mobility and their health because they remain more sedentary. Says Michelo: "I used to walk with calipers, but because they are too expensive, I have decided to use a wheelchair. Calipers need to be replaced (but) the wheelchairs are given. But we like walking more than we like a wheelchair." Organizations such as the Church Association of Zambia and Family Health Trust have donated wheelchairs from time to time. For the women who attended boarding schools, the missionaries are often credited with their rehabilitation services. Otherwise, the women mention family members and sometimes doctors as having been the providers of these services. Unfortunately, accessing continued rehabilitation services in hospitals was often unaffordable following the end of socialism.

Issues of inaccessibility are rampant. According to Eleni "mobility and discrimination are still a big issue because WWD are encouraged to stay at home. The government is not giving any response with regards to mobility, It wants us to stay in our homes. Transportation issues are (a plan) to keep you in your house." Because of the poor condition of sidewalks, or entire lack of them, the women often must ride the wheelchairs in the streets. "It is dangerous in the roads! People get upset when we are walking together on the road, taking over and causing congestion with the wheelchair. They say 'you are nothing'

¹¹ Traditional is understood as remedies made of roots, herbs, and powdered remedies made by and generally administered by a traditional healer. Often, these would be accompanied with tattoos, cuttings, and incantations. (Reported by the women interviewed)

and ‘you act as if you are somebody!’” says Lusungu, “And minibuses never want to pick us up. You go there on time and wait, they will refuse to put you on. They say there is no room for the wheelchair. We can even stand there for some hours and we will just feel bad and go home. You will not go out.” Others like Mutinta argue that they will even be ignored because drivers believe they are waiting for a free ride. Before the privatization of the bus system in Lusaka, the government subsidized minibus transportation to half the price for PWD and free for the wheelchair. (personal communication, 2010) This is no longer the case. The women are relegated to the home because of this inability to access public transportation.

Other issues specifically concerning the compounds in which the women live include inaccessible toilets and baths. As these are public and often have steep stairs, they need to crawl in and cannot stand nor squat. The compounds themselves are difficult to access. The roads are dirt and rock, often deeply rutted by the yearly rains and poorly kept. Garbage is strewn everywhere, which limits wheelchair access. In the rainy season, many of the more affordable neighborhoods become flooded. As recounts Ethel: “The waters (were so high) they got inside (my home) so I had to move. I am planning to get out of this place because I am afraid the waters might be higher next time.” Even accessing the most basic of needs is difficult. Mary acquired her disability by falling from a tree when she was ten and recalls: “when I was not disabled I was doing things on my own. But now, I need to stay with someone who can help me fetch water when I need water for drinking.”

5.3.2.2 Reproductive Rights and Freedoms

Table 10 – Children and Child Rearing

CHILDREN		
Biological children	10	Tawona, Totela, Natasha, Ethel, Afi, Michelo, Lusungu, Mutinta, Nataizya, Mary
No biological children	5	Meseret, Eleni, Catherine, Malaika, Bupe
Takes in orphans/children	6	Meseret, Totela, Ethel, Afi, Lusungu, Malaika
Children from many fathers	6	Natasha, Ethel, Afi, Michelo, Lusungu, Mary
Child from rape	2	Afi, Michelo
Child(ren) die(s)	5	Tawona, Ethel, Afi, Lusungu, Nataizya

Of the fifteen women in our sample, ten have biological children. Six of the ten women had many fathers for their children and two had children as a result of rape when they were teenagers. Often, when a lover or a husband made these women pregnant, they were left to take care of the child alone.

“It is tough, says an Ubuntu representative, no one wants to be associated with impregnating a disabled woman but they want to have a nice time with them because there is a belief that they are pure and holy. In most cases, they conceive and then the women are left alone. (...) If she is made pregnant, she will always be the one to blame. ‘You did not feel pity for yourself, why did you go to this extent?’ the nurse will ask. ‘You didn’t need to do this!’”

Misconceptions about WWD means that many people do not believe they can get pregnant. This belief was widespread in the past. For many of the older women in our sample, their pregnancies were met by surprise and confusion from their community, and sometimes even anger. Positively, all the women who had given birth said they had received adequate care, similar to other women, when it came time to give birth. It would seem that, at least in the medical field, their rights were respected.

As indicated, children are generally seen as important and a necessary step in life in Zambian and African culture. They are essential for support. One woman who was unable to have children, Malaika, resented it, and felt that her life had been significantly more difficult because of this inability. She said that it was a painful experience to not have children: “I would ask help from others to get water but was told ‘Send your own children!’ This made me very sad. If I had my own children, I wouldn’t be suffering like this.” Yet, even when the women have their own children, this is still seen negatively by many community members. Afi shared: “we are treated badly, people will shout at you... they will not help. They say ‘you are a burden, you should not have children... why are you washing clothes if you can’t even hang it up yourself?’ They forget that having children is important, they are the ones that are helping me.” The same refrain was repeated by many of the women.

Many women in our sample have taken in or been given other people’s children to take care of. The concept of the extended family in Zambian culture is an important consideration. Some will argue that the children entrusted to them are a gift, because they would be unable to do anything for themselves otherwise. Others say that it is because they are in this subservient position that they are ‘forced’ to take on this extra burden. Malaika has taken care of the orphans of her brother and sister – at one point, she was caring for eighteen people. At the end of research, she had six orphans under her care and three of them (including a two-month old baby) were on ARVs to treat HIV. Although she said that at her age it was very difficult for her to take care of them all, they wanted to stay with her.

Of the five women who have no children, four of them are part of the high capabilities development group. These four stated that they did not have children because they preferred to wait to find a husband who would take care of the children with them. It

was a conscious decision. Says Eleni, “I want to become stronger, to marry, to have children. But what kind of man would I marry? Disabled or non disabled? This is a difficult question. Would his family accept me? I would be considered a burden.” Recognizing the burden of childbearing and childrearing and the importance of having someone assist in this made many of these women question whether or not to have a child. The other women represented in the high capability development group waited until marriage – in her early 40s – to have another child after having been impregnated and left by a man when she was young. One of the women we consider part of the medium capability development group highlighted how now she wished she had waited and planned for her children because she would be better off. Michelo says: “One thing I have come to learn is that we, as disabled women, we should be planning when having children. I think that is the most important thing I’ve come to learn. If I was alone, I think it would not be a big burden, maybe I could manage to look after myself.”

The reality is that women have significant difficulty achieving this capability, this choice in reproduction. Because they are subordinated into the role of child bearers, they rarely have a choice in the matter. Either through coercion as young married women, through social constructs, or through impregnation following rape, they are left with little choice with respect to their fertility. The concept of abortion was never discussed during the interviews, which leads us to believe it is generally not an option. This results in early pregnancies and the loss of education or employment opportunities as the burden of childrearing falls upon the women. For those who decided to not have children, it was not necessarily because they did not want children. They realized that as women with disabilities, they would risk being left by their partners and would have to bear the responsibility on their own. They rather wait until they could find someone trust worthy, or not have any children at all. Overall, it can be affirmed that the right to freely decide on their reproductive health is lacking.

5.3.2.3 Freedom from Abuse

Table 11 – Abuse and Injuries

ABUSE / INJURY		
Parents	3	Mary, Malaika, Ethel
Other Family Members (including in-laws)	5	Tawona, Catherine, Ethel, Michelo, Malaika
Husbands	5	Tawona, Totela, Ethel, Lusungu, Mary
Community	4	Meseret, Tawona, Malaika, Mutinta

<u>ABUSE / INJURY</u>		
Rape	3	Catherine, Afi, Michelo

The case of emotional and verbal abuse will be mostly discussed further, under the affiliation capability. For physical and sexual abuse, which is what we are considering when discussing bodily integrity and health, there are many examples in these women's lives. We preface this section by stating that our personal Canadian concept of abuse may not be entirely shared by our sample group. Physical violence towards children and wives as a mode of correction is widely practiced. (CSO, 2000) However, we consider that severe beatings leading to injury or unconsciousness are noteworthy and separate from correction, and should be considered as physical abuse in any context. Some of the women were willing to discuss these instances of abuse. Others were less forward about abuse that clearly did occur, either because they were unwilling to share it or, potentially, because they did not consider what occurred to be abuse. As they are used to being put down and suffer a variety of corporal punishments throughout their lives, it may become less noteworthy or simply be accepted as a fact of life.

Mary's example highlights this case:

"When I was young, my parents used to find me sitting. You know, when you are lame you like to stay where you are. But the parents found that I was still sitting where they had left me. They had to beat me up and tell me 'no stand up, start walking'. When they found that I hadn't washed some plates, I hadn't cleaned the house, they would beat me. So that time I thought that maybe my mother hates me. Now that I have grown up, I have realized that my mother was teaching me. She wanted me to grow up like the other children were growing. Because if my mother had not treated me the way she used to treat me, I wouldn't manage to clean my own house and maybe I wouldn't even have managed to use crutches, because I was feeling too shy to crawl or even to walk."

A few other women also report that later in life they appreciated that they had been hit and beaten (under similar circumstances as those described above) as children because it taught them to be stronger.

Ten of the women reported some form of physical abuse in their lives. Interestingly, it did not matter which capability development group they belong to – abuse was across the board. Very often, abuse was at the hands of the caregivers, be it the biological parents, the family members who would take them in or their stepparents. When they were children in a

reconstituted family, the women generally suffered abuse at the hands of the new partner. From hiding or locking away food, to increased labor in a house, to physical beatings, the stepparent often seemed to be a cause of the abuse. This abuse did not appear to be limited only to the persons with disabilities, but to all stepchildren. It would, however, tend to be more severe.

Later in life, abuse did not stop. Six of the women admitted to having been abused by their husbands. As discussed previously, spousal abuse is very common in Zambia and is considered acceptable in certain cases, often as a form of correction. Due to this, we assume that the rate of abuse is even higher than what was reported. Ethel's first husband was the first of many husbands that beat her, sometimes to the point of unconsciousness.:

"This husband was able bodied, and he was very rude and too jealous. He didn't want me to go to work. He beat me until I fainted after the first born died at three months. He would sell my clothes when I went to work! When I would mention these lacking clothes, he would beat me. He beat me regularly, maybe three to four times a month. Finally I ran away in 1986. One day, he found me and beat me very badly. My boss and friend told me to take him to the police. He left me alone after that."

Sexual abuse and rape is another serious issue faced by women with disabilities. According to Natasha, it is a big problem because of society's lax views on rape. "Most PWD get raped, it's done in homes by family. It's a taboo (for the women) to talk about it. There is a fear of retaliation, of being killed. Very few come out and say they are raped. There is also shyness and fear of laughter." Three of the women admitted to being raped in their youth, all by close friends or family members. This is Michelo's story: "At the time, a cousin was staying with the family in Lusaka. He started sexually abusing me when I was 14 years old, he was 18. He said 'if you talk, I will kill you.' He made me pregnant. I didn't know because I had never menstruated before. I gave birth at 15 years of age. It was a very difficult birth." In Michelo's case, she benefited from a loving father who did everything in his power to ensure she could return to school after the birth by transferring her to a new school and saying her absence was due to malaria. Furthermore, the cousin was arrested and brought to court. However, not all situations are the same. Often, the women are further belittled and ignored, such as Afi: "Following the rape, I was kicked out from my uncle's house because he blamed me for having ruined my education. I had to live with other family members, I really suffered because I had nothing to take care of the baby with. Most of the days, I went sleeping with hunger." Another woman discussed how she had been sexually propositioned by her supervisor at work and only narrowly avoided rape. Because of their

disability, these women are seen as all the more vulnerable and as something that can be taken advantage of.

Infidelity, as discussed by Nataizya and Mary, is a form of abuse with sometimes life threatening consequences – STIs and HIV. Despite the high HIV infection rates in Zambia (roughly 15%), there is still severe stigma associated to the illness. When Mary admitted to being infected, it was only following many assurances that it would not be revealed to others in her surroundings. Mary was infected following her husband's multiple infidelities and forced sex. Because of the gendered power relations at play, and as a person with a disability, these women are often unable to negotiate safe sex with their partners. Many women go from man to man to have access to support for themselves and their children. Furthermore, when they are in a monogamous relationship, they are at risk if their partners are unfaithful, or if they are HIV positive and do not disclose this. This was the case for Afi, who died in 2010 following infection from a partner who did not disclose his status. The women find themselves stuck in very difficult relationships or marriages because of a lack of rights and a fear of retaliation. Sometimes, they stay so they can answer the most basic need – to survive. Michelo highlighted this:

“I am seeing that now WWD are dying of HIV/AIDS because they are being abused, by men, maybe just searching for food, maybe just having sex with a man so he would give them money to pay rentals, maybe to buy food. So I haven't seen any changes and I have seen that many disabled women are not in marriages. They are just being used by men and after that they dump them.”

Although some of the gendered abuse is 'expected' according to certain social norms and gender roles, it can be seen by the discourse of the women that it is still not something they approve of or want to suffer. Most of these women decry the situation of women in Zambia. We must also consider the role of agency and survival strategies; some choose to stay as a means of economic survival while others leave and try to survive by themselves.

5.3.2.4 Conclusion

This second capability was somewhat more difficult to achieve than the first one studied and seemed to be hindered by misconceptions regarding disability and gender. Rehabilitation and mobility have always been and continue to be an issue for our sample. Even those who are in a higher economic group or who have support from family and friends find it very difficult to obtain proper mobility aids or rehabilitation services. Societal

attitudes also lead to barriers to their mobility in their community. When looking at reproduction, the ability to reproduce, and the consequences from that reproduction, highly affects the lives of women. The Panel on Reproductive Health of the Committee on Population (Tsui et al, 1997, quoted in Nussbaum, 2001) in the United States defined the requirements for reproductive health as being:

1. Every sex act should be free of coercion and infection.
2. Every pregnancy should be intended.
3. Every birth should be healthy.

According to these standards, many of the women in our sample would not be rated as having access to reproductive health. Through rape, infection, abuse, unintended or forced pregnancies, and so on, they are unable to achieve this capability.

Abuse, writ large, is a controversial issue, meaning different things in different contexts. However, it can be argued that it has impacted the lives of many of the women. Whether at the hands of family, stepparents, husbands, employers, or the community, the majority of the women, irrespective of their development level, reported abuse. This confirms previous research highlighting the power dynamics that structure the lives of women and that seem to make them and their bodies less valuable than those of men. This is compounded by their disability, which often leads to increased levels of discrimination and abuse.

5.3.3 CAPABILITY 3: Affiliation

The Affiliation capability has both an internal and an external component. To achieve the *internal* component is to be able to live with and towards 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 and to have compassion for that situation; and to have the capability for both justice and friendship. To achieve the *external* component is to have the social bases of self-respect and non-humiliation; to be able to be treated as a dignified being whose worth is equal to that of others. Our analysis will be done by identifying information provided by the women that relates to five specific categories: (1) having the ability to create strong and positive family ties; (2) living in an inclusive environment; (3) being recognized as an equal by one's peers (independent of gender, social classes, disability or health status); (4) having been taught self-respect since childhood; and (5) having the ability to marry without coercion or derision.

5.3.3.1 Family Ties

Table 12 – Family Support

<u>FAMILY SUPPORT</u>		
No mention of parents	1	Afi
Supported by both parents	6	Tawona, Natasha, Ethel (at first), Michelo, Bupe, Mary
Support by father	2	Catherine (after some time), Lusungu
Support by mother	4	Meseret, Totela, Catherine, Mutinta
Support by siblings	6	Meseret, Tawona, Afi, Michelo, Malaika, Bupe
Support by aunt/uncle	6	Tawona, Natasha, Afi, Michelo, Lusungu, Mutinta
Support by grandparents	2	Totela, Malaika (tiny bit)
Loss of support through family member death	7	Tawona, Totela, Afi, Michelo, Nataizya, Bupe, Mutinta

Table 13 – Family Constitution

<u>FAMILY CONSTITUTION</u>		
Parents separate	3	Catherine, Malaika, Bupe
Parents separate due to the disability	3	Lusungu, Mutinta, Mary
Parents remarry	4	Catherine, Malaika, Bupe, Mary
Polygamous family	2	Natasha, Ethel

Table 14 – Conflicts with Family

<u>CONFLICTS WITH FAMILY</u>		
Rejected by family	4	Eleni (mother dies, only girl), Tawona (certain members), Afi, Malaika
Conflicts with siblings	3	Ethel, Mutinta, Mary
Conflicts with step-parent	5	Catherine, Natasha, Ethel, Malaika, Bupe
Sexual abuse by family	1	Michelo
Property grabbing	2	Tawona (mother undergoes wife cleansing), Michelo

The women who had a lot of support from their parents and family during their youth tend to have reached a medium to high level of capability development by having accessed emotional support, education and health, as well as financial support from time to time. The support of their family ensured the development of some basic capabilities, such as nutrition, growth, education, health, and ability to create bonds. Says Bupe: “I think maybe

the lifestyle my parents led helped a lot. They laid a good foundation. So you know family has been a great backbone (...) for me. The love of my parents has kept me going.“

When that support is no longer present, or is affected through life events, the consequences can be significant. Four women were fully rejected by their families at some point in their lives. This harkens back to the inequality of WWD and the view that they are lesser. Ethel's explains:

“I think in Koseni many people can explain deeply, they can tell you how we are being neglected by our relatives. Neither our fathers nor our mothers (help us). So that is how we are found in the streets. (...) We are not happy that time to be in the streets. (It is) just because of the way we are being neglected by our parents. (...) All my brothers (half and full) mistreat me. They do not help me, they abuse me, and take advantage of me. They are too selfish. They are the ones that have let my businesses (fail) by robbing me. Right now they are rich but they cannot even contribute to their disabled sister.”

The stigma associated with disability in Zambia, and having a child with a disability, can be strong enough to cause the dissolution of marriage for certain people. In fact, three women indicated that their disability was the apparent cause of their parents' divorce. Moreover, all women whose parents divorced, no matter the cause, found themselves in a more difficult situation; abuse and neglect seemed to arise in many reconstituted families. However, this conflict in reconstructed families is not only due to the disability. As an example, Malaika's parents divorced while she was still able bodied.

“My parents divorced when I was 12 years old. My siblings and I suffered a lot after the divorce. My father remarried, and the children were not kept well, we were chased out and sent to our mother. When we arrived at our mother's, she was remarried and sent us back to our father. We lived in misery and cried a lot. We were left alone with our father and didn't always make it to school because we had no support.”

Disability can however exacerbate the difficulties faced in reconstituted families. In the case of Ethel, her father married a second wife when his first wife failed to produce male heirs. “Dad used to be very good before he married the second wife. He used to tell his mother he had to work very hard so that in the future the disabled child would not suffer. He wanted to take care of me. Things got worse after he married again. She would pressure him to not love me. She was very hard. He was not the same as before, he didn't love me as before.”

There are women who were supported by their families in their youth but did not achieve the level of capability development expected of them. Other factors can explain this, such as death of benefactors later in life, early pregnancies, and abuse from other family

members or trusted persons. For Afi, the role of her extended family was essential in her life as a child. It took nearly twenty years to reconcile with the uncle who had kicked her out following her rape and pregnancy. Unfortunately, he passed away only a few years later. “Now, I no longer have people who I can say can make my life better since my husband and uncle have passed. My uncle had promised he would help me look for capital (for my business) and that he was going to buy a plot of land and make a two-room house so I could live there and sell things. My plans have fallen through. Now, Koseni is there to help with my life.”

5.3.3.2 Inclusive Environment

An inclusive environment means an environment where the women are not discriminated against due to their disability, they are seen as equals and treated as such. In relation to this theme, the women discussed two particular environments: school and work. Many women were sent to institutions for PWD, most of them being boarding schools. Some of the women argued that it was positive because they realized they were not alone in their disability, while others argued the opposite. “If you isolate persons with disabilities, if you put them aside, they will have that isolation mentality whereby they say ‘them’ and ‘we’,” says Bupe. Adds Catherine, “institutions brought out a lack of confidence, where you can’t fight for yourself, where you don’t know how to take care of yourself. If you take a child into integrated schools, they can be beaten but they can also beat back! You strengthen yourself. There is a need to sensitize others and this starts well if done in school.” Here, the women argue what Long and Sen have argued: agency must be nurtured from a young age.

ZAPD agrees that institutionalization is not desirable and that mainstreaming children into regular schools is what is being advocated. However, it counters that due to limited funding, services for children with disabilities in regular schools are very poor and the children must rely on others. As well, the weak transportation and communications systems and inaccessible buildings make it difficult for WWD to go to these schools.

Those who went to inclusive schools tended to say they did not notice discrimination during their youth. Mainstreaming helped develop their self-confidence and diminish their sense of being ‘othered’. It is only when they tried to enter into roles typically reserved for able bodied people that they started to face discrimination, like in the workforce. For Meseret, she never felt different when she was in school -- at least, not until she reached vocational school. There,

“teachers only saw my disability. They did not encourage or accept me like I was used to. I wanted to be a secretary but the school enrolled me in home economics because of my disability. I didn’t recognize this initial discrimination. PWD are expected to do handicrafts, to not be able to do other things. But I ended up joining secretary school. Still, after one year, the teacher comes and asked why I chose this career, why I did not go to home economics, it is best to do that instead.”

Catherine’s story is similar:

“In 1997 when ZAMCOM and UNESCO Zimbabwe held a filmmaker course for 6 weeks, I was among 5 participants selected. When I went to film school, it took time for my fellow students to accept the fact that I too was studying film. I was the first and only student with a disability. As disability is always associated with pity in Africa, some of the tutors and fellow students treated me like I was sick. This was hard for me because it was like blocking my progress in life. However, I proved to be the best student, with awards on graduation.”

5.3.3.3 Recognized as Equal

Simply said, these women, by and large, are not recognized as equal, neither by their family, their husbands and lovers, nor by society as a whole. Says Ubuntu:

“The general perception of WWD as equal is not there. It’s like even when they get on the bus in town, it’s only normal that others will have to wait for them to walk in and sit. But it is not done in good faith. It is done out of pity. ‘Ah it’s a disabled person, why do they make the trouble to come here. They are not equal’. There are only a few individuals that make their presence understood and say they are equal.”

ZAPD echoes that view:

“The Zambian and the African society has put women not as equal to men. This is not to say they are not human beings, but the perception has been that everything has been done for men first; for women, second. Now, we are talking of another element, of disability, which in itself is a worldwide problem. If in general disabled persons suffer discrimination and they suffer all forms of negligence, then (...) you can begin to understand the gravity of the problem for women with disabilities. They are really at the bottom of everything.”

Every woman was able to cite examples of having been severely mistreated or told they were less than others. When Natasha was a small child, a thief came to the house and tried to steal the spare parts of the car. All the children were afraid and when she told the stepmother, she replied: “Why were you afraid? You shouldn’t be scared, you are already dead. If you died today, we won’t even cry.” Even during moments of severe distress, the fact that they had a disability made others less caring to their plight. Tawona explains: “I had

a baby girl but she died at three years from hunger and malnourishment. This pained me too much and I decided to leave for Lusaka to find relatives. When we came upon my relatives, they just humiliated me and said 'what have you come to do here? You are a WWD'."

The act of begging is itself an act of abasement. By sitting on the floor, dressing dirty and making themselves look miserable, the women used the pity of others to survive. It is important to note it is done out of desperate need, not desire. As says Totela: "When begging, we were shouted by the people, we were embarrassed by the people, some they don't know how to talk. Some they have blasted us. No wonder we have decided to stop. I was even crying when someone told me rubbish things. I was embarrassed. No wonder I decided to stop." Ethel adds: "People see us begging and they think we are useless. I think we need to work hard in Koseni so the able bodied people see that we are just as good as them, we are people like them and we can even do better than them."

When looking at gender relations, women are seen as lower than men, no matter if they have a disability or not. They are expected to take care of the house, the children, the finances, and often getting the capital to support the family. The women said they felt as if men can take at will, without contributing. Says Totela: "In the family life, the men are first. Yeah, us ladies, (there is) nothing we can do without men. (...) It's not fair, it has to be balanced. It's not fair." However, for some women, this condition was not even objectionable. When discussing rights with Nataizya, the concept of being equal was not even present:

Interviewer: So, how do you think women are respected in the community? Do you think women are treated the same as men?

Nataizya: No. There is a difference. Because we differ. Men, men are men. Women, we are ladies. So there is a difference. Yeah, a man has got a lot more rights than a woman. Let's say if your husband says "I don't want you to be moving up and down"¹². That is a right. Refusing you to move up and down.

Interviewer: And can you tell your husband that your refuse him to go up and down?

Nataizya: Um um! No, I can't, I can't.

Interviewer: Ok. Do you think that is ok?

Nataizya: Um hum. It is.

¹² In this context, "moving up and down" means to sleep with others, to have other lovers.

Interviewer: So you don't think that you should be allowed to tell your husband that you don't want him to move up and down?

Nataizya: No, I can't. I am not supposed to.

The problems leading to inequality lie on all sides, according to Catherine. "I have known PWD who, because of their background, such as families mistreating them and being in institutions, judge everyone else. There are also able bodied who have never come across PWD but have just heard about them and how difficult they are. What is needed is integration to learn about each other, to appreciate and respect each other." Bupe adds that "the (charity) mindset of able people, I think that needs to change. As much as the able need to pay some particular attention to us, and we appreciate that, it shouldn't make us feel bad. It shouldn't cause us to want to depend so much and not be able to do something for ourselves."

Some women have managed to carve important roles for themselves in the community, but always through an uphill battle. In the case of Eleni, her family abandoned her once her mother had passed because they had no use for a girl child with a disability. Her family only accepted her once she was successful. The case of Catherine is similar: "Despite people trying to overlook me, now they have realized that I can do the work and everyone wants me to direct their work despite the fact that I am a woman and a woman with a disability." It took unwavering determination to be recognized as able like others.

5.3.3.4 Taught Self Respect

As discussed, the women receive very little respect from the community or, for many of them, from within themselves. They have a lot of difficulty valuing themselves as they have spent much of their lives being pushed down by their families, in-laws, and community. Many of them have been beaten or rejected due to their disability and are seen as a burden. This has understandably colored the way they view themselves and what they think they can accomplish. This was clear when they were asked what one of their talents or skills was. Very few women were able to identify a true talent, many citing their faith as their only talent.

For many of the women, those who are supposed to be there to teach them love and self respect are the ones that are berating them the most. When Ethel was entering her last year of high school, she had a confrontation with her father where she accused him of not providing her with enough supplies to go to boarding school. She told him that if he did not

get her what she needed, she simply would not go. That night, he came home drunk and asked her once more if she would go to school. She refused and he beat her to the point of unconsciousness. Following the beating, Ethel still put some blame on herself. "I didn't eat or drink for three days, I was very grieved and regretted my disability. If I wasn't disabled, I would have run away and my father would not have beaten me." In their communities, they are often put down. In the case of Mary: "I will always greet the neighbors as is tradition, but the neighbors will answer in a mean manner. They say they don't want to associate with disabled. They talk behind my back, tell lies and stories."

However, it does not mean that all women are faced with this type of treatment, or that its effects on self-esteem cannot be reversed. Following the capacity building training with SWI and LLT, Totela commented on how she could see things needed to change. "Ok, I don't want those problems which we were having last time to be continued. Like begging, I don't want to be continuing. No wonder I force myself to be stronger in whatever I want to do. I want to be strong because if I am strong everything will be changing in the future."

Others say that their opinion of themselves is what matters most. If they see themselves as equals, they gain respect. In the case of Catherine: "My disability is my motivation. God looks at me like a person, not like a crutch. Most of the time women are judged by the fact they are women and their physical appearance, even when we prove our potential. I have learnt to be positive and face life as a fighter because of my experience as a person with a disability. (...) I have learnt to compete among men not women." Natasha is another example:

"I have accepted the way I am, this has changed people. People will still laugh at you and not accept you if you don't accept yourself. Ignorance is one thing but you also need to show people how they need to handle you. You need to be tough; they can't think you are special. Sympathy is not enough. I wasn't who I am today, I didn't use to talk, I kept quiet. Now, I warn those who should know better and people respect you for that. No one would abuse us and our rights if we stood up for them."

Finally, Bupe: "I think determination and believing in myself that I can do something is what has helped me in life. Like, after discovering that I am able to do the art I do. When I discovered I am able to do certain things, this is something that has been driving me on because now it has made me think I can do bigger things."

5.3.3.5 Ability to Marry

Table 15 - Marriage

MARRIAGE		
Never married	4	Meseret, Eleni, Catherine, Bupe
Impregnated and left	4	Natasha, Lusungu, Nataizya, Mary
One marriage	6	Tawona, Natasha (late in life), Michelo, Malaika, Mutinta, Nataizya
Many marriages	5	Totela, Ethel, Afi, Lusungu, Mary
Abused by husband	4	Totela, Ethel, Lusungu, Mary
Husband dies	3	Totela, Ethel, Afi
Husband leaves	1	Malaika
Leaves husband due to abuse	2	Ethel, Lusungu
Rejected by in-laws	7	Tawona, Totela, Ethel, Afi, Michelo (x2), Lusungu, Malaika
Husband is openly unfaithful	3	Malaika, Nataizya, Mary

Interestingly, the women who had never been married are the ones who seem to be the most successful in their lives, in comparison to the other women in our sample. This could be linked to the burden of socially expected roles of women, whereby they must take care of the man, the children, and the house. They are rarely able to leave the house and work or pursue their own aspirations. Natasha did not get married until very late in her life. In her late thirties, she met her future husband. “One day he said ‘I want to marry you, I really do, it is different.’ ‘People don’t marry disabled women,’ I said, ‘they just leave them and dump them. Me, I know my rights. I’ll get you locked up if you tempt me.’ Yet he was serious, and we married later that year.” Natasha is a very strong willed woman who has been involved in the disability movement for many years. By asserting her rights and waiting, she met a man that would love and respect her. Moreover, she managed to achieve a lot over the course of her life as a single woman, and now as a married woman.

Catherine has also waited all her life for marriage. She adds that along with her disability, the fact that she was a victim of sexual abuse as a child has surely colored her view on relationships with men. “I’ve had a few relationships, but no marriages. I realized that WWD often are taken advantage of, and not only by the able but the disabled to. They get impregnated and men run away. If I am going to go into a relationship, I am going to have to be very careful. I don’t want to have any man use me.” By the end of research, she had entered into a relationship with a foreign man. “What I liked about him (is) the way he

treats a woman. It is very different (from Zambian men). He respects me, follows me with my own decision. Zambian men sometimes want to impose. Want to rule. But him, no.”

Entering into marriage for WWD can be very difficult. First and foremost, WWD are often left out of traditional coming of age ceremonies. According to ZAFOD, “women with disabilities are not sexually initiated, they are not relationship initiated. No one teaches them what to do or how to do it. That has a cultural implication that has a barrier to their marriage.” Since they often do not pass through these rites, it leaves them more vulnerable once they enter into relationships. All of the women who are traditionally married. They have not undergone the civil marriage and do not benefit from those extra protections, such as division of wealth upon divorce. According to Michelo “no disabled who have fallen in love with able bodied have been married ‘straight’ (in the legal method versus only living together).” Moreover, five have been married (traditionally) more than once, while another three (who have only had one marriage) had children with men before this marriage. This indicates the difficulty for women to be considered equal to other women and to maintain relationships with men. They are seen as not being worthy of marriage, as something to be used and pitied but not married. Some authors argue that marriage in Zambia is not considered to be as permanent as it is in other places and this could also be a factor for increased divorces and remarriages. (Taylor, 2006)

Seven of the eleven women who have been married said that they had been rejected by their in-laws. This had not been a question in the interview – this information was volunteered - and so the number could be higher. “Marriage for women is very difficult as they are rarely accepted by their in-laws. If someone does marry her, the bridal price will be almost free. This means that she is worthless: you can do anything to her,” says ZAFOD. Even if they are with a man who loves them and wants to be with them, the influence of the in-laws can be significant in stopping a marriage. Michelo’s experience demonstrates this. In 1998, she met a man who paid a libola to marry her. She became pregnant after sleeping with him with the knowledge they were to be married. However, once he announced the marriage to his family, his mother said that if he married her, she would disown him. He sided with his mother and so, because of stigma and discrimination, she was left pregnant and alone.

Even late in life, and after a long relationship, disability has been used as an excuse for divorce. Malaika was married in 1978. One day, she slipped, fell and lost strength in her legs. Now that she had difficulties, her relatives started saying “How can you (husband) stay with a disabled woman who can’t even have children. Just chase her!” They had been

married for about twenty years, yet her husband disowned her completely, threw her away. “He said I couldn’t do anything because I was disabled and I couldn’t bear children. ‘Just get out’ is what he said,” recounts Malaika.

5.3.3.6 Conclusion

The Affiliation capability has many subcomponents that were differently achieved by the women. Overall, when looking at family ties, this support depended on the initial choices made by the parents and family members to accept the women fully or not. When the family did not treat them differently than others, they faced significantly less challenges at creating strong links later in life, at believing in themselves and respecting themselves. However, there were some who faced neglect and abuse at the hands of their family and still managed to become strong willed and active women. It could be argued that this was an internal characteristic the women had from the onset. Alternatively, it could be due to other supports that were not mentioned during the interview.

Overall, the gender of the women was not necessarily the most important factor when looking at the affiliation capability; disability, and the perceptions others had of this disability, was the limiting factor. While gender roles and power differentials relegated the women to certain positions of subservience and vulnerability, this was (unfortunately) not different than other women in their surroundings. Their disability and the way they were viewed concomitantly was the main factor.

5.3.4 CAPABILITY 4: Environmental Control

The Environment Control capability has three components: educational, political, and material. To achieve the educational component is to be informed by an adequate education (including but not limited to literacy and basic mathematical and scientific knowledge) and to be able to express oneself using imagination and thought. To achieve the political component is to be able to participate effectively in political choices that govern one’s life and to have the right of political participation, protections of free speech and association. To achieve the material component is to be able to hold property (both land and movable goods), not just formally but in terms of real opportunity; to have property rights on an equal basis with others; to have the right to seek employment on an equal basis with others.

Our analysis will be done by identifying information provided by the women that relates to six specific sub-categories: (1) to have access to education; (2) to be able to assemble and participate in the community; (3) to be heard in politics; (4) to have one’s

rights recognized; (5) to be able to hold property (movable and immovable); and (6) to be able to access employment.

5.3.4.1 Access to Education

Table 16 – Level of Education

LEVEL OF EDUCATION ATTAINED		
Incomplete Grade School	5	Malaika, Lusungu, Mutinta, Afi, Mary
Grade School	2	Nataizya, Tawona
Incomplete High School	2	Natasha, Totela
High School	6	Meseret, Eleni, Catherine, Ethel, Michelo, Bupe
Vocational Training	8	Tawona, Totela, Catherine, Natasha, Ethel, Afi, Michelo, Mary
College	3	Meseret, Eleni, Bupe
International (technical/art)	1	Catherine
University	1	Meseret
Mainstream school	6	Meseret, Eleni, Catherine, Natasha, Nataizya, Bupe

Table 17 – Limits to Accessing Education

LIMITS TO ACCESSING SCHOOLS		
Starts school late (after 7 years old)	6	Meseret, Totela, Afi, Lusungu, Mutinta, Mary
Interrupted school for a period due to disability	5	Meseret, Ethel, Afi, Lusungu, Mary
Stopped school due to lack of funds	4	Tawona, Totela (Grade 9), Malaika (G3), Mutinta
Stopped school due to distance	1	Natasha (Grade 9)
Kicked out of school due to pregnancy	4	Afi, Lusungu, Nataizya, Mary

A large proportion of the women had to start school later than normal, or interrupt it for a period of time, due to their disabilities and the treatments they had to receive. Six women attended mainstream schools; of these six women, five are part of the high capability development group. This is fairly indicative of the issues surrounding segregation from society and institutionalization and their effects on persons with disabilities. Only six women finished their secondary school education, including four of the most developed women. The other two, Michelo and Ethel, have achieved significant levels of capability development on many fronts but were curtailed later in life through other events, such as the death of their support system or being cheated by said support system.

While four women attended college or higher (and one woman has a master's degree), another four women were forced out of school due to an early pregnancy. At the time, it was policy in the country that if a girl was found to be pregnant, she would be removed from school. "After the rape, I became pregnant. I was examined at school before final tests and they found that I was pregnant but I didn't know. Then I went home with a message from the school saying that I was sent back, I was caught, I was pregnant. I had to stop school," recounted Afi. It was the same story for the other three women who were pregnant in their teens. Another five women had to interrupt their schooling due to distance from the school or a lack of funds. For some, it was due to discrimination within their own family. When Natasha was a child, her stepmother was very difficult. She did not believe she, as a girl with a disability, was worth the expense and told Natasha's father not to waste more money on her education as she would never be able to work. And so she was taken out of formal schooling.

For Totela, stopping school was a financial imposition. "I am not the one who had decided to stop schooling. It was financial. I didn't have anyone to support me. After my father died, I was just remaining with my mother and she was not doing anything (...) so she was not managing." She has always hoped to return to school. "If I do schooling then things will be better in the future." Unfortunately, with the burdens the women now carry, such as supporting their children and husbands, it is often very difficult to access school. Either they are busy supporting a family, are unable to access the funds necessary to go, or consider themselves too old to try to change their lives. Still, many women have undergone vocational training at some point in their lives. The training is in subjects that seem 'compatible' to WWD, such as tailoring, design, and doormat making. The majority of the women were those that had not finished their schooling, although many who had finished high school still needed vocational training to have skills leading to revenue,

For Michelo, the most important thing that a WWD needs is education. When asked what she would do if she had a child with a disability, she said: "My first priority would be the child with a disability because I know that if I educate her or him, I think it would be good for them. They would be able to look after themselves very well because of education. For me I thank my parents for having sent me to school." ZNADWO agrees with this argument: "Parents must be taken to account in this because they are the ones who take care of education. (...) Some will not consider their child with a disability as one of their children. They are not keen on educating their disabled child and this will be a problem for employment later. Parents are the most important factor."

5.3.4.2 Community Participation and the Right to Assemble

The roles of women in their communities were hard to assess. These women mostly participate in disability organizations and church related activities, as well as a few community organizations. They are not necessarily openly barred from participating, but sometimes their obligations at home and their lack of mobility can limit them. As well, overt and covert discrimination can be a deterrent. This being said, the act of community participation was barely mentioned in the interviews, so our data is limited. Whenever asked in what kind of groups or programs they participated, most women answered church and the Koseni Women's Club. Some added that they wished they could participate in other community groups but did not. Overall, the women tended to say that their roles were limited to that which was socially expected of them – as the 'typical woman' who is cooking, cleaning, and fetching – and overall their communities largely ignored them, or discriminate against them. "When living in communities, people think you have no rights to talk, you are not human, they treat you like you don't exist. The community will even judge if they see you crawling. But I like to help and do chores!" says Michelo.

There is still discrimination from society itself when large groups of WWD are together. Some of the women even suggested that it is seen as abnormal to have so many of them together at once; it highlights a reality many people would rather forget. Says Ethel:

"In Zambia, we are very different, we have different rights. We are not considered. The first to abuse and intimidate us are our fellow women who are able-bodied. On Women's Day, we couldn't participate in the march because the women said 'No, you will disturb our line! You can't put the disabled to the front. It won't be colorful!!' How can you feel when we are people like them but they say it won't be colorful! Since we are on the wheelchairs, they don't consider us women as they are."

Although their purpose was the same as the rest of the women's groups, to advocate for their rights, they were told to not join in because it would be unsightly. Although they have the right to assemble, it is still often poorly viewed

Two exceptions would be Catherine and Natasha. Catherine is a founder of Zambian cinema. "For Zambia, I am one person who has really contributed in the development of the movie industry. It's not money that is essential, it's changing mentalities, seeing how you do things and carry issues," she says. She has also played an active role in the disability movement over the years. Natasha has also been active in the disability world and has played important roles in her own community. "In Habitat, we formed a women's club and I was chosen as treasurer. I also taught the women how to use machines, how to sew.

Whatever they need, I offered. Over time, there were too many people in the group, there were arguments and I decided to be less active in it.” Despite their successes, it must be remembered that they continuously fought for this inclusion and recognition, and continue to do so today.

5.3.4.3 Heard in Politics

While Zambian women have been making inroads in politics, their participation is still limited. These inroads are even less significant for women with disabilities. Tawona recounts how, during campaign periods, candidates reach out to the disability community. “When we are about to vote, they accept us. But after voting, no one cares. We are being humiliated. Our rights are not powerful. After voting, they insult us.” Ethel echoes that sentiment and adds that once elections are done, “again, they start mistreating us. (...) We are nowhere. We are nothing.” A representative of ZAPD was quoted as saying “I think it is up to us as disabled persons to do more to be accepted. (...) And when it comes to enforcing laws and conventions, it should somewhat fall upon those concerned to advocate towards the government.” It is very telling when even the government body responsible for PWD argues that it must be left to PWD to bring government to task, and not up to government to fill its roles and responsibilities.

Michelo argues that without mass movements and advocacy, WWD will never be heard. “The only time the government helped is last year with that ZMK1 million we were promised after we demonstrated up to State House. It’s when they realized ‘These people they are angry now, I think they need to be given something.’ (But) without any demonstration, without any movement, the government will not create law. (...) When you are just seated (like) we are here, nothing will come (of it).” Michelo feels that as soon as they stop being loud and advocating for their rights, they are pushed aside.

Many of the women believe that if there were more people within the government that understood their situation and that were aware of the difficulties faced by women with disabilities, being heard and getting support would not be as complicated. According to Bupe, even the Ministry of Community Development and Social Services is unaware of the reality of women with disabilities. “If (even MCDSS) doesn’t understand and they think we just want to go begging at their doorstep ... what of someone in a different place? (We need to) sensitize the MCDSS, they are the people who need to understand this issue about PWD is all about! If they do not understand, then it will be very difficult for the whole nation to really get the advocacy about PWD.”

5.3.4.4 Rights Recognized

The reality is that very few of the women know what are their basic rights. The example of Nataizya was the most flagrant. When asked what her rights were, she responded: “My rights are... I am supposed to have one man. I am not supposed to have a lot. And I am supposed to keep myself, to not move up and down. I have to keep my husband.” When asked if she knew of any rights within a list, including her rights as a person, right to participate in organizations, right to associate, a right to life, a right to not be harmed, and a right to have children, she said that no, she did not know these rights. It is unfortunately not surprising that many of these women do not know their rights, or do not necessarily advocate for them. It is a question of dominant relationships of power where the women generally find themselves in a situation of poverty, of low social capital, and with limited education. The concept of rights is not often disseminated in these contexts.

According to Natasha “very few PWD know their rights. They feel that they can’t discuss the issues, such as: marriage, abuse by husband and family, impregnation and abandonment. (...) Government can protect those rights but we need to know them for them to protect them! Government is composed of people, and it is people who abuse us.” If the women themselves do not know what their rights are, it makes it very difficult to advocate for them. Moreover, the community at large does not know about them, or does not care to know them. At a national level, “the Disability Act is not being enforced according to our requirements ... services are being provided wrongly. ZAPD is not working hand in hand with NGO and DPO,” says ZNADWO. “Most of our legal tools are not being applied.” Ubuntu agrees and adds that “there may be legal instruments, but they are hard to find and never applied. WWD don’t even know about the facilities because if they are ever advertised, they often can’t access them.” “Most people don’t know their rights, says Catherine. I go back and blame organizations like ZAFOD and ZNADWO, they are supposed to be on the ground, going to the women and in a simple way let them appreciate and understand their rights. But they don’t.”

For those who did know their rights, like Natasha, Bupe or Ethel, it came from having had access to education and employment, from being able to interact with the rest of society. “Well, I have the right to life, the right to accommodation, says Bupe. There are a lot of rights! (laughter) (I learned about them) through education of course, through school. I took a bit of law in my accounting diploma. And then just recently we had a workshop on human rights, HIV and AIDS.” For the women of Koseni, they had been more sensitized

following training with SWI, LLT and ZAMDHARP, as well as with an HIV/AIDS rights course.

Catherine was an active member of the disability movement. However, she became disillusioned by “the huge amount of talk versus the amount of work that needs to be done. People use the name of disability to get somewhere but advance without letting other advance as well.” As an alternative, she started advocacy through art. In 2009, she released her first feature-length movie *Suwi: Faith Without Limits*, a movie tackling the issues of disability, HIV, and street children. It was very well received in movie festivals around the world and at home in Zambia. “Almost every two weeks I am receiving mails from countries asking for movies to be submitted to film festivals.” By using a different medium to advocate for rights, she continues the fight.

5.3.4.5 Ability to Hold Property

“The problem is that we have no capital, this is why we are suffering, says Totela. Otherwise, if we have capital, it can be easy for us to change our situation. I have problem finding food, taking the children to school, buying uniforms...” Under these conditions, owning property seems impossible. There is a general sense of fear and anxiety over finances. A major impediment to saving is the fact women live day to day. “Life for WWD is very bad. It is surviving from hand to mouth first, and business comes second,” says ZNADWO. The concept of saving money was foreign to many of them before accessing the training by SWI. Following the training, Ethel was of a different mind. “I want to be financially empowered, I want to keep the money in the bank. Right now it is too little. I just take some for the education and some for the material to sew. So I need, I want to go far, I want to go hard so that I can be putting money into the bank. (So that my children can be safe).”

Another issue faced by women is property grabbing. In the case of Michelo, when her father passed away, his relatives grabbed everything. At the time in Zambia, property rights were not strictly enforced. Relatives grabbed everything, the house was sold, and they were only left with their clothes, their bed, a bucket and plates. It was following this event that she and her family really started to suffer. She had to leave school due to lack of finances. Although property rights are now somewhat more protected in Zambia following the new constitution, the case of property grabbing still occurs. ZNADWO and ZAFOD are two organizations that include this issue within the scope of their programming.

When we consider material possessions, such as furniture and other goods, it is generally the women who have acquired them themselves. This was true whether or not

they were married. This comes from the fact that they have purchased them with their own money, made from begging or previous employment. When asked about who controlled money, Tawona said: “It was my own money from my own begging. (laughter) That was my own money so I was the one in charge. But since he (husband) has started working, it is coming from his own pocket that is why he is taking charge of that. If that was my money I could buy whatever I wanted.” When it is the husband who is the sole earner, women are no longer able to control purchases or the flow of expenses. Malaika confirms this concern: “I control my money. Money is problem. If you give it to another person, they can just run away from you and go with your money!”

5.3.4.6 Access to Employment

Table 18 – Access to Employment

EMPLOYMENT		
Never held formal employment	8	Tawona, Totela, Afi, Lusungu, Malaika, Mutinta, Nataizya, Mary
Informal trading	8	Tawona, Totela, Ethel, Michelo, Lusungu, Mutinta, Nataizya, Mary
Begging	9	Tawona, Totela, Ethel, Afi, Michelo, Lusungu, Malaika, Mutinta, Mary
Crafts/self employed	10	Totela, Catherine, Natasha, Ethel, Afi, Michelo, Lusungu, Malaika, Mutinta, Bupe
Formal employment	7	Meseret, Eleni, Catherine, Natasha, Ethel, Michelo, Bupe

Accessing employment is difficult for most people in Zambia. According to Ethel “mostly us disabled people in Zambia, we don’t have access to work, even if we are educated. Able-bodied people are just roaming about, even the (university) graduates are roaming about. What of us?” Michelo adds that “there are so many disabled who have been to school, who have completed their education and college, but they didn’t find jobs. Why? The government has been neglecting us. (The government is corrupt), the jobs go to family members.” As well, jobs are inaccessible as required infrastructure such as elevators is not in place. Totela adds: “the problem for us WWD is that in jobs now, there are not so many women working. People think we cannot do anything, They just know us to be sitting at home being a housewife. They don’t know that even us we can do something with them.” Some of the women have accessed formal employment, but most have only worked in the informal sector or in the creation of handicrafts and other products. Those who started begging said they had to because they had lost their support system and had no way to support themselves.

Seven women have held formal employment. Of those are the six that finished high school. Those who did hold formal employment spoke of the serious difficulty they had in accessing these jobs. Many were turned back once their disability was seen, never given an interview, or they were offered different jobs where the public would not see them. Says Eleni: “For me, discrimination really started when I applied to a job competition. I was invited for an interview, but when I appeared and they saw my disability, they tried to discourage me by changing my appointment constantly.” Eleni ended up being hired at the National Library, but only after a long period of searching and being turned down due to her disability.

Once WWD do get hired, getting promoted rarely, if ever, happens. “Promotion is not for disabled people, says Meseret. I was hired as an accountant. Even after I got my BA or MA, I am not given a promotion. Promotions don’t happen, PWD keep the same jobs.” Even if the women had held formal employment, many were not able to keep these jobs due to abuse from employers, not being paid a fair wage, closing of the company due to privatization following SAPs, lack of funding for the organization, or the stoppage of governmental incentives for the employment of PWD. According to Natasha, in addition to being responsible for the provision of education and training, there is a need for government to create employment opportunities afterwards. “NGO and government were both present in my life. I received skills training from the government but they need to provide us with something more. What do you do after training? There are no jobs. They can’t just train people and then dump them on the street.”

Eight have never held formal employment. Main factors are likely their education – none of these women had achieved higher than grade nine– and a lack of marketable skills for employers. Informal trading and self-employment have become one of the few solutions for these women. Moreover, the fact that some of the women who hold formal employment also need to work in informal trading is another sign of the economic precariousness faced by these women. They need to use many different ways to earn wages and support themselves and their families. In Mary’s case, she used to buy beer outside of Lusaka and bring it in to sell. However, when she married her fourth husband, he immediately stopped her from doing business. “He stopped me from doing business, so then I would stay at home but I would stay with hunger. He would bring nothing home, so that’s when I decided I needed to be in the street.”

When neither formal nor informal employment was enough, many women in our sample relied on begging. For Totela, the reasons the women go to the streets are that “we are facing problems for house rentals, for supporting our children to school, for taking care

of our children. And (we need) some money at home. No wonder we involve ourselves in the streets. But it's not good, it's not encouraged." Following training with SWI and LLT in 2009, Michelo had stopped begging. In 2010, she and her husband started up a bean selling business with an elder from her church. "So, at first we were just doing fine, he (the elder) would go to Mpika, bring beans, and we would sell them. But the last trip we gave him about ZMK960 thousand. He went to go buy beans but then he went to sell them at the border with Congo. He sold there, and he never brought the money. That is what has brought me to be back in the streets." Unfortunately, this type of abuse is not uncommon. NTD commented that this is one of the big difficulties faced by their clients: "Usually, what they will do is send some friends to get materials to trade, and sometimes they will be robbed by these friends."

For Malaika, although begging does provide money, it is no longer the answer. "Why did I stop begging? When we started forming our club of Koseni, that is when I was discouraged to be going in the streets begging. Because when we were forming, we were just telling the whole members to please, please stop begging. Because in begging, sometimes it's good, but sometimes it's not good." Following the training with SWI and LLT she now sells some small commodities from her house. "I am no longer going in the streets. After the workshop is when I stopped going into the streets because it hurt me so much. That is when I started selling some things." Ethel concurs and adds that "before, I thought maybe begging could be the life for me. But after having the training with SWI, I am very much encouraged. Begging is no longer as good as I thought it was."

Most of the women had big dreams when they were children, they wanted to have a career but they stopped pursuing their dreams. Tawona wanted to be a writer or a teacher, but failing out of Grade nine stopped her. Ethel wanted to be a lawyer or a journalist. One day, she even applied for the job as a journalist. "I went to the interview and they said they couldn't afford to have me as the job needed someone who can walk fast, who can do things fast. Since I am disabled, I must do things slowly. So, I didn't get it." Michelo had dreamed to be a mechanic: "I always dreamed to be a car engineer. I wanted to be a car doctor. That was my dream, even now that is my dream. What stopped me I think is my disability. I was discouraged by my family to apply, they said I couldn't do it." All of these dreams were taken away from them, due to their disability and the belief that they could never achieve their goals.

Accessing markets for the purpose of selling their products and making a profit is also very difficult. Michelo attributes this as another significant reason for the women being

in the streets. “You’ll find like I am making the bags and I have nowhere to sell them. You’ll find that the time I have moved, maybe to go to the shopping centre and sell handmade bags, the able bodied have already reached that place. So for me it will be difficult to sell those bags.” They are pushed out of the markets, which makes supporting themselves or their children untenable.

5.3.4.7 Conclusion

Education is absolutely essential to being in control of one’s environment. Having knowledge and the confidence that comes with that made the women more involved in their communities, more desiring of further education, more active in politics, and more aware of their rights and how to advocate for them. Furthermore, the more educated the women, the more chance they had to have had formal employment that included job security and proper payment. Out of the fifteen women interviewed, there was only one who had managed to find formal employment despite not having finished her high school education. In her case, she attributed much of her success on different forms of support from her family and her own personal motivation to survive and improve upon life.

Overall, being poor, marginalized, and un(der)educated can severely limit your ability to understand the environment you live in and how you can interact with it and change it. When the women were provided with more education and skills training, they were able to apply these to their daily lives and find new solutions to the challenges they were faced with, such as opening a small trading table in front of their house or producing bath mats for sale. Being empowered with the confidence to know that they could impact and control the environment in which they lived further strengthened the agency of those women.

CHAPTER 6: ANALYSIS

We began our research with an affirmation: *despite being labeled as a vulnerable group needing external assistance, and considering the various social and economic constraints they face and which may be exacerbated by their physical condition, women with physical disabilities express their own agency by developing specific capabilities while interacting with their own social worlds*. We set out to show that the women in our case study are not unwitting victims but agents of change in their own lives and in the environment around them. They adapt to the situations they face and find new ways to survive and navigate through their social world. We sought to confirm this affirmation and explore two subsequent questions. Based in the concepts of Amartya Sen's Capabilities Approach and Norman Long's Actors Oriented Approach:

1. What are the processes that lead to capability development, or lack thereof, for the women in our sample?
2. What are the support and constraints faced by the women in our sample to reaching the functionings they target?

We also had two hypotheses:

1. The government and civil society play an essential role in providing the women with the tools and conditions to develop their own agency and develop the capabilities and functionings they find important.
2. The disability itself is not sufficient to explain the social status of the individuals in our research; it is essential to include their social world and their individual characteristics, such as gender, disability, and environment.

We will first answer the two questions through the objectives we had set for ourselves in the study. We will then explore the two hypotheses we had posed. Finally, we will conclude with a confirmation or negation of our initial statement.

6.1 What Are the Processes Leading to Capability Development?

As previously discussed, we align ourselves with Sen's view on the interconnectedness and equality of all capabilities - theoretically, no one capability can be considered more important than another. This is important as capabilities cannot be taken individually, realized in a vacuum from other capabilities; the processes leading to the

development of one can bring about the development of others. One thing that is variable is the value, classification, and hierarchy attached to each capability depending on the context in which they are being sought after.

Through our analysis, we identified that many aspects of the four capabilities we chose (bodily health, bodily integrity, affiliation, and environment control) were shared amongst each other. In other words, the development of certain capabilities was essential for the development of others. Let us take the affiliation capability and the bodily health capability. Here, the development of close relationships with family and friends then permitted the women to access support throughout their life. They could access medical support, health interventions, food and shelter from a young age. This can be seen for most women, but the case of Bupe is particularly highlighted. Her family had always considered her equal to all the other children, gave her the medical and rehabilitation services she needed to be as mobile as possible, sent her to a mainstream school, and encouraged her to achieve all the functionings she wished. In the case of women where that close kinship was lacking (such as following rejection from the family or another type of separation from familial supports), access to the materials necessary to develop the bodily health capability was limited. Similarly, to develop sub-aspects of one particular capability, other sub-aspects also needed development. Here, we highlight the environment control capability. By having accessed education and training, the women were then able to apply and compete for jobs and employment. In the event they could not access employment due to other barriers (like infrastructure or stigma), they could access vocational training to find trades in which they could work.

The development of the environmental control and affiliation capabilities, and in particular the education and self-respect sub-aspects, were important to ensuring women would then participate in other parts of life, including employment, activism, and politics. This is not to say that education was absolutely essential for this, as there are many examples outside of our case study of people with limited education being strong members of society, but it did tend to help women attain these future goals. The degree to which education was essential cannot be determined from our particular research. As education is often touted as the panacea to poverty and development issues, it would be an interesting avenue for future research. Conversely, the hindrance of certain other capabilities and functionings could then negatively affect those that already had been or were going to be developed. As an example, lacking bodily health then lead to disability which limited accessibility and inclusion, part of the environmental control capability. We can also

highlight the case of Ethel who, although having been put through school and highly educated, was constantly beaten, emotionally attacked, and robbed by partners and family members. These conflicts then hindered her ability to access employment, to have food and shelter, and to own property.

This first question was further answered through a life history analysis and the capabilities framework. Our first objective served to answer this question: *“Through a life histories approach, identify and analyze the processes that have led women to their current capability development level”*. Through discourse analysis and observation, we identified 3 different capability development groupings.

1. High-level of capability development.
2. Medium level of capability development.
3. Low level of capability development.

These levels were created to more easily identify women and their capability development; they were inspired by the Human Development Index (HDI) and its levels of human development for countries (low, medium, high, very high). The HDI is calculated through a combination of: quality of life/health (life expectancy at birth), education (mean years of schooling), and standard of living (GNI per capita). (UNDP, 2011) In our case study, we used observation and discourse analysis from the life histories to then compare how the women of our sample attained the four capabilities. From there, we classified them into the three levels. It is important to keep in mind that these levels are only representative within the group of fifteen women that were interviewed and cannot be compared and extrapolated to the general population since we did not collect data with them. These levels are relative to the context in which they are applied. The levels outline the differences in the life courses of the women in our case study and suggest possible reasons for the attainment of different levels. Below, we explore the levels and further discuss the interrelationships between capabilities and how this has affected the women and their development.

We note that this classification contains many limits, and we maintain our critique of labeling and classification previously discussed in the theoretical framework. Even with the in depth interviews that were conducted, it is particularly difficult to classify the women into three groups. As all capabilities are achieved to varying degrees, between women and even within each individual, and can be affected by punctual life events, some women may have appeared more or less ‘developed’ during our interviews than they really were. Furthermore,

as mentioned, the detail and depth of information gathered varied between interviews. This lacking information certainly limits our ability to properly compare the women. This method could have been more effective had we conducted an analytical research with a set questionnaire where all information received was symmetrical. Some of these limits are further discussed below. Despite this, we still consider it important to create these groupings to better understand the processes involved in capability development.

6.1.1 High Level of Capability Development

When considering what a 'high level of capability development' in our sample group means, it does not mean that the women had achieved every functioning they wished, that they were living outside of poverty, nor that they were considered equal by society. What it meant was that they were active members of their community, were healthy, educated (either formally or informally), confident in their abilities, and able to network and benefit from their social supports. These women were aware of their rights and responsibilities and those of others, and they were strong advocates for these.

The women¹³ in this group have been able to overcome the adversity related to their disability, have a larger vision for their lives and the lives of others around them. They are strong willed and employ their agency to bring about change. They have achieved more than what is socially expected of them as women with disabilities, in that they have accessed formal employment which makes them significantly more independent, financially or otherwise. Most of these women were never married, or waited until much later in life to get married. This indicates an interesting relationship between the work and time burden of the usual roles of women and their ability to achieve high capability development. Moreover, as marriage is generally considered to be very important for women in Zambia, it is interesting that these women achieved many more capabilities than those who were married despite the social stigma attached to women being unmarried.

There were many similarities between the women in this group, indicating important processes leading to capability development. From childhood, they received support (emotional, financial, physical, etc) from their families or adoptive families. They also overcame a variety of challenges in their childhood (such as rape, abandonment, war, pregnancy, and illness), which helped them develop their sense of self-worth and agency from a young age. All of them, except one, had achieved a high level of education, both formal and informal, finishing at least their high school. Some even pursued post-secondary

¹³ These women are Meseret, Eleni, Catherine, Natasha, and Bupe. (Profiles of these women can be found in Annex 1.)

education. None of these women, except one, had married. The one woman who did marry waited until she was in her late thirties to marry. Finally, all women were visionaries, had big hopes and dreams for themselves, their families and their community. This drive to build something bigger than themselves and the belief that they would be able to achieve it is indicative of high development of many capabilities.

6.1.2 Medium Level of Capability Development

A medium-level of capability development indicates that these women have achieved significant capability and functionings development at different instances in their lives but were somewhat hindered by various difficult situations and conflicts, such as: rape, early pregnancy, robbery, and sustained abuse. The women¹⁴ in this group tended to be educated, to have held formal or successful informal employment, to have built strong affiliations, and to have been active members of their society; yet they still had significant difficulties achieving the functionings they sought. They were confronted with barriers along the course of their lives, generally significant ones in their later years.

As discussed above, there were a few cases that were particularly hard to classify:

- Nataizya would have been considered in the high development group if she had finished her education, was more aware of her rights, and was more active in seeking equality. It is difficult to ascertain her actual condition, as the interview was very poor, and limited in scope due to language barriers as well as lack of comfort and familiarity with us. We had never met the participant before the interview. Moreover, no follow-up interview was possible.
- The development level of Mutinta was also difficult to ascertain as the data gathered from the interview was limited due to the translator being unknown to the participant and there was no follow up interview. Although researchers are encouraged to use translators that are unknown to the participants to create an environment of anonymity, this is not always the best course of action. Our research participants preferred to have friends present for support. In this case, the lack of comfort of the participant limited our ability to access information.
- A third case, that of Ethel, was also challenging. She had completed her education, went to technical training, and had held gainful employment. These characteristics

¹⁴ The women in this level are: Totela, Ethel, Michelo, Lusungu, Mutinta, and Nataizya. (Profiles of these women can be found in Annex 1.)

would lead her to fall under the high development group. However, a negative environment and conflicts continuously hindered her: physical abuse by her father, abuse by husbands, and economic and emotional abuse by siblings, to name a few. She described herself as destitute, with few social supports, and with very low morale.

Similarities are hard to identify in this group as they seem to be women who have achieved certain development objectives but were hindered somewhere along the way. The most common reasons cited for the curtailment of their development included:

- Stopping education (due to lack of funds or pregnancy);
- Loss of assets through property grabbing following the death of the father, which then led to loss of support for education;
- Abuse by husbands, which led to separation and loss of assets and supports;
- Financial setbacks through abuse from family, husband, friends;
- Need to support many people (husbands, children, orphans); and
- Lack of personal drive and belief in equality, believing that they are less valuable than others

Overall, it would seem that the women we have classified in the medium level had accessed many of the same supports as children and youth than the women in the high level. However, conflicts and negative interactions with other actors later in life curtailed their development. This is indicative of the changing nature of capabilities and their dependency on a variety of factors. If the women initially found themselves in a positive arena for development and then suddenly were faced with a large conflict and a more hostile environment, their ability to achieve the functionings they sought was severely taxed.

6.1.3 Low Level of Capability Development

A low-level of capability development indicates that these women find themselves significantly limited in their ability to access opportunities for capability development and to achieve life goals. These women¹⁵ would have received limited education, have limited financial independence, suffered from various health difficulties, and have limited control over their own bodies. Issues relating to procreation (either having given birth at a young

¹⁵ These women are Tawona, Afi, Malaika, and Mary. (Profiles of these women can be found in Annex 1.)

age or being unable to have children), rejection from their family, the inability to create many strong bonds of affiliation and social support, having rarely or never been gainfully employed, and having once or more been without shelter, have all impacted these women.

All women in these groups had these characteristics in common:

- Stopped education early due to family or financial reasons;
- Abuse (physical, emotional, and sexual) at the hands of family;
- Abuse from men (husbands or boyfriends, rape);
- Never held formal employment, giving them limited control on their finances;
- Loss of support from family, through rejection or death of family member;
- Poor medical services and rehabilitation;
- Infected or affected by HIV/AIDS;
- High caregiver burden (responsible for many people: children, orphans, husband, extended family); and,
- Generally, low self-esteem and limited agency (likely linked to years of mistreatment)

The women in this group have all undergone prolonged periods of being neglected and abused, from childhood all the way through to adulthood, either by their family members, friends, the community around them, and romantic and sexual partners. All of them mentioned repeatedly how insignificant they were made to feel by those who should have been there to protect and support them. Furthermore, whenever they did access processes leading to capability development, such as schooling or rehabilitation services, either antagonistic actors curtailed them or the environment in which they lived became hostile following a conflict. For example, all of the women had to stop school due to either pregnancy (through the action of outside actors forcing them out of school through paternalistic policies, rendering the arena of the school hostile) or lack of support (due to abandonment by caretakers and/or falling into poverty due to a change in economic circumstances). Later in life, they were further subjugated into the roles expected of them: housewives, mothers, caretakers, and providers. Their bodily health and integrity suffered at the hands of other actors, such as through rape or through infection with the HIV virus. Through continued conflicts and difficulties overcoming challenges, the development of their sense of self-esteem and their agency stagnated.

This being said, all of these women still tried to find ways to break out of the situation of poverty in which they found themselves. They resorted to begging to survive and then

they sought out friends and small organizations with which to band together to find solutions. They learned small trades and artisan skills and found financial support from charities and religious groups. Although their current capability development and ability to achieve the functionings they wish is quite low, it does not mean that they are not able to exit this situation. This is where the concept of agency is so powerful, and where we can continue to argue against branding persons as vulnerable and destitute. Despite the challenges they face, these women continue to try to find coping mechanisms; they are active actors in their own lives, seeking their own solutions.

6.1.4 Concluding Remarks on Processes Leading to Capability Development

Certain processes, such as receiving proper medical care and rehabilitation throughout life to achieve the bodily integrity capability; accessing education and attaining the level of education required to achieve the employment capability; being given the opportunity to support oneself and one's family through employment, thus achieving the bodily health capability; being challenged and able to overcome these challenges, thus developing agency and self confidence; and so on, led to the development of capabilities and functionings. Some of these processes required extensive support from outside actors, while others less so; all of them needed dedication and effort from the women. Interestingly, as capabilities are intertwined, the 'processes' leading to the development of one capability also inevitably lead to other capabilities. As an example, receiving education also leads to the development of relationships, self-confidence, inclusivity, the ability to think critically, and the opportunity to participate in one's community. All processes occur differently for each person and can be assisted and curtailed through the influence of outside actors, the women themselves, material possessions, and the conditions in the environment surrounding them. We consider these to be *supports and constraints*. They are explored below, in section 6.1.2.

This section permits us to confirm our first hypothesis, whereby we affirm that disability itself is an insufficient explanatory factor by which to understand the capability development that women with disabilities can attain. From all that was said throughout the interviews and observed while in the field, it appears that capability deprivation for the women in our sample is not simply caused by disability, or by gender, but by a multitude of factors including the environment and social context in which they live, the particular cultural repertoires that surround them, the actors they interact with, and the relative poverty in which they live. However, disability would overall exacerbate the complex situations in which

some women find themselves, further impeding the expression of their agency and the attainment of the functionings they seek. This impediment depends upon each and every person, and each and every context. This lends further credence to Sen's (1999) assertion that desirable capabilities and functionings must remain ill defined, permitting each society and each person to determine what is valuable for them within that particular context. It is a less ethnocentric framework than that taken by Nussbaum.

From the data collected in our research, we can identify some of the main impediments capability development of WWD. They are gender and the relations of power that result from the socially expected roles of women, poverty, and the actors in the women's social world. With respect to gender, on the whole, it was the women who did not follow the typical path of marrying young, having children young, and taking care of the household who managed to achieve higher capability development levels. As they had less people depending on them, they had the ability to choose their path, to fully utilize their agency. Developing their agency, this ability to choose, did not happen in a vacuum. It was something that was nurtured from a young age and continued to be throughout their lives by actors that included themselves. For those who did not have this support, or had it but were later curtailed in their development due to other conflicts (such as abuse at the hands of partners, falling into poverty following a critical event, or the loss of supports such as family members), the ability to choose was also curtailed.

6.2 Supports and Constraints Faced by WWD in Achieving Functionings

Through the analysis of the women's discourse, the various actors' perspectives and the literature on the situation of persons with disabilities and women in Zambia, we were able to identify a list of supports and constraints faced in the achievement of functionings and capabilities. The main supports were social through their family, their friends, and themselves. The government and NGOs had the potential of being of great assistance ;the organizations that fought for recognition of rights and against stigma were the most important at the policy level while as those who provided education, training, and emotional empowerment had the largest impact at the individual level.

The main constraints faced by the women were related to societal infrastructure. They included: stigma (which affects their ability to participate and be included in all aspects of life, including education, marriage, and health), infrastructure inaccessibility, power differentials, gender oppression and violence, infighting within the disability movement, and

limited physical mobility. These constraints affect the opinions of potential allies and supports and impact the women's ability to participate and develop due to their inability to access the same goods and opportunities as others. Furthermore, they can greatly affect the women's views about themselves and persons with disabilities, reinforcing self-deprecating views and limiting the women's abilities to develop their agency.

The nature and impact of supports and constraints upon capability and functioning development depend on many factors. We will focus on the factors outlined in the Capabilities Approach: (1) their personal characteristics, (2) the basket of material goods available to them, and (3) the environment, or social world, in which they live. (Mitra, 2006) As with capabilities themselves, it is impossible to completely separate these factors from each other. They interact with each other and influence each other's outcomes. However, for the sake of brevity and clarity, we will study them individually. Certain aspects of each factor will inevitably overlap with others. Furthermore, the role of actors will be essential in the analysis. We addressed this second question by focusing on our second and third objectives:

- *To critically analyze what impact being a woman with a physical disability born, raised, and living in a developing country has on the development of her capabilities.*
- *to understand the role of social actors (organizations of all sorts including government, NGO, churches, and families and friends) and the arena, or entourage (be it the neighborhood or other social spaces such as markets and schools where women go) in the development or hindering of capability development.*

6.2.1 Personal Characteristics, or the Individual

There are a few personal characteristics that we were able to identify as being particularly relevant to the capability development of the women in our sample: their gender, age, impairment, sense of self worth, agency, marital status, education, and health status. The impact of each of these characteristics can only be properly observed within the context in which the women live - the material goods they have at their disposal and their environment.

Gender:

Through an evaluation of capabilities, we are able to assert that the power relations at work in the lives of the women of our case study tend to relegate them to positions that limit their ability to use their agency and achieve the functionings they wish. Societal

expectations tend to push women towards the roles of caregiver, homemaker, farmer, and sexual partner. From the discourse of the women, there is an image of the perfect Zambian wife: one who is subservient to her husband and her in-laws, who does all the errands, carries the baby on her back, carries things on her head, bears many children, fulfills her husband's needs, takes care of the house, and provides nourishment and education. There was limited encouragement for women to be educated and outspoken in politics and society, although this was slowly starting to change. As women with disabilities, being accepted in either type of role, as the subservient caretaker or as the outspoken woman, was all the more difficult. As their disability inhibits certain movements and actions (such as carrying the baby on the back and fetching water), they are not accepted as full women by their in-laws and their community.

In Zambia, patriarchy is still very present as seen by the limited participation of women in politics and positions of power as well as the many rights violations and positions of subjugation detailed in the context chapter. This limits the ability of women to be accepted in society or valued for the work they do. This reality was clearly seen with the Koseni women as they are, for the most part, the main or even the sole providers in their family even if most are married and live with other able bodied family members. They have little to no control over their fertility and many have been physically and sexually abused; in fact, over half of women report having been physically assaulted by their partners. This difference between the sexes can also limit their interaction and cooperation. Women are essential actors in society, not only for the simple fact that they constitute half of the population, but also because they take care of a wide range of people and have to take many responsibilities. Importantly, with the shifting interest by development organizations, women are being targeted as the main recipients of aid and training. Without support and collaboration from the men in their environment, women are 'ghettoized' and development stagnates. This dynamic was seen throughout the time spent in Zambia, within the Koseni organization (women complained about their husbands, and about the lack of support) and within the population overall. Unfortunately, changes in mentality are taking sometime to take root in Zambia.

Age:

The age of the women influenced their capability development on a few fronts. For the women who were born and experienced the onset of their disability during the socialist period, access to medical intervention, rehabilitation, education, and employment was

easier and free. This means that these women were provided with more opportunities to develop their capabilities and access the functionings they sought. Those who were born later or who experienced disability later in life were faced with more barriers in accessing these services. It is telling that the women who find themselves within the high capability develop level are amongst the oldest in our sample group. This also permits us to validate the life histories approach we took for our analysis. Had we only observed the current situation of these women through a transversal study and not considered their past, we would not have been able to make these realizations.

Impairment:

The physical impairments they have in the context in which they live have been a constraint to many of the functionings they seek. The women highlighted the inability to continue education due to mobility issues, the inability to access employment, the inability to marry due to stigma, and so forth. However, when they were in an environment where their disability was not an issue, either because the environment was accessible or because the people around them did not consider their disability as an issue, there was no deprivation of functionings. An example would be Michelo becoming the chairwoman of Koseni and being well respected within this social group. Within particular arenas, or environments, what can be perceived as impairment in one would not be so in another. In the case of Koseni, the diplomacy and leadership skills of Michelo are valued and lead her to be voted in as chairlady while as, in the bigger disability world, some of her personal characteristics, such as being economically poor and not holding permanent employment would make her less interesting as a candidate for a similar sort of position. Brought further to the general Zambian society, the fact that she is a poor woman with a disability and holds no formal employment makes her seem less valuable and less valid. The Disability Initiative Foundation (DIF) highlighted this during their interview when they mentioned that they could access higher levels of government for their advocacy because, as professionals and higher-class people, persons without disabilities had more respect for them.

Sense of Self Worth:

Self respect and belief in oneself are essential for women achieving their dreams, as seen through Catherine and Natasha in particular when they highlighted that the only way they overcame challenges was by accepting who they are and making other people accept them as well. It was by defying norms and challenging close-mindedness that they chipped

away at some of the barriers erected against them. Some of the other women also saw the importance of belief in oneself following the training given by SWI. Many of the women said that they now believed that they could do more than 'just beg' and strove to find new ways to adapt and overcome. When that strength was not present, and either self-doubt or depression set in, the women tended to be less well off and returned to patterns of dependency and vulnerability (such as begging). This was seen with Ethel, Mary, and Michelo who, despite being educated and trained for a variety of jobs and fields, received little respect from the community. We believe this lack of respect for WWD as persons is one the main reason so little is being done to improve their situations and to have them integrate within society. Because they are seen as weak and unable, they are not considered to be part and parcel of their community. Unfortunately, this mentality has even transferred into the way they perceive themselves. This was clear when they were asked at the beginning of the workshops to identify one of their skills or talents. Very few women were able to identify a true talent, many sighting their faith in God as the only one they possessed.

Bupe highlighted this when discussing her fellow women in Koseni: "They need to believe in themselves. If they can believe in themselves, it will drive them. So if women can first of all believe in themselves, recognize what they have within themselves, that will be a stepping-stone. Within Koseni, I think that's an issue." The project developed by SWI with Koseni focused on empowering the women to trust in themselves, their members, and their skills, even if they were still largely dependent on charity and begging. They all had strong skill sets and knowledge that was not being utilized due to the various situations they found themselves in. Overtime, they themselves noticed that there was no dignity or safety in begging and that cooperating to create small businesses and IGAs would be a better way to ensure their survival.

Agency:

Related to self-respect and belief in oneself is the concept of agency. As was defined by Sen, an agent is "someone who acts and brings about change, and whose achievements can be judged in terms of her own values and objectives". (Sen, 1999:19) These women fought for their survival and the survival of their children. They found a variety of income generating activities - piecework, formal work, selling handicrafts, bartering, etc. - and when they are stopped from accessing them (due to lack of education, lack of employment opportunities, discrimination based on their disability, or pregnancy), they have

come to rely on begging. Begging was not their first choice, it was in fact their last, but it was the way that they found to survive when they had no support. Although it can be seen as an act of abasement, it is also in its own way an act of agency in the face of very difficult odds. Furthermore, the ability to chose to exit this way of life and try to find other ways around systemic oppression, such as through the creation of the Koseni Women's Club, participation in various NGO, and the advocacy roles that different women play, are also all acts of agency. These women proved that they were not one of the 'Poor' defined by the World Bank, to be pitied and needing all forms of assistance to escape destitution. As stated by Pithouse (2003), they are ever changing, evolving and fighting. They all faced different challenges and did what they could to surmount them.

6.2.2 Material Characteristics, or the Goods

Here, we are looking at the basket of material goods available to the women, including income, shelter, clothing, and so forth. We also include the wealth and resources of the state or community in which they live as these are important to the creation of an accessible and inclusive environment where capability development can thrive.

Individual

The amount of material goods available to the women and their families during their childhood did not seem to be as important a factor in initial capability development as a supportive and inclusive environment. Similarly, when they managed to achieve certain levels of capability but then were faced with a setback, it was in large part due to their gender and related roles (pregnancy, property grabbing, limited types of employment available, expected to stay in) and their disability (inability to access infrastructure, stigma). Their economic situation, although impacting them presently, did not necessarily lead them to the lives they now live. Many of the women were born to non-poor families during a prosperous period in Zambia's history. Those that received help of all sorts (emotional support, basic needs, love) from their families succeeded in further developing and accessing things like higher education and employment, while those who were pushed away and ignored did not.

As adults, women are generally faced with many more burdens and responsibilities and they are expected to provide for their families. As many of the women in our sample were unable to access formal employment (*secure* employment) they needed to find other ways to answer these. They took on various artisan projects, piecework, and, when necessary, some would beg. The fact that they do not have a steady source of income that

can provide enough for the survival of their family, and that they must take on all the additional charges related to their role as caretaker and mother, means that their free time is significantly taxed. The women that have gainful employment or have found ways to finance their survival and those of the people they support are more able to develop other capabilities, such as societal involvement, adult education, advocacy, sports, and recreation.

State (or Community)

That being said, having resources available at higher levels, such as government is crucial. Where states are able to access the funds and expertise required to make their infrastructure (roads, buildings, transportation system, etc.) accessible to persons with disabilities, to fund large-scale societal interventions (education, advocacy campaigns) to diminish stigma and increase awareness of the reality of various disabilities, and to prevent, treat, and rehabilitate disabilities, the environment in which PWD live can become significantly less discriminatory. Unfortunately, in the case of Zambia, and in particular the case of the peri-urban areas where most of the women in our sample live, funding and infrastructure are extremely limited. What funding does exist is controlled by a few government actors, NGO, and churches and does not yet seem to be enough to create significant change.

6.2.3 Environmental Characteristics, or the Context

As described previously, the Zambian context is one where poverty is high, the rights of women are low, social support structures are being torn apart in the cities, and support systems can often fail. These all contribute to the tensions faced by the women in their life course. There are different levels of social environments that must be considered, including the overarching Zambian society, the closer community in which women live their daily lives, their lieu of employment, their families, and so on. This returns to the concept of arenas described by Long: every context and every environment is different and will have different impacts on the actors within it and the conflicts between them. Many of the barriers caused (or exacerbated) by the environment were detailed above in the personal characteristic section. As mentioned, these three factors (personal characteristics, material good, and environment) interact with each other.

Stigma and Labeling

The stigma associated with disability can be seen in the local expressions and sayings used when discussing disability. A derogatory term used to identify PWD in Zambia is *bakufa*, which means ‘the dead’. As was further described by Catherine, those “closest to the clouds are those that are most powerful”. ‘Closest to the clouds’ are men without disabilities, followed by women without disabilities, closely followed by men with disabilities and, much further down by the ground, closest to the grave, women with disabilities. Because of stigma, ignorance, and prejudice, WWD are marginalized. This effectively cuts out a large swath of population from participating in the community and in the development of society. As was mentioned by many persons interviewed, and visible in the country’s statistics, the girl child is already less likely to attend school than the boy child. When she has a disability, this is even more unlikely.

As children, most of these women faced discrimination by family and community members and were relegated to housework because they were not viewed as being worth the expense of education. Once in the school system, they were encouraged to go towards employment ‘meant’ for PWD, such as tailoring. Finally, when looking for employment, their disability would, more often than not, be cause for rejection and dismissal. Even if they were educated and driven, their difficulties in mobility were cause for discrimination from society.

We argue that the labeling process hinders women’s capability development. As they try to overcome societal challenges, attain employment, education, marriage, and so on, the reality of their physical disability is that they are seen as incapable, different, and vulnerable; this impedes their progress. Ethel’s continued efforts to find new income generating activities, only to be constantly foiled by her brothers who would rob from her because they did not value her and did not see her as deserving support is an example of this.

Actors: Who Are the Allies?

Family and parents are essential actors, and were noted more often than any other as the most important people in the lives of the women in our sample. Their role is from the moment of conception and throughout their lives. If parents were present and supportive from the moment of disability onwards, the women had a much higher chance of developing their capabilities and accessing the functionings they wished. Parents were particularly important with regards to ensuring the education of their children. However, the fact that they still faced a lot of adversity throughout their life highlights that family and friends are not

the only factors that matter when considering actors. This is where the larger society comes into play. Government and civil society must be brought into the fray.

As has been shown, in Zambia there are many disability actors who work towards similar objectives, with similar populations and in similar catchment areas. This was confirmed by many of the organization leaders and members, as well as their clients. It is a consequence of limited funding, competing objectives and fragmentation of ideas. When there is a conflict within the organization, often they will fragment into smaller groups instead of attempting to resolve the issues. There are however some important tools and methods that have succeeded in helping very marginalized people in Zambia, such as microfinance for women, education programs, advocacy towards society as a whole, and the work of NGO dealing with gender abuses and/or HIV/AIDS (Lewis, 2004; Human Rights Watch, 2007). By focusing on the best practices of these NGO, newly emerging associations, such as the Koseni Group for Women in Lusaka (described below), could succeed in developing a successful framework for service delivery and action. As well, possibilities such as South-South and North-South partnerships, such as one with the Ethiopian National Association for Women with Disabilities or the Shared World Initiative, could succeed in guiding new organizations and work towards progress in the capability development of women with disabilities.

This section permits us to refute our first hypothesis, that government and civil society play an essential role in the development of capabilities for WWD -- with a caveat. Through the discourse of the women, many organizations, and our own observations, we found that, in fact, government and civil society were not the main actors in the lives of women with disabilities. In reality, the most important actors were families, friends, and religion or religious organizations. As a general rule, the women did not feel as if they had received much support in their lives. Excluding a few exceptions, such as Catherine and Bupe, the opinion is that they were generally forced to face the difficulties of life alone where they should have been supported. To them, the government has the responsibility to assist them in their rehabilitation, education, and employment as well as in the protection of their rights. When discussing the disability movement – meaning grassroots organizations, outspoken individuals, and large NGO – the view is negative. According to them, there is too much division, too much selfishness, too much backstabbing. People are only working for themselves and do not try to help the group as a whole. According to Natasha, these issues “start at the top. If government were to stop looking at us as ‘others’, if we were included,

there would be no barrier. The government needs to change the status of WWD in the country. But there is so much 'us' versus 'them', it destroys everything."

These larger actors could, and should, have a significant impact. There are a few factors that limit their role, such as lack of funding and interest in disabilities, a lack of skilled worker, corruption, and a lack of coordination between various actors. Under Kaunda and the socialist policies of the First Republic, the government played an important role in providing free access to treatment and mobility aids, dedicated jobs for PWD, and training centres. This helped PWD and WWD achieve the capabilities they wished. During the interviews, the majority of women lamented this loss that followed the SAP as well as the coinciding cuts to social funding. Following the SAP, the MCDSS (including ZAPD) was seen as sometimes providing a little bit of food or money, but no continuous support. At the macro level, disability is not seen as a priority in a country faced with severe poverty, malnutrition, illiteracy, and an HIV pandemic. The view is short sighted as these issues can themselves lead to disability and the inclusion of PWD in the development of the country would be beneficial overall. To achieve this, more consistent support, advocacy and sensitization at a national level, scaling up of pilot projects, learning best practices from successful governments around the world are needed.

Additional important issues related to the failings of government and civil society are resources and their mismanagement through incompetence and corruption. Throughout the interviews, many participants indicated the squandering of the limited resources available to disability organizations through corruption from the leaders, hiring of unskilled workers due to their connections with organization or government leaders, and a general disregard for hiring persons with disabilities. As has been shown, in Zambia there are many disability actors who work towards similar objectives, with similar populations and in similar areas. This can be explained through Long's Actors Oriented Approach (2001): many actors with similar objectives but different ways of conceiving solutions and actions interact in the same arena. Very often, when there was conflict within an organization, it would either loose membership or fragment into smaller groups instead of attempting to resolve the issues. This was similar in the event of infighting between organizations: instead of finding common ground, there would often be increased conflict leading to break up of partnerships and networks.

The failures of coordinating bodies in managing their affiliates, providing for their membership, and listening to needs were often cited as reasons for the fragmentation and multiplicity of actors. We observed that, just as just as the NGO ZNADWO exists because of

the inability of other actors to properly advocate for women with disabilities, its own inefficiency is one of the main reasons given by the women of Koseni, and many other women and women's groups, for the creation of their own organizations. Those who were supposed to be there to assist them were not. When considering the role government and NGO can play in the capabilities development of women with disabilities, this is a significant loss. They are failing in their role as the main coordinating bodies, main donors and welfare providers. The lack of resources, mismanagement, and misunderstanding of mandates is at the heart of the problem.

It is understandable that there are difficulties inherent to partnerships and collaboration, such as power differentials, cultural hindrances, differing values and objectives, and, to lesser degrees, hidden agendas. (Johnson and Wilson, 2006) These have been seen at various moments and between many actors of the disability movement in Zambia. However, the benefits of partnership and networking cannot be ignored and were constantly referred to as a desire and a need by many of the organizations we interviewed. These benefits can include sharing and developing best practices, mutual education and learning, diminished dependency on handouts and aid through development of income generating activities, and rapid capacity building (Bobiash, 1992; Johnson and Wilson, 2006; Marrakech Declaration, 2003). The use of these tools as well as collaboration with all kinds of actors (government, civil society, church groups, and families) can be an important factor in creating organizations working for the promotion of rights for WWD.

As mentioned, the main actors in the lives of women (in the sense that they had the longest lasting and continuous impact) are their family and extended family members (uncles and siblings in particular). The role of friends, both local and international, was also often mentioned as well as that of religion and religious organizations. Moreover, the women are very important actors in their own right. The decisions they make, how they deal with challenges, their drive and motivation, their hopes and dreams: all of these influence their life paths and social worlds, and are manifested by their agency.

6.2.4 Concluding Remarks on Supports and Constraints to Achieving Functionings

The role of actors in supporting women in the achievement of the capabilities they seek is undeniable. By being part of their environment, or arena, and being present to assist when conflicts and challenges arise, outside actors play an important role. Similarly, if they wish to curtail or simply not assist in capability development, they can be seriously detrimental. Importantly, the women's own self worth and belief in their abilities are absolutely essential in the expression of their agency and the attainment of their goals.

When this is not present, capability development stagnates. Finally, the conditions surrounding the women and the environment in which they live have a serious impact as well. If poverty and lack of materials are the reality, many capabilities (such as education and bodily health) will be impacted. Moreover, if the environment is hostile, in the sense that it is not inclusive and promotes discrimination and stigma, the barriers will be very hard to overcome.

CHAPTER 7: CONCLUSION

Our analysis has provided us with the platform to test the applicability of Amartya Sen and Martha Nussbaum's Capabilities Approach on the study and explanation of disability and disability issues. While we only explored a fraction of the capabilities and functionings detailed by Sen and Nussbaum, the framework can be extrapolated to far larger and more complex analyses of society, conflict, power differentials, and development. The CA can be a very powerful tool in the fields of critical disability and gender studies as it focuses on multiple factors (the self, the environment, the material goods) for understanding exclusion and inaccessibility. While proposing a more complete way to measure human development than simple capital growth, the Capabilities Approach focuses in on the particularly important role of individuals in their own development and that of the society in which they live. Agency, then, is both a goal of and a tool for development. We were also able to explore the suitability of Norman Long's Actor's Oriented Approach to the study of social movements, conflict, and development. Long's approach has generally been used only for the analysis of development programs and interventions, yet we found its framework focusing on cultural relativity, actors, conflict, and arenas to be quite robust for understanding the processes involved in the capability development of WWD and the fragmentation of the disability movement within a 'developing' context.

Methodologically, we were able to challenge certain assumptions regarding how data collection should be done with marginalized populations, as shown by our use of translators that were known to the participants instead of strangers. This choice was made once having consulted with our research participants prior to commencing interviews: they preferred to share the intimate details of their lives in front of those who already knew them best. The trust and comfort of the participant with those present during the interview is foremost and can provide surprising access to information. This is not to say this method could and should be used for all types of social research, but it should be a consideration. Our return to the field a year later had always been intended, with the purpose of data restitution to the participants. As researchers, we had the ability to access people, organizations, and resources that would have been out of reach for our participants. By bringing the information gathered and our conclusions back and reaching out to those who could help effect change, the women and organizations we worked with were able to directly benefit from their participation. We believe that this last step in our fieldwork, although not

always taken, is essential and all researchers should be encouraged to take it. Finally, the ability to have a flexible methodology and adapt our research to the context once in the field was essential. With this, we were able to better target our research questions and research objectives to the ever-changing environment in which our participants lived.

With regards to our data collection, there are a few particular actors that we now consider essential to the understanding of capability development but that were unfortunately not included. They are: family, close friends, religious groups, and international organizations. The first three had not been identified as a priority in the lead up to the field yet were mentioned by the women as being the most important actors in their lives. Future research targeting these actors could provide important insight on their perceptions of the lives of women with disabilities as well as their roles and responsibilities in their upbringing and capabilities development. Actors from the international community, while identified as important, were hard to coordinate with once in the field and did not constitute an important source of information while there. Considering the significant role they can and do play, this could also be an interesting avenue for future research.

At the onset of our research, we argued that, despite being labeled as a vulnerable group needing external assistance, and considering the various social and economic constraints they face and which may be exacerbated by their physical condition, women with physical disabilities in Zambia express their own agency by developing specific capabilities while interacting with their own social worlds. We sought to understand what were some processes that led to capability development, or lack thereof, for the women in our sample and to what extent they reached the functionings they targeted through the development of said capabilities.

Our research indicates that the women with disabilities in our sample use many methods to not only survive but sometimes even thrive. While many may not necessarily be thriving, they are confronting many challenges with innovative methods. They are not passive victims, waiting for support - although this support would greatly benefit them and assist them in navigating a particularly complex environment - but active agents in their own lives, utilizing their agency whenever possible. In part due to the environment in which they live, the lack of proper programming and funding in that environment, and the overall disinterest in disabilities by the larger development world, they must continuously find ways to fend for themselves.

That being said, their situation is in no way easy. As women, they already face many barriers to achieving the life they value; because of the stigma and discrimination that is associated to their disability, they are all the more pushed aside. They face many serious challenges, such as: lack of education; lack of employment; increased risk of abuse, sexual abuse, and infection by HIV; discrimination in their community; difficulty accessing services; and so on. The power dimensions existing within society with regards to gender are important to consider. Women are not readily encouraged to be outside of the home nor to find employment; they are expected to get married and become caretakers. However, in reality, the women we interviewed were all active economic agents, generally the main breadwinners in the family (Michelo, Mary, Malaika, and Tawona) and often led a monoparental household (Ethel, Lusungu, Totela, Meseret, Afi). They are almost always fighting an uphill battle for recognition, support, and equality. Often times, they do not win that battle.

We found that women with disabilities in our sample developed the capabilities they sought when they had the necessary external supports from actors in their environment (ranging from family, to community members, to the government), when they had the necessary material goods required to access these capabilities (such as for education or ownership of property), and, most importantly, when they believed that they could overcome hurdles and conflicts put in their way through conviction in their self worth and agency. When some of these factors were missing, the capabilities and functionings they sought were harder, if not impossible, to attain.

The underlying purpose of our research was to show women with disabilities in a different light: not as vulnerable and destitute but as active and strong agents in their own lives and communities, fighting to achieve the capabilities and functionings they desire. We do not dismiss the very challenging situations in which they live, nor presume to say that they are not, in fact, vulnerable and victimized on many occasions. It is in part because of their continued struggle and quest to succeed in the face of these very grueling and sometimes dehumanizing conditions that we were all the more interested in how they had achieved what they had and why they were where they were in their lives. We wanted to reconsider vulnerability and how we classify people. Although it is human nature to label and classify, these boxes can also implicitly limit people's freedom to do and be what they want to be. The question of disabilities and the acceptance and integration of persons with disabilities is an important one. As Eleni so deftly put it: "Disability is a burden for all. At

some point in their life, every person will have to deal with some form of disability. We need inclusion. It is not a problem for only women with disabilities or other people with disabilities. If people do not recognize this, it will not change. We need to include others, to work together against the problems.”

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ANNEX 1: INTERNATIONAL PROGRAMS

The following are some of the international initiatives and programs that have been implemented over the past few decades targeting both disabilities and women.

- The **International Year of Disabled Persons** was declared in 1981 and was the first true global event targeted towards the improvement of the conditions of persons with disabilities. It led to the **United Nations Decade of Disabled Persons** (1983 – 1992) and the creation of the **World Program of Action Concerning Disabled Persons**. According to Loeb, “the Program emphasizes the right of persons with disabilities to the same opportunities as other citizens and to an equal share in the improvements in living conditions resulting from economic and social development”. (Loeb, 2006)
- The **International Day of the Disabled**, December 3rd, was first declared in 1981. Its objectives is to “promote a better understanding of disability issues with a focus on the rights of persons with disabilities and gains to be derived from the integration of PWD in every aspect of the political, social, economic and cultural life of their communities”. (UN Enable, 2010) The day is celebrated around the world, and has been an important rallying point for the disability community in Zambia.
- In 1993, the UN General Assembly approved the **Standard Rules on the Equalization of Opportunities for Persons with Disabilities** (Resolution 48/96), which set specific targets and indicated a strong moral and political commitment on behalf of the States towards equality for persons with disabilities. (Loeb, 2006)
- **The African Decade of Persons with Disabilities** was declared from 1999 – 2009 by the African Union. Its objective was to raise awareness about the situation of all persons with disabilities on the continent; to enhance the quality of life, full participation and empowerment of all categories of disability; and to “identify solutions tailored to the African experience that enhance participation, equality and empowerment of all Africans with disabilities” (AFDPD, 2010) It was extended for a further 10 years in 2009. The website provides very little data on what has been achieved in the past 10 years and what future attainable objectives are which makes it difficult to evaluate what changes have come from it.
- **African Decade for Women** was declared by the African Union in 2010 and will last until 2020. Its objective is to call upon all African states and leadership to participate and implement programs for the development of women. It focuses on ensuring their

equality in all matters and reaching already established development goals. It is yet unclear what role, if any, disability plays in this movement.

- The World Health Organization launched the **World Report on Disabilities** in 2011. The Report is the first update to the WHO's world-wide disability statistics in nearly 30 years. (WHO WRD, 2011)
- The World Bank has also been instrumental in the foundation of **the Global Partnership on Disability and Development (GPDD)**. The GPDD states that its main objective to "increase collaboration among development agencies and organizations to reduce the extreme poverty and exclusion of the substantial number of children, women and men with disabilities living in poor countries" through capacity building, knowledge sharing, research and networking. It is a newly formed organization but it clearly indicates to global commitment to insuring the rights of all persons, no matter their health status. (GPDD website, 2009) The Zambian Agency for Persons with Disabilities (ZAPD) is a member of the partnership.

ANNEX 2: DETAILED DESCRIPTION OF THE WOMEN

High Capability Development Level

Bupe	
Age	44 years (8 December 1965)
Nationality	Zambian
Disability	Polio at age 4 Has a malformed right shoulder (unknown cause) Had a workplace accident that severed tendons and nerves in the left hand Had fibroids in early 2000 which incapacitated her until a hysterectomy was done.
Family	Parents treated her normally and supported her Has three siblings who are deaf, disability was not a taboo Has three siblings (out of 8) that are deaf When parents divorced, father remarried and the step mother mistreated them (would beat the two deaf girls sometimes) Has always kept some siblings or lived with other siblings. They are very supportive of each other Currently living with her brother
Marriage and children	Never married, never had children Unable to have children
Education	Finished high school and did a 2-year accounting course. Took computer classes
Employment	Worked for 8 years as an accountant in the Copperbelt but left due to workplace frustrations Worked in a bridal accessories store in Lusaka until she had the accident that cut her left hand Now does arts and crafts and produces bridal accessories from home
Begging	Has never begged

Catherine	
Age	42 years (born 10 October 1968)
Nationality	Zambian
Disability	Medical malpractice when received an injection in the left leg that pierced the nerve. The nerve was destroyed. Now, the padding on the hip of the right leg has worn out due to increased pressure and needs an operation. Muscles in the left leg have atrophied.
Family	Parents separated in 1974 because of tribal differences Father remarried and stepmother mistreated her, would make her do all the work and impede her from going to school. Her mother and siblings have always been very supportive Was raped by a close family friend in 1982

Catherine	
Marriage and children	Has never married and doesn't have children but has been proposed to many times. Currently in a relationship that could lead to marriage but is apprehensive of losing her independence. Is considering adopting a child if when she is ready for children. Not sure if at her age she will be able to have any
Education	Finished high school Studied Development Activism in Namibia Studied Theatre and Stage Management in Zimbabwe Studied tie and dye, tailoring and design for 2 years in Livingstone Studied filmmaking in South Africa for 2 years
Employment	Worked as an activist for PWD Formed the Zambia Association of Physically Handicapped Travelling Theatre Group Worked for Disacare (organization that builds wheelchairs and accessible bikes) Worked in the South African film industry (1999-2001) Works as a filmmaker, CEO of Vilole Images Productions, founder of the International Film Festival of Zambia Sits on many boards
Begging	Has never begged

Eleni	
Age	Between 41-45 years old (1965-69, unsure)
Nationality	Ethiopian (b. Horata)
Disability	Limited lower limb mobility due to polio
Family	Was given up to a boarding school by her father after her mother passed because "men are not meant to raise women" There met an American woman who became her surrogate mother, maintained contact throughout her life. Lost sight of her family until she was on television for her success with EDWNA and now people are interested in her
Marriage and children	Never married, no children. Has been scared by the experiences of other women who were left by their husbands due to the disability
Education	Finished high school, did some training in college
Employment	Works at the National Library as a database operator and is an executive member and founder of EWDNA (a very large and successful NGO for women with disabilities in Ethiopia)
Begging	Has never begged

Meseret	
Age:	39 years (1971)
Nationality	Ethiopian (b. Bale Goba)

Meseret	
Disability:	7 years old, limited lower limb mobility due to war (Was shot and beaten during the Ethiopia/Somalia war)
Family:	Most of her family, except for mother and two siblings, died in an attack during the war. Was separated from them and thought she had been orphaned Her older siblings found her many years after the attack in a boarding school. Now, keeps her mother, a niece and a nephew in a house she rents
Marriage and children	Never married, no children but would like to if could find the right man. Doesn't want to care for a baby without a father
Education:	Finished high school, did vocational training as a secretary and then as an accountant Has obtained her BA, was undertaking her Masters in Administration in 2009
Employment:	Works as an accountant for the Ethiopian government and is an executive and founder of EWDNA (a very large and successful NGO for women with disabilities in Ethiopia)
Begging	Has never begged.

Natasha	
Age	41 years old (24 December 1969)
Nationality	Zambian (Tumbuka tribe) (b. Myombe)
Disability	Disability due to medical accident. Had swelling in legs at 2 years, an exploratory operation was done and the doctor nicked the nerve in her leg.
Family	Father had two wives, stepmother didn't want to educate her or "waste money" on her. Now keeps her husband, mother, older sister, nephew and 3 children in a house she earned with Habitat for Humanity
Marriage and children	Has had 3 children 1 st child at 21 years with a boyfriend who left her when she became pregnant. Child was raised by her and her parents. Married in 2007, had baby girl in 2008 and a baby boy in October 2010
Education	Finished grade 9, had to drop out because the school was too far. Has done a knitting and tailoring course as well as an industrial tailoring course.
Employment	Has had many fairly successful jobs (tailor, administrative assistant, artist, trainer in tailoring and arts and crafts) Co-runs Ubuntu Organization for PWD
Begging	Has never begged

Medium Capability Development Level

Ethel	
Age	45 years (1965)
Nationality	Zambian (b. Chingola)
Disability	Polio at age 5
Family	Father had 2 wives (married a second when Ethel's mother didn't produce sons). Has 23 other siblings Stepmother would beat her and deprive her of food. All her siblings mistreat her, ignore her and steal from her. Father beat her once until she was unconscious when he was drunk. Never touched her again. Repeatedly ignored, insulted and robbed from by her family. Has led to many failed business ventures. Keeps a niece and her two children
Marriage and children	1 st child (1985, died at 3 months) to first husband (1984-1987). Left him because he beat her so severely 1988, lived with a second husband but left him after 7 months because of beatings 2 nd child (1997) to 2 nd husband (1995-1997) in Lake Tanganyika. He left her because his family didn't want a PWD in the family. Wanted her back when she had a boy but she refused. 3 rd child (2002) to 3 rd husband (2001-2008, PWD). Left him after she lost 4 pregnancies (miscarriages that she blames on witchcraft and where they lived) and he didn't want to move. 2 nd husband wants to be married to her again, has said he would accept her children as his.
Education	Finished high school (is the only fully educated one in her family) Did a 3 year college course in cutting and design
Employment	Worked in a clothing factory until it was privatized Worked on a 3-year contract as a midwife and tailoring teacher for World Vision Tried to do piggery, barter system and farming but would be robbed by her brothers or family of whom she asked help.
Begging	Started begging in 2001. Now begs on the rare occasion when necessary, but doesn't like to

Lusungu	
Age	42 years (10 October 1968)
Nationality	Zambian (b. Kitwe)
Disability	polio at 4 years causing near total paralysis (and withering of limbs) in lower extremities
Family	parents divorced due to her disability, lived with family members until 12 yrs and then moved in with her father until she was 20. Then with her brother for 9 years, then moved away from her family. Now takes care of 8 children in all (5 orphans from brothers who have died)

Lusungu	
Marriage and children	Has had 6 children, 3 have died 1 st with her cousin/boyfriend (1986), died at 9 months 2 nd , 3 rd (1988, 1992) with her first husband (1988-1993; PWD who would physically abuse her, was a drunk and drug abuser), both died from measles. Left husband. 4 th , 5 th , 6 th (1997, 2000, 2002) with a man she cohabitated with (1997 – 2003) Currently a man wants to marry her.
Education	finished grade 7 and then stopped because the school was too far from where she lived. She then became pregnant at 16 and her father took it as her not wanting an education.
Employment	Never had formal employment, normally taking care of children, sewing, knitting, cleaning, selling fruits in the streets. Now survives off doormat and table cloth making as well as small selling from her home
Begging	Started begging in 1999 when the city confiscated the things she was selling because she didn't have a permit. Seems to have stopped begging since September 2009 (post SWI)

Michelo	
Age	37 years (25 June 1973)
Nationality	Zambian, Soli (b. Lusaka)
Disability	Polio at 6 months. She is also very small in stature – probably due to early pregnancy
Family	Family was very well off but father died. His family grabbed all the possessions so they became poor. Lived with her maternal uncle for some years. Parents were very supportive of her, including lying to the school system to ensure she could continue schooling after giving birth.
Marriage and children	1 st child (1987): Was sexually abused for years by her cousin. Became pregnant at 14 on her first ovulation (never had a period so didn't know she was pregnant until much later). Cousin was jailed for two years and his father (her uncle) pays for the child's education 2 nd child (1998) to a policeman who she was engaged to. He left her when his family threatened to disown him for marrying a WWD 3 rd and 4 th child (2003, 2004) with current husband (also PWD)
Education	Finished grade 11 (then father died and couldn't continue) Did a year of tailoring and design at a college, funded by uncle
Employment	Worked as a receptionist for a few different organizations Lost her employment when last company closed due to corruption Worked as a tailor and reception for a South African lady. Was asked to move to South Africa with her but her mother disagreed. Stayed in Zambia. Produces bags, tailoring, barter system. Is the chairlady of Koseni (unpaid work)

Michelo	
Begging	Started begging in 2003 when she and her family were chased away from the in-laws for having a disability. Still needs to beg sometimes to pay for rent and food (husband doesn't work)

Mutinta	
Age	40 years old (October 1970)
Nationality	Zambian (b. Kasama)
Disability	Disability due to cerebral malaria. Is very small in stature and has lost the use of her lower extremities
Family	Parents divorced when she became sick Lived with an uncle who was mistreating her and then went back to her mother until she was 27. Moved with her siblings afterwards and then married. Lives with her children, husband, 2 nephews, 1 niece and her sister.
Marriage and children	Has had one husband (in 2000) and four children (2003, 2006 and twins in 2009) Husband seems to be very supportive
Education	Stopped school after grade 5 because she couldn't afford it.
Employment	Has never had formal employment, sells commodities (charcoal, beer, beans, etc.)
Begging	(no data on when she started begging)

Nataizya	
Age	44 (born in 1965)
Nationality	Zambian
Disability	Mobility issue due to arthritis in both knees. (when she was in 39) No disability before. Rehabilitated through physiotherapy. Now gets around fairly well, uses a crutch
Family	2 parents (never divorced) 6 siblings
Marriage and children	1 boyfriend in high school, led to pregnancy 1 child, died at 20 years of age 1 husband, no children
Education	Finished to grade 8, kicked of school out due to pregnancy
Employment	Owns a small shop by her home. A table to sell groceries and food, with a shelter. Very proud of it.
Begging	Has never begged.

Totela	
Age	35 years (1975)
Nationality	Zambian
Disability	Disability due to polio in right leg
Family	Parents died in 2001 but were good to her
Marriage and children	Married in 1998 (husband died in 2005) and had 3 children (2 boys, 1 girl 1999, 2003, 2005). Children no longer live with her, are living with grandparents who are sending them to school. Married again in 2010. Considering having children again.
Education	Was in school until grade 9, failed out because lack of financial support when father died. Did a tailoring and training course as well as a sports coach course.
Employment	Never had formal employment. Tried selling goods but the city confiscated them due to lack of permit. Sometimes works as a coach and referee in Paralympics sports (soccer and basketball)
Begging	Begged since 1998. Stopped in 2010

Low Capability Development Level

Afi	
Age	died at 39 years of AIDS on August 14, 2010 (1971-2010)
Nationality	Zambian (b. Ndola)
Disability	disability due to polio at age 7
Family	Parents gave her to an uncle after her disability. Lived with him until he kicked her out for spoiling her education following a pregnancy from rape. Lived with family members intermittently, but left because her disability and children were seen as a burden. At time of death, was living with her 4 children and her "sister" (mother's cousin, 18 years). The sister had a child in May-June 2010.
Marriage and children	has had 5 children: 1 from rape, 1 from her first marriage (baby died at 2 years), 3 with second husband has been in 4 relationships: 2 marriages, 1 engagement but found out man was married, 1 boyfriend (he is apparently the one who infected her)
Education	completed until grade 7 at school. Was kicked out after becoming pregnant following a rape
Employment	Never had formal employment Did knitting, tailoring, doormat making.
Begging	Begged since 2003 (when her husband died). Before she was supported by her husband and her family. Unsure if she stopped begging.

Malaika	
Age	56 years (10 July 1954)
Nationality	Zambian (b. Kitwe)
Disability	Difficulty walking due to three falls: one in her late teens, one in her mid twenties and one in her forties. The last one is the one that made her need crutches
Family	Parents divorced Her and her brothers were chased away when and lived from family member to family member.
Marriage and children	married in 1978, her husband left her after her third fall because she now was a WWD and also couldn't bear children. Came back to her a few years later and she has been caring for him since (had TB and suffered a stroke during June 2010) Has no biological children (couldn't conceive) but has taken care of over 18 children at one time or another. Currently caring for 2 children, one who is on ARVs
Education	Dropped out of school in grade 3 because her family didn't support her.
Employment	When younger, worked as a maid Can do sausage making, knitting, etc.
Begging	started begging in her childhood to support her brothers and sisters and then again in her 40s when her husband left her Has now stopped begging

Mary	
Age	38 years old (1972)
Nationality	Zambian (b. Lusaka)
Disability	disability at 10 years after falling from a tree Spent 2 years with a witchdoctor to be healed and her parents had to pay 3 cows to get her back.
Family	Parents separated due to her disability. Lived with her mother, step father and 7 other siblings.
Marriage and children	Has had 4 children, currently pregnant. 1 st child in 1987 (boyfriend) 2 nd child in 1997 (first husband who she left when found he had a second wife) 3 rd child in 2000 (2 nd husband, PWD, died) 4 th child in 2002 and 5 th child due early 2011 (current husband, able bodied, ignores her and infected her with HIV. Is planning on divorcing him)
Education	Had to leave school in grade 7 because she became pregnant and was kicked out. Did training in tailoring and design later on.
Employment	Never had formal employment, was supported by her family until she moved to Lusaka in 1995.

Mary	
Begging	Started begging in 1995 in the streets and at mosques. Still begs

Tawona	
Age	38 years (1972)
Nationality	Zambian (b. Mpika, Northern Province)
Disability	Polio at 3 years
Family	Parents treated her well but when father died, mother was forced to marry his younger brother. He mistreated them all (Was chased out years later) Mother in law has beaten her because she disagrees with the marriages Siblings were kind to her in childhood but not so much now Most relatives ignore her and don't help. Keeps younger sister, brother, 4 nieces and nephews
Marriage and children	Married in 1993 to a man with a disability Has had 5 children: 1994, 1997, 2000 (died at 3 years from malnutrition), 2003, 2004
Education	Failed grade 9 because had to miss some school when her father died. Did 3 months of tailoring until the funding from her uncle ran out
Employment	Never formally employed Sold fish in her village Did tie die and tailoring
Begging	Started begging in 2003. Stopped in 2010 when her husband stopped drinking and started working again (as a tv and radio repairman)

ANNEX 3: NUSSBAUM'S LIST OF ESSENTIAL CAPABILITIES

Martha Nussbaum's list of essential capabilities consists of ten capabilities. We analysed four specific capabilities, although five of Nussbaum's capabilities were used to create our list (some aspects of Capability 4 were added to Capability 10 as we saw education and the ability and freedom to express oneself as essential to the political aspect of Capability 10). We omitted certain sub-categories because, due to limits in our data, they could not be explored. These are struck out from the list below. The numbering is according to Nussbaum's list. (Nussbaum, 2000)

Capabilities Used for the Analysis

2. Bodily Health. Being able to have good health, including reproductive health; to be adequately nourished; to have adequate shelter.

3. Bodily Integrity. Being able to move freely from place to place; having one's bodily boundaries treated as sovereign, i.e. being able to be secure against assault, including sexual assault, child sexual abuse, and domestic violence; ~~having opportunities for sexual satisfaction and~~ for choice in matters of reproduction.

4. Senses, Imagination, and Thought.

- Being able to use the senses, to imagine, to think, and reason – and to do these things in a “truly human” way, a way informed and cultivated by an adequate education, including, but by no means limited to, literacy and basic mathematical and scientific training.
- ~~Being able to use imagination and thought in connection with experiencing and producing self-expressive works and events of one's own choice, religious, literary, musical, and so forth.~~
- Being able to use one's mind in ways protected by guarantees of freedom of expression with respect to both political and artistic speech, and freedom of religious exercise.
- ~~Being able to search for the ultimate meaning of life in one's own way. Being able to have pleasurable experiences, and to avoid non-necessary pain.~~

7. Affiliation.

A. 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 and to have compassion for that situation; to have the capability for both justice and friendship. (Protecting this capability means protecting institutions that constitute and nourish such forms of affiliation, and also protecting the freedom of assembly and political speech.)

B. Having the social bases of self-respect and non-humiliation; being able to be treated as a dignified being whose worth is equal to that of the others. This entails, at a minimum, protections against discrimination on the basis of race, sex, sexual orientation, religion, caste, ethnicity, or nation origin. In work, being able to work as a human being, exercising practical reason and entering into meaningful relationships of mutual recognition with other workers.

10. Control over One's Environment.

A. Political. Being able to participate effectively in political choices that govern one's life having the right of political participation, ~~protections of free speech~~ and association.

B. Material. Being able to hold property (both land and movable goods), not just formally but in terms of real opportunity; and having property rights on an equal basis with others; having the right to seek employment on an equal basis with others; ~~having the freedom from unwarranted search and seizure.~~

Capabilities Not Used for the Analysis

1. Life. Being able to live to the end of a human life of normal length; not dying prematurely, or before one's life is so reduced as to not be worth living.

5. Emotions. Being able to have attachments to things and people outside ourselves; to love those who love and care for us, to grieve at their absence; in general, to love to grieve, to experience longing, gratitude, and justified anger. Not having one's emotional development blighted by overwhelming fear and anxiety, or by traumatic events of abuse or neglect. (Supporting this capability means supporting forms of human association that can be shown to be crucial in their development.)

6. Practical Reason. Being able to form a conception of the good and to engage in critical reflection about the planning of one's life. (This entails protection for the liberty of conscience.)

8. Other Species. Being able to live with concern for and in relation to animals, plants, and the world of nature.

9. Play. Being able to laugh, to play, to enjoy recreational activities.

ANNEX 4: INTERVIEW GUIDE FOR WOMEN WITH DISABILITIES

Interview Guide: Life history guide for women with disabilities

Women with disabilities in Zambia: the effects of civil society on the protection and promotion of human rights and freedoms

Researcher: Dr. Nathalie Mondain, University of Ottawa

Student Researcher: Michèle Meilleur Sarazin, University of Ottawa

Explanation of the study

This is a study being undertaken by a researcher from the University of Ottawa. The objective of this study is to understand how women with disabilities have seen their lives impacted by these disabilities and what role non-governmental organizations have played in their lives.

1. Introduction of interviewer and of the study. Read out consent form. Obtain signature or provide signature if respondent is illiterate

2. Please could you tell me the story of your life from when you were born until now. Please tell me about all this events, people and places that were important to you.

PROBES:

- Origin of disability
- Significant differences to life noted before and after (if applicable)
- Description of household where grew up, siblings, co-wives, grandparents and their interactions before and after the disability. Differences between yourself and your siblings
- Rural or urban?
- Description of childhood / schooling and leaving school
- First employment and subsequent employment
- Cohabitation, marriage, divorce
- Rehabilitation, services offered, hospitals, clinics

3. Can you tell me about who has helped you throughout your life to adapt to your disability? What did they do? Did it help? Are they still present?

PROBE:

Family, friends, community, government (hospitals, hospices), local clinics, organizations for persons with disabilities

4. Are you able to participate in your community?

PROBES:

- What is your employment?
- Can you participate in religious or cultural events?
- How are you treated when buying food or at the market?
- Are you active in local politics or organizations?
- Are you ignored, neglected or abused?
- Can you move about freely (mobility)?

5. Do you see any difference between how you participate in the community versus women who do not have disabilities?

PROBES:

- Same rights and legal protection
- Respect in the community
- Access to services

6. What do you think could be done to improve your situation? Which person or group that has helped you before or that is helping you now would be most useful?

PROBES:

Specific services (microcredit, rehabilitation, health care), important issues (neglect, abuse, violence, education), support groups, legal action, government legislation...

Government versus non-government

Hand-outs versus training/education

7. How do you imagine the rest of your life? What would you really like to happen? Do you think this will happen?

PROBES:

employment, marriage, housing, family, old age, rehabilitation, equality, legal protection.

Do you have any final comments or questions?

Do you know of other women with disabilities that are not followed by (name of refereeing organization)? Could you provide them with information regarding this research and give them our contact information if they are interested in learning more?

Specific points to check out at end:

Age, marital status, number of children, educational level, origin/type of disability, age at which the disability was acquired

ANNEX 5: INTERVIEW GUIDE FOR ORGANIZATIONS

Interview Guide: non-governmental and governmental organizations working with PWD and/or WWD

Women with disabilities in Zambia: the effects of civil society on the protection and promotion of human rights and freedoms

Researcher: Dr. Nathalie Mondain, University of Ottawa

Student Researcher: Michèle Meilleur Sarazin, University of Ottawa

Explanation of the study

This is a study being undertaken by a researcher from the University of Ottawa. The objective of this study is to understand how women with disabilities (WWD) have seen their lives impacted by these disabilities and what role non-governmental organizations have played in their lives. Please see attached information letter for additional information.

1. Introduction of interviewer and of the study. Read out consent form. Obtain signature or provide signature if respondent is illiterate

2. Organization Background

- Can you tell me about your organization?

PROBES: What is the mandate

Who is the target population

What services do you offer

Where does your funding come from

Does your organization also work with government / NGO (depending on the organization interviewed)

What role do you play in the community?

To whom are you accountable?

Do PWD/WWD participate in your organization and its administration?

3. Legal tools

- Are you aware of any legal tools or legislation that relate to persons with disabilities and/or women? Does your organization use them and their principles in its programming? Do other organizations (government or NGO) use these tools and promote their principles?

PROBES: Convention on the Elimination of All Forms of Discrimination against Women

Zambian Persons with Disabilities Act

Protocol to the African Charter on Human and Peoples' Rights on the Right of Women in Africa

International Convention on the Rights of Persons with Disabilities

African Decade of PWD

- Are they useful?
- Are they being applied by the government through laws, programs and funding?

4. Perceptions

- What are the main disabilities you deal with and what are the causes?
- To what extent do they receive services, jobs, health care, legal protection?
- What about women with disabilities (repeat two previous questions)
- In reality, are PWD or WWD seen as equal to others? If not, how are they perceived by the general population?

5. Barriers to services and possible improvements

- Can you tell me any barrier you may see for providing equal services to women with disabilities? What must be changed or improved?
- PROBES: Gender, disability, funds, human resources, political will, culture
Education, community awareness, increased participation from PWD/WWD, changes to the medical community perceptions

6. Role of your organization

Can you tell me what your organization is doing and can do to improve the lives of WWD?

- PROBES: Is your work accountable? To who?
Is it participatory? With who?
Is it sustainable? How?
How do you think the community and WWD perceive your organization?
What improvements can your organization make to its services?
What do you consider to be important success stories for your organization?

7. Future hopes and directions dreams

Can you talk about how you see your organization and its work evolving? What role do you hope to play in this evolution?

- PROBES: New programs or services?
Increased participation of the target population?
Increased involvement of government?
Increased funding (through the state or donors)?

Do you have any final comments or questions?

Do you know of any other organizations that work with persons with disabilities and women with disabilities? Could you provide them with information regarding this research and give them our contact number if they are interested in learning more?