The Role of Disability Rights Movements in the Ethiopian Development Agenda

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DECLARATION

I, the undersigned, hereby declare that the work contained in this thesis is my original work, and that it has not been submitted in its entirety or in part to any other University for a degree, and that all the sources used have been acknowledged by references.

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Signed:

Date: 10 December 2010

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ABSTRACT

Despite the ever increasing number of persons with disabilities (PWDs) in Ethiopia and the resulting conditions of abject poverty, efforts made to curb the existing situation, thereby improving the lives and citizenry contributions of PWDs, has been minimal. Consequently, poverty and insufficient participation of PWDs continue to be the distinctive features characterizing the disability sector and movement in Ethiopia. This research was aimed at investigating the role, involvement and impact of PWDs and the Disability Rights Movement (DRM) in Ethiopia in realizing the effective inclusion of disability in the country's development agenda, with a specific focus on Poverty Reduction Strategy Papers (PRSPs).

A *qualitative research paradigm*, using a case study design, was employed as a research method in this study. Data were collected using two data collection methods; namely, *key informant interviews (KIIs)* and *focus group discussions (FGDs)*. Purposive sampling and snowballing techniques were used to select 44 people who participated in ten key informant interviews and three focus group discussions (each FGD attended by 8 to 10 participants). The researcher was flexible enough to conduct additional KIIs and FGDs until the data saturation point was reached. Semi-Structured Interview Guides were employed as data collection tools. A thematic content analysis was conducted following a systematic process of coding data and grouping codes into categories and emerging themes. The study was conducted in Addis Ababa, the capital of Ethiopia, in collaboration with the Federation of Ethiopian National Associations for People with Disabilities (FENAPD) – the umbrella Disabled People Organization (DPO) in Ethiopia.

The results of the study revealed that the disability movement in Ethiopia has not been active enough in ensuring the involvement of PWDs in the country's development endeavours. It was also reiterated that, even if the Ethiopian government was one of the first signatories of the UN Convention on the Rights of Persons with Disabilities (CRPD), the practical recognition that it has so far conferred to disability and PWDs in its development plans has been less than satisfactory. The study also underlined the fact that some recent progresses, such as the mentioning of disability in the currently under-review third PRSP document of Ethiopia, should be strengthened in order to pave the way for a more comprehensive inclusion of disability. Imminent challenges and opportunities facing the Ethiopian disability movement have also been explored in the study.

It is hoped that the results of this study will provide the pertinent disability stakeholders in Ethiopia, including the government, with useful, timely and concrete research evidence, especially as Ethiopia is now engaged in a process of launching its latest PRSP documents.

OPSOMMING

Ten spyte van die immer toenemende getal mense met gestremdhede (MMG's) in Etiopië en die gevolglike volslae armoede, is daar uiters min pogings aangewend om die bestaande situasie te bedwing en só die lewensgehalte en burgerskapbydraes van MMG's te verhoog. Gevolglik bly armoede en die ontoereikende deelname van MMG's eienskappe wat die gestremdheidsektor en -beweging in Etiopië kenmerk. Hierdie navorsing was daarop gemik om 'n ondersoek te doen na die rol, betrokkenheid en invloed van MMG's en die Beweging vir die Regte van Gestremde Mense (BRGM) in Etiopië om gestremde mense doeltreffend by die land se ontwikkelingsagenda in te sluit, met spesifieke klem op Armoedeverligtingstrategieë (AVS'e).

'n *Kwalitatiewe navorsingsparadigma,* waartydens 'n gevallestudie gebruik is, was die navorsingsmetode van hierdie studie. Inligting is verkry deur twee data-insamelingsmetodes, naamlik *onderhoude met belangrike segspersone (OBS'e)* en *fokusgroepbesprekings (FGB's).* Doelgerigte seleksie en sneeubaltegnieke is gebruik om 44 mense te kies, wat toe aan 10 onderhoude met belangrike segspersone en 3 fokusgroepbesprekings deelgeneem het. (Elke FGB het uit 8 tot 10 deelnemers bestaan.) Die navorser was buigsaam genoeg om meer onderhoude en groepbesprekings te hou totdat die inligting 'n versadigingspunt bereik het. Semigestruktureerde onderhoudsriglyne is gebruik as instrument om die inligting in te samel. 'n Tematiese inhoudsontleding is gedoen ná 'n sistematiese proses om inligting te kodeer en kodes in kategorieë en duidelike temas te groepeer. Die studie is uitgevoer in Addis Abeba, die hoofstad van Etiopië, in samewerking met die Federasie van Etiopiese Nasionale Verenigings vir Mense met Gestremdhede (FENVMG) – die oorkoepelende organisasie vir gestremde mense in Etiopië.

Die bevinding van hierdie studie is dat die gestremdheidsbeweging in Etiopië nie aktief genoeg is om die betrokkenheid van MMG's in die land se ontwikkelingsondernemings te verseker nie. Daar is ook bevestig dat, selfs al was die regering van Etiopië een van die eerste ondertekenaars van die Verenigde Nasies (VN) se Kongres oor die Regte van Mense met Gestremdhede (KRMG), die praktiese erkenning wat tot dusver aan gestremde mense in dié land se ontwikkelingsplanne gegee is, geensins bevredigend is nie. Die studie lê ook klem daarop dat onlangse vordering, soos dat gestremde mense genoem word in die derde AVS-dokument van Etiopië, wat tans hersien word, versterk behoort te word. Só kan die weg gebaan word vir 'n meer omvattende insluiting van gestremde mense. Naderende uitdagings en

geleenthede wat die gestremdheidsbeweging in Etiopië sal moet aanpak, word ook in hierdie studie ondersoek.

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The exceptional commitment and love of my parents, Mrs. Tiruwork Negussie and Mr. Bogale Wakenè, has been and will always be a source of courage that enables me to confront the challenges of life. I simply have no words to thank you enough, folks! I also wish to thank my brother, Getachew G. Michael, for his unceasing brotherly support.

Glory be to Jesus Christ with whom nothing is impossible!

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ABBREVIATIONS AND ACRONYMS

AAU	Addis Ababa University
ADA	Americans with Disabilities Act
CBOs	Community Based Organizations
CBM	Cristoffel Blindenmission
CRDA	Christian Relief and Development Association
CRPD	Convention on the Rights of Persons/People with Disabilities
CSA	Central Statistical Agency
CSOs	Civil Society Organizations
DAG	Development Assistance Group
DFID	Department for International Development (United Kingdom)
DPI	Disabled Peoples' International
DPOs	Disabled Peoples' Organizations
DRM	Disability Rights Movement
EEPRI	Ethiopian Economics Professionals' Research Institute
EFPD	Ethiopian Federation of Persons with Disabilities
ENAB	Ethiopian National Association of the Blind
ENAD	Ethiopian National Association of the Deaf
ENADB	Ethiopian National Association of the Deaf Blind
ENAID	Ethiopian National Association on Intellectual Disabilities
ENAPAL	Ethiopian National Association of People Affected by Leprosy
ENAPH	Ethiopian National Association of the Physically Handicapped
ENDAN	Ethiopian National Disability Action Network
EWDNA	Ethiopian Women with Disabilities National Association
FDGs	Focused Group Discussions
FENAPD	Federation of Ethiopian National Associations for People with Disabilities
GTP	Growth and Transformation Plan
HDR	Human Development Report
HIPC	Highly Indebted Poor Countries
ICF	International Classification of Functioning, Disability and Health
ICIDH	International Classifications of Impairment, Disability and Handicap
IL	Independent Living
ILO	International Labour Organization

IMF	International Monetary Fund
IYDP	International Year of Disabled People
KII	Key Informant Interviews
MoE	Ministry of Education (Ethiopia)
MoA	Memorandum of Association
MoFED	Ministry of Finance and Economic Development (Ethiopia)
MoH	Ministry of Health (Ethiopia)
MoLSA	Ministry of Labour and Social Affairs (Ethiopia)
NEWA	Network of Ethiopian Women Associations
NGOs	Non-governmental Organizations
NUDIPU	National Union of Disabled Persons of Uganda
PASDEP	Plan for Accelerated and Sustainable Development to End Poverty
PHC	Population and Housing Census
PRSPs	Poverty Reduction Strategy Papers
PWDs	Persons/People with Disabilities
RI	Rehabilitation International
SDPRP	Sustainable Development Poverty Reduction Plan
SNEPS	Special Needs Education Program Strategy (Ethiopia)
SWG	Sector Working Group (Rwanda)
TDVA	Tigray Disabled Veterans Association
UDPK	Union of Disabled People of Kenya
UN	United Nations
UNDP	United Nations Development Program
VSO	Voluntary Service Overseas
WWD	Women with Disabilities

DEFINITION OF TERMS

Disability: Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.[1]

Impairment: Any loss or abnormality of psychological or anatomical structure or function.[1]

Handicap: A disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role that is normal, depending on age, sex, social and cultural factors, for that individual.[1]

Right: A justified, recognized, and protected (violation of which is unlawful) claim on, or interest in a specific tangible or intangible matter.[2]

Disability Rights Movement: The organization or gathering of people with disabilities and people advocating the disability cause around a set of specific shared concerns and common interests.[3]

Independent Living (IL): A way of looking at disability and society and a worldwide movement of people with disabilities who proclaim to work for self-determination, self-respect and equal opportunities. This notion of 'Independent Living' (IL) was first coined in the 1960s by some four students with disabilities in the US led by Ed Roberts. These students were later known as the 'Rolling Squad', due to their contribution to 'start the IL ball rolling'.[4]

Poverty: A condition where people's basic needs for food, clothing, and shelter are not being met.[5]

Development: Process of economic and social transformation which is based on complex cultural and environmental factors and their interactions.[6]

Poverty Reduction Strategy Papers: "Represent a country's macroeconomic, structural and social policies and programs to promote growth and reduce poverty, as well as associated external financing needs." [7 (p.34)]

Key Informants: Persons who are either involved with a certain issue as a regular part of their job or as part of their volunteer activities or, because they are knowledgeable about that community, its citizens, and its history.[8]

Focus Group Discussion: A form of qualitative research method in which a group of people are asked about their perceptions, opinions, beliefs and attitudes towards a product, service, concept, advertisement, idea, or packaging.[9]

Mainstream: The prevailing current attitudes, values, and practices of a society or group.[10]

Inclusion: Engaging the uniqueness of the talents, beliefs, backgrounds, capabilities, and ways of living of individuals and groups when joined in a common endeavor.[11]

CHAPTER ONE

1. INTRODUCTION

This Chapter outlines the background to the study, the motivation of the researcher, the research problem, the aim and objectives of the study, the research questions and the significance of the study. It also provides a summary outline of all the chapters.

A strong and vibrant Disability Rights Movement (DRM) is a major contributor to the effective recognition and socio-economic mainstreaming of disability in a nation. However, the Disabled Peoples' Organization (DPO) activities and movement in Ethiopia have so far been unsatisfactory, when compared with those of other African countries with similar socio-economic circumstances to that of Ethiopia.[12] This weakness is often attributed to various internal and external factors, such as lack of capacity within the disability movement, resource constraints and limited knowledge about disability in the society. There is a need for a transformation of attitudes in the society at large and among PWDs themselves, based on increased education and, more importantly, adequate research evidence. This study attempts to produce an in-depth analysis into issues pertaining to DRMs in Ethiopia and their contribution in the development affairs of Ethiopia, mainly in efforts to reduce poverty by virtue of the Poverty Reduction Strategy Papers (PRSPs).

Note that the terms 'Disability Rights Movement' (DRM) and 'Disabled People's Organization' (DPO) are used interchangeably in this research.

The following section outlines the background of the study.

1.1. Background of the Study

> *Where, after all, do universal human rights begin? In small places, close to home - so close and so small that they cannot be seen on any maps of the world. Yet they are the world of the individual person; the neighborhood he lives in; the school or college he attends; the factory, farm, or office where he works. Such are the places where every man, woman, and child seeks equal justice, equal opportunity, equal dignity without discrimination. Unless these rights have meaning there, they have little meaning anywhere. Without concerted citizen action to uphold them close to home, we shall look in vain for progress in the larger world.*
>
> *(Eleanor Roosevelt: Remark at a presentation of the Universal Declaration of Human Rights – UDHR - at the United Nations Commission on Human Rights. New York, March 27, 1958).*

The researcher has found the above quote to be a brief, but illustrative, encapsulation of what it means to create an all-inclusive society in which everyone can fully participate. This is, in fact, one of the premises on which this study is based.

The Federal Republic of Ethiopia is one of the oldest countries in the world, and is located in East-central Africa (commonly known as the Horn of Africa). It covers an area of over 1,127,127 square kilometres, which makes it the ninth largest country in Africa. It is bordered to the west by the Sudan, to the east by Somalia and Djibouti, to the south by Kenya, and to the northeast by Eritrea, which declared its independence from mainland Ethiopia in the early 1990s. According to the latest National Population and Housing Census carried out in 2007 by the Ethiopian Central Statistical Agency (CSA), the country is currently the second most populous nation in Africa with an estimated population of close to 80 million, just behind Nigeria. Ethiopia is a predominantly agrarian society, also marked by considerable geographical diversity with high mountains, plateaus, deep gorges and river valleys; the latitudinal differences of which range from 4620 meters above sea level to 116 meters below sea level.[12] *Figure 1* shows the official map of Ethiopia.

Fig. 1: The Official Map of Ethiopia

Poverty and inadequate socio-economic participation of persons with disabilities (PWDs) have been described as the distinctive characteristics of the disability sector and movement in Ethiopia.[13] Persons with disabilities form part of every community and often represent the majority of the most disadvantaged and underprivileged sections of society.[14] Studies have shown what they describe as the intrinsic linkage between poverty, disability and the discrimination faced by PWDs.[15] It is indicated that poverty and disability are in fact closely interwoven; so much so that poverty can be considered as both the cause and consequence of disability. According to the World Bank, one in five of the world's poorest persons has some form of disability; and the United Nations suggests that 82 percent of PWDs in developing countries live below the absolute poverty line threshold.[15 (p.4)] These figures become evident particularly when we look at the situation in Ethiopia - one of the poorest nations in the world[16] where the interrelated nature of disability and poverty can be noticeably observed, as we shall see later in this study.

There are a few national legal and policy documents which provided their respective definitions for the term 'disability' in the Ethiopian context. The earliest definition was incorporated in what was known as *the Rehabilitation Agency for the Disabled Order No. 70/1971*, declared during the imperial regime of Emperor Haile Selassie I. This document has since been repealed by subsequent laws. Order No. 70/71 stated:

> Disabled people... are people who, because of limitations of normal, physical or mental health, are unable to earn their livelihood and do not have anyone to support them; including any persons [sic] who are unable to earn their livelihood because they are too young or too old.[17]

Another document that provides the definition of disability in Ethiopia is a recently enacted proclamation dwelling on the employment situation of PWDs, and is known as *the Right to Employment of Persons with Disability Proclamation No. 568/2008*. Per this Proclamation:

> A person with disability is an individual whose equal employment opportunity is reduced as a result of his physical, mental or sensory impairments in relation with social, economic and cultural discriminations.[18]

The absence of up-to-date statistical evidence on disability issues in Ethiopia makes it difficult to state specific figures that demonstrate the vicious cycle of relationships between poverty and disability prevalent in the country. What may be considered as the latest relatively comprehensive statistical data available in this regard is the nationwide disability-specific survey commissioned in 2002 by the Japan International Cooperation Agency (JICA), according to which PWDs constitute 7.6 percent of the Ethiopian population.[19] Even this survey, however, was primarily based on the limited census input provided by the National Population and Housing Census conducted in 1994 which bears little credible data on disability. Some of the major factors that have curtailed the availability of reliable disability-specific information in Ethiopia include: inadequate definitions of disability and PWDs, confusion or misconception of terms, omission of different disability groups and the unwillingness of families, due to cultural reasons, to disclose their members who have a disability.[20] We will delve further into this issue in subsequent chapters of the study.

Likewise, attempts to ensure the involvement of PWDs in socio-economic and political endeavours of the country have been minimal. Of course, the current Ethiopian Constitution, promulgated in 1995, is said to be the first Constitution ever to mention the word 'disability' in one of its provisions: Article 41 of the Constitution of the Federal Democratic Republic of Ethiopia (1995) reads: *"… the State shall, within its available means, allocate resources to provide rehabilitation and assistance to the physically and mentally disabled."* [21(p. 99)] It can also be said that the recognition, accorded to disability matters by the government and other pertinent stakeholders in Ethiopia, has improved over the past few years. Nonetheless, the continued exclusion of PWDs, coupled with entrenched erroneous attitudes towards disability, has thus far constrained the disability sector generally as well as in its contribution to the development and poverty reduction initiatives of the country.

The motivation that initiated this study is described in the next section.

1.2. Motivation

As a member of the disability community in Ethiopia, and as a person with a disability himself, the researcher has been keenly interested in observing developments occurring in the field of disability, locally, regionally and globally. He notices that although Ethiopia is said to be undergoing a major socio-economic transformation, equally evident is the fact that PWDs (close to 10 percent of the total population of the nation, as stated above) remained precluded, as national deliberations are being made on different issues that affect the disability community.

This thesis, therefore, emanated from a curiosity to explore research evidence which clarifies the notion of '*Disability Rights Movement (DRM)'* and the current status of the role of the Ethiopian disability movement in the country's ongoing development agenda.

1.3. Statement of the Problem

It is apparent that the impact of the disability movement in Ethiopia on development initiatives of the country has been less than satisfactory when compared with such movements in countries of similar socio-economic status as Ethiopia. Consequently,

PWDs and DPOs have hardly been taken into account, in either the planning or implementations of national development policies, such as PRSPs. There is, therefore, a need to study the disability movement in Ethiopia and its role in the socio-economic development of the country, thereby highlighting existing gaps and indicating how these gaps can/should be filled.

1.4. Aim of the Study

The aim of this study was to investigate the efforts being exerted by the Disability Rights Movement in Ethiopia to ensure the recognition of disability and PWDs in national socio-economic endeavours. The study also explored the major causes and determinants that affected the role of DPOs in the Ethiopian development agenda, including the PRSPs.

1.5. The Research Questions

The following are the research questions:

1. What constitutes a 'Disability Rights Movement' (DRM)?
2. What roles have DPOs in Ethiopia played so far in terms of realizing the effective inclusion of disability in the country's socio-economic programmes, most importantly in the PRSPs?
3. What factors have facilitated and/or hindered the involvement of DPOs in the Ethiopian development agenda?

1.6. Objectives of the Study

The objectives of the study are:

1. To describe DRMs and investigate their roles.
2. To explore the involvement of DRMs/DPOs in the Ethiopian development initiatives, specifically in the PRSP process.

3. To elucidate factors that facilitated and/or hindered the DRM/DPO activities in Ethiopia, with a particular emphasis on: *(1) the opportunities; (2) challenges* and *(3) the way forward*.

1.7. Significance of the Study

The caveat asserting the need for the inclusion of disability in socio-economic development endeavours, such as PRSPs and the Millennium Development Goals (MDGs), is resonating in all the pertinent international, regional and national forums. This scenario has been encouraged further by the declaration of the UN Convention on the Rights of People with Disabilities (CRPD) in 2007. As mentioned in the preceding sections, many African countries are also making promising attempts to work in tandem with these developments. Nevertheless, the progress seen in Ethiopia in this respect is still far from satisfactory. One of the most important perspectives, from which to analyze this situation, is to study the roles and participation of PWDs and the DRM in the overall development agenda of the country, with a particular emphasis on PRSPs. It would appear that no detailed research of this sort has been conducted previously in Ethiopia. Accordingly, such a research undertaking is expected to be of paramount importance, especially as Ethiopia is currently engaged in revising and launching its latest PRSP regime for the next five years.

1.8. Outline of Chapters

This section summarizes the overall content and structure of the thesis.

This thesis is composed of 6 chapters. Chapter 1 is the introductory part where the background of the study is explained, together with the aims, objectives and motivation of the study. Certain research questions are also raised here.

Chapter 2 contains a detailed literature review, focused on the concept and philosophy of the notion of DRM, its history and emergence, as well as the evolution of the Ethiopian disability movement. The PRSP process and the recognition accorded to

disability issues in this process are also reviewed in this Chapter, including the relevant experiences of a few African countries from which some lessons may be learned.

Chapter 3 explains the methods applied in conducting the study. The research setting, study sample, techniques of data collection and analysis, the number and representation of the participants of the study are all outlined in this Chapter.

Chapter 4 presents the findings of the study based on the stated objectives. It outlines the main themes and sub-themes that emerged from the study with a core focus on the disability movement in Ethiopia. The attention so far conferred to disability matters in the Ethiopian development initiatives, principally in the PRSP process, is also covered in this chapter.

Chapter 5 discusses the findings of the study presented in the previous chapter. The discussion accentuates the main themes that emerged from the study. Due emphasis is placed on issues like the perceived elements of a disability movement and factors that have restricted the participation of PWDs and DPOs in discussions concerning development in Ethiopia. Existing opportunities and challenges are also discussed here.

Chapter 6 concludes the study and makes some recommendations, based on the findings of the study. The recommendations are targeted at indicating the measures needed to redress existing weaknesses and gaps, as well as consolidating strengths identified, based on the objectives of the study.

CHAPTER TWO

2. LITERATURE REVIEW

2.1. Introduction

This Chapter contains literature that has been reviewed under the following sub-topics: the history and emergence of DRMs/DPOs; DRMs in Ethiopia; PRSPs in Ethiopia; and the involvement of DPOs in the Ethiopian PRSP Consultative Forums. The chapter then concludes with a brief summary.

2.2. The Concept, History and Emergence of the DRM

Before exploring the perceived and actual role of DRMs/DPOs in advancing the development interests of PWDs, it is relevant to discuss the notion and philosophies underlying the 'Disability Rights Movement', together with an account of its history and emergence as a social/civil rights movement in the international, regional and national arena.

2.2.1. The Concept

Though there exists no universally agreed definition for the term 'movement', it is generally described as "the organization or gathering of people around a certain issue or set of issues; or around a set of shared concerns and common interest".[3 (p.21)]

Literature shows that there is a detailed conceptual and philosophical framework that allows a certain movement to be considered a *Disability Rights Movement (DRM)* as such; although the extent to which this conceptual framework is understood and applied might differ from country to country, due to obvious differences in socio-economic and political circumstances. The basic concepts and philosophies of the DRM to be seen in this chapter are, therefore, applicable to any given movement that aspires to be a DRM, properly so called.

First of all, it is believed that a DRM should necessarily entail the following three peculiar phases in its evolvement as a social or civil movement: [22]

Phase One: Providing a clear definition of the problem that the movement seeks to address, including the very sources causing the identified problem.

Phase Two: Offering the solutions; this usually aims at the enactment of appropriate policies, laws and strategies that the movement considers vital to redress the problems and their sources that it has clearly identified.

Phase Three: On condition that the policy and legal changes deemed necessary in the second phase have come into effect, the third phase ensues in order to deal with any aftermath – remnant problems - that may continue to exist despite the legal and policy changes. This also includes addressing some new problems that may arise out of the very solutions introduced.

Since the overall essence of DRM is encompassed in these three important phases outlined above, it is important to dwell on the specifics of each of these phases, which is what the following sections will do.

A) Identifying the Problem and Its Sources

Proponents of the DRM explain that the identification, definition and clarification of the problem(s) that a movement intends to challenge, together with the solutions that it offers, make up the cornerstone of a disability movement in any given society.[22 (p.138)] A movement that calls for a solution to a certain socio-economic and perhaps political problem should initially develop an understanding of the problem and its sources; and this involves defining the problem by explaining both what the movement deems wrong, and what it considers the origin of that problem.[23] With this stance, the movement has identified the problems that PWDs and their organizations worldwide seek to eliminate, or at least alleviate, despite the contextual differences between countries/societies. Many argue that the aggregate effect of the problems that PWDs routinely grapple with can generally be referred to as '*oppressive marginalization'*.[24] It is, therefore, to offer solutions to this menace called *oppressive marginalization* that a DRM had come to the

fore in the first place.[22 (p.150)] However, the process of identifying the problem does not stop there – in just naming the problem. Instead, it goes further into explicating this problem by making important distinctions between some key, often misinterpreted and confused, notions constituting the problem; these notions are, 'marginalization and stigmatization', on the one hand, and 'disability and impairment', on the other.[22 (p.140)] Making these distinctions clear would also clarify what exactly a disability movement should be targeted at.

Stigmatization, says the DRM, refers to a process whereby an individual happens to be viewed as having an attribute that is deeply discrediting; hence those who have dealings with him/her fail to accord him/her the respect that they are otherwise supposed to extend.[22 (p.140)] Whereas, *marginalization* is a process whereby one is kept outside, "on the margins of", activities in the mainstream of one's society;[22 (p.142)] or, as some references say "it is a process which denies one's citizenship and access to resources, education, employment, housing and other areas of life, including one's autonomy over one's life".[25 (p.115); 26] On the basis of these definitions, the fundamental difference between the two notions may be summarized as follows. Stigmatization generally occurs *in the realm of the inner, private circles of the individual, involving interpersonal encounters such as with family, friends or informal groups where the interaction is typically spontaneous, informal and personal*.[26] Marginalization, though, is said to generally occur *in the realm of secondary groups, in which interactions tend to be formal, impersonal and non-spontaneous*; thus, it generally refers to one's relationship to the economy and policy of one's own society.[26] With this clear distinction in mind, the DRM philosophy then underlines that, while it would prefer to see a society where PWDs are neither stigmatized nor marginalized, its *focal concern* is geared towards eliminating *marginalization*, which refers to a person's engagement with the society, the polity and its establishments at large.[22] Consequently, the concept of stigmatization and its focus on primary or inter-personal relations, instead of economic and political rights, does not fall within a DRM's ambit.

Similarly, the distinction between 'disability' and 'impairment' has for long been one of the terminology issues argued among the different stakeholders both within and outside

the disability sector.[27] What is accepted in the DRM as the *accurate distinction* between these terms was illustrated as follows, based on a study once conducted in the United States:

> The distinction between 'impairment' and 'disability' is made very clear in the classic study of the place of deaf people in the mainstream of the towns of West Tisbury and Chilmark, Massachusetts, where there were many people who were congenitally deaf. However, since everyone in these towns spoke sign language, they were not actually 'disabled'; meaning, they were not excluded from the mainstream of social activities in their respective towns. Conversely, it was also noted that left-handedness may be a disability where basic utilities such as door handles, banisters, guard rails or even a computer mouse are designed solely for right-handed people. However, the latter is not an impairment since no limb, organ or mechanism of the body is lacking. Societal attitudes too come into play in this differentiation between 'disability' and 'impairment'. Left-handed people, for example, were once exposed to exclusion; in fact, the term 'sinister' derives from the Latin term translating as "on the left hand", and teachers used to do their utmost to encourage, even require, left-handed students to write with their right hand. Poor eye sight and the consequent use of corrective lenses is another case in point. Spectacles are now a necessary aid for many with a visual impairment; but they have been so 'normalized' that wearing glasses or contact lenses is no longer regarded as a mark of a disabled person.[22 (p.140)]

So, it follows from the foregoing exemplified explanation that *disability* refers to a social condition, disadvantage or restriction of activity caused by a certain *social milieu*, resulting in the exclusion of PWDs from participating in the mainstream of social activities. Whereas, *impairment* is a *physical or biological condition* in which all or parts of the limb, organ or mechanism of the body such as sensory or cognitive functions are lacking.[27] Thus, it is asserted that the focus of a DRM should rest on the notion of *disability* rather than impairment.

Having clarified these key conceptual frameworks as such, it can be deduced that a DRM is, in principle, mainly targeted at the elimination of the marginalization, and subsequent oppression, of PWDs by disabling societal attitudes.[28 (p.2)] As for *the source* of this problem, the DRM philosophy states that the *oppressive marginalization* of

PWDs in any given society is rooted in one or the joint effects of the following three factors: [22]

1. *Societal prejudices and/or misconceptions;*
2. *Presumably positive intentions in the minds of people without disability as they manifest in their interactions with PWDs; and*
3. *The dominant or hegemonic ideas and practices commonly regarded as 'acceptable' within the non-disabled majority.*

The first two of these *root causes* are indeed self-explanatory; so we will not delve much into those. Succinctly, though, it can be said that *societal misconceptions* towards PWDs may differ from society to society; examples of such misconceptions existing in Ethiopia are provided in the next section which talks about the disability movement in Ethiopia. The second root cause (i.e., *positive intentions of people without disabilities*) may also amount to becoming a source of oppressive marginalization in some cases. We have plenty of examples demonstrating this fact; the caveat in this case is that PWDs should always be asked what sort of help they need, prior to extending any backing, even when the intentions behind the help are absolutely positive. The third source, *dominant or hegemonic ideas and practices*, is what some disability activists refer to as 'plausibility structures', as explained in the quote below:

> A *'plausibility structure'* is one that provides for an unobtrusive control of the premises upon which decisions are rendered plausible and, thus, acceptable. That is, the dominant ideas and practices, or the plausibility structure, by virtue of its control over the definition of the situation of persons with disabilities, enables otherwise decent people to adopt policies and programs which they regard as reasonable, plausible, but, which the movement views as a major source of the oppressive marginalization of persons with disabilities.[29]

Based on the foregoing descriptions of the *sources of oppressive marginalization*, one may conclude that: the oppression of PWDs does not always derive from a 'backward' set of traditional views of the so called 'uneducated' society; rather, it stems mainly from

the dominant and supposedly 'reasonable approach' which, although often well-intended, in effect marginalizes PWDs. An anecdotal example once given by a well known writer with disability concerning his personal experiences about the idea of 'rehabilitation', a practice often regarded as 'reasonable and plausible', helps us understand the *dominant sources of oppression* even better:

> The implicit message that I received in 'rehabilitation' was that I was deficient and abnormal and in order to become a 'valued' person I would have to overcome my disability. I thus became increasingly determined to conquer my disability and this, in turn, led to what I would describe as 'declaring war on my own body'. Rehabilitation, I believe, is inextricably linked with oppression and a direct result of our social and cultural commitment to 'normalcy' as a kind of 'perfection' where normal standards of ability, appearance, and behavior are the criteria for what is allowable: if you don't measure up you are inferior.[30]

These are, therefore, *the problem* and *its sources*, per the conceptual underpinnings of the DRM. As explained above, once the first phase of exploring and clarifying the problem is done, the next phase follows: *proposing the solution.*

B) The Solution

The DRM-proposed antidotes to the core problem diagnosed as *oppressive marginalization* adhere to a three-pronged approach[22 (p.144)], each pertaining to:

1. *Change of ideology;*
2. *Causing policy and legislative modifications and enactments in favor of the disability cause; and,*
3. *Realizing the creation of disability-based advocacy organizations; DPOs and NGOs alike.*

Obviously, *ideological transformation* tops this list of prescriptions. It basically consists of a demand by the DRM for the replacement of pre-existing disability misconceptions in a nation, including *dominant or hegemonic views*, with one that the movement amplifies

as acceptable. A typical example of this is the quest to change the 'medical' and 'charity' models of disability with the 'social' or 'human rights' models. Proponents of DRM argue that the consideration of PWDs as objects of charity (otherwise known as the c*harity model* of disability) infringes upon the inherent human rights and productive value of PWDs.[31] Equally, defining disability from a purely medical and physiological perspective (which is known as the *medical model* of disability) leads to a mistaken understanding of disability as nothing more than the physical impairment of a person.[31] As said in describing the problem and its sources, the DRM outlook claims that disability is the social outcome of a physical or mental impairment, more than it is anything else; this is also called the *social* and *rights-based model* of disability.[24]

Policy and legislative modifications and/or *enactments of new ones* refer to creating the legal/policy platforms that can redress the grievances identified by the movement and legitimize the solutions that it supports.[30] In the absence of these public policy and legal tools, says the DRM, PWDs would continue to be subject to a systematic oppressive marginalization.

The *creation of pro-disability organizations and associations*, including NGOs, CSO and CBOs, is another fundamental element of the three-pronged solution package. This solution is predicated on the assertion that PWDs should be given the latitude to create organizations of their own by which they can be held responsible whether these organizations succeed or fail.[22 (p.144)] Hence, it is yet another reminder of the quest for independence and autonomy.

C) The Aftermath: Post-change Issues

More often than not, a DRM has to deal with certain issues that may prevail after the core problem and solutions are disclosed and implemented as stated in the foregoing sections. Such *post-change* issues could be either new problems emanating from the changes caused by the movement; or they could just be remnants of the old and replaced system.[22 (p.130)] For this reason, a DRM should inevitably pass through a third phase of addressing the *aftermath of a change*.[22 (p138)] An example constituting this phase is the lack of enforceability of policies and laws, which is particularly evident in

countries like Ethiopia where implementation of polices is a major challenge as we shall see in depth later. Other main issues to be addressed in this phase include: [29]

- The *quality* of the opportunities provided for PWDs;
- *Beneficence* (to what extent do PWDs actually benefit from the changes effected); and
- *Efficiency* of the enacted legal and policy framework, as well as that of the whole system.

One of the outcomes of a DRM-brought change could be a rise in the consciousness of PWDs themselves.[29 (p.119)] It is asserted that such a change, while it is a desired outcome, might produce its own ramifications which the third phase being discussed here is supposed to tackle. Raised consciousness, it is argued, may in time be transformed into an *empowered consciousness*, which is defined as "acting together to empower others and an insistence on active, collective control over the necessities of life: housing, school, personal and family relationships, respect, independence and so on".[29 (p.119)] This situation, in turn, engenders pride, instead of shame, on the part of PWDs as to who and what they are. Nonetheless, as desirable and constructive as such a development is, it may also result in a phenomenon of resistance in which all attempts to eliminate the impairment happen to be forthrightly rejected by PWDs.[32] The cumulative effects of such an evolution are summarized as follows:

> One result of a raised consciousness, and the subsequent pride, is the development of a positive self-identity embracing all aspects of one's self, impaired and unimpaired alike. In other words, rather than viewing impairment as a deficit, people with impairments would view their respective impairment as part of a whole, complete self. On the other hand, however, such pride may, as with any pride, merely precede a fall, or at least, what people would take to be a fall. For example, some people who are deaf refuse cochlear implants. Many reject the operation because it suggests that 'deafness is pathology, something to be corrected or eliminated'. For those who accept deafness as 'part of a whole, complete self', such an operation is not necessary. In fact, an association of the deaf had once recommended that there be a ban on cochlear implants in children 'so they could grow up and

> decide to choose a deaf identity or a hearing one'. This might well seem either odd or incomprehensible.[32]

All in all, it is in the light of the foregoing philosophical background that the DRM notion evolved. It is against these essential features that the completeness or otherwise of a DRM in a given society should be assessed. As said at the beginning of this chapter, it is evident that the substance and tenacity of a movement may differ from country to country; largely depending on how well-acquainted the movement is with the key components detailed above. Furthermore, a movement may also be categorized as emergent or mature based on how organized, impactful and influential it is in a society.[28 (p.19)] An emergent movement is supposed to gradually develop into a mature one, though the pace at which this transition occurs may indeed vary from society to society.

Even if it is admitted that DRMs in different parts of the world encounter different types of challenges, it is worth noting that there are also certain *shared difficulties* which disability movements have triumphantly surmounted regardless of where they are located; North or South, East or West. The following quote concisely summarizes this phenomenon describing the shared challenges that DRMs pass through, which also set an example for similar movements that are either emerging or struggling to survive elsewhere.

> By any standards, this growth [of the DRM] was remarkable, but there are four reasons why it was even more remarkable than [it] appears at first sight. First, all organizations controlled by disabled people suffered from chronic under-funding throughout the decade, even from national and international agencies which are supposed to support such developments. Second, many politicians, policy makers and professionals had no faith in the viability of a new movement which was being built by people who had so far seemed passive and dependent. Third, the new movement was built in the teeth of opposition from the traditional voluntary organizations which, up to now, had been in control of disability; and this opposition was often active rather than passive. Finally, because of the disabling environments that disabled people encounter, the difficulties involved in simply finding ways to meet, communicate and organize should not be underestimated.[28 (p.20)]

Due to the fact that a DRM sets out to confront and change an entrenched socio-economic and political stratum that stands against PWDs, some proponents of the movement, notably Tom Shakespeare, refer to it as a "liberation movement".[3 (p.21)] In fact, that is essentially what it is, as can be understood from the details provided above.

2.2.2. History and Emergence

Records show that the words and acronyms *Disability Rights Movements (DRMs)* and *Disabled People's Organization (DPO)* came to gain international prominence especially at the beginning of the 1980s; with the historic advent of Disabled Peoples' International (DPI) as an entity echoing the disability cause globally.[3 (p.22)] This situation had resulted in an unprecedented boom in the creation of national organizations of PWDs worldwide. In fact, the 1980s are regarded by most disability rights activists throughout the world as a decisive decade that saw the beginning of a meaningful recognition of disability on the international, regional and national fora as a multi-faceted issue in its own right.[4]

This, however, does not mean that there never were any initiatives in different corners of the world prior to the 1980s. Since disability is a matter of recurring existence in any given society, organizations claiming to 'represent' and 'safeguard' PWDs did exist as far back as the 1890s.[4 (p.5)] It was also prior to the onset of DPI that the United Nations had ostensibly begun recognizing the issue of disability and proclaimed the *UN Declaration on the Rights of Disabled People* in 1975; followed by the declaration of the *International Year of Disabled People (IYDP)* in 1980.[4 (p.2)] In addition, there was an international organization called *Rehabilitation International (RI)*, another predecessor of DPI, recognized by the UN as an advocate of the disability cause internationally.

Yet, all these international initiatives, in which sizeable operating resources were invested, lacked some crucial components that, in current levels of understanding about disability, make an initiative a *movement* legitimately standing *for* and *with* PWDs. Firstly, almost all of the aforementioned establishments were based on the premises of the *medicalization* and *individualization* of disability; asserting that disability is all about

the impairment of the individual, nothing more and nothing less. This position espoused that *rehabilitation* and, in some cases, *cure* of the impairment are the only solutions to the problem; that disability and PWDs should be considered only in terms of *special services* and *special provisions*, as *special people, the vulnerable* and *the other*. These views were also espoused in what was called the *International Classification of Impairments, Disabilities, and Handicaps (ICIDH)* which was created in 1980 by the World Health Organization supposedly to provide a unifying framework for the definition and classification of disability.[33]

Moreover, in cases of the few organizations that were established by PWDs themselves prior to DPI, there used to be an exclusive focus on certain specific types of disabilities, precluding all other disabilities not falling within the specified categories.[4] In other words, there was a predominant tendency to be *uni-disability (single-disability)* entities, as opposed to being *multi-disability* or *cross-disability* representatives.

Encouraged by various successful civil rights movements of the 20th Century, such as Feminism and those based on anti-racism ideals, proponents of the Disability Rights Movement had gradually begun to manifest a resonating voice criticizing the traditional state of affairs mentioned above. Actually, it was in resistance to the inadequate representation of PWDs during the Rehabilitation International World Congress of 1980, held in Winnipeg, Canada, that the very idea of launching DPI, together with its famous slogan '*Nothing About Us Without Us'*, was incepted.[4] Opponents of this RI Congress in Winnipeg, involving only a few resolute disability activists representing nearly all parts of the globe, formulated two important decisions that may be considered as cornerstones for subsequent developments seen in disability movements worldwide. These decisions were: [4 (p.3)]

1. Setting up an international body of PWDs upholding the tenets of *human rights*, *equalization of opportunities*, *independent living* and *cross-disability representation*; a move that incited a visible digression from the previous traditional trends that perpetuated the charity-oriented, purely medicalized and individualized approaches to disability.

2. Charging the then few disability activists throughout the world with the responsibility of planting national disability organizations in their respective countries and regions.

Shortly afterwards, numerous DPOs were established in all corners of the world, though to a varying strength and scope of growth, with a grip on the notion of a rights-based approach to disability. In 1981, DPI was officially established at an international Conference held in Singapore, with its members comprised of country-specific National Assemblies called Disabled People's Organizations (DPOs) which, at present, represent about 120 countries.[4 (p.5);]

The past three decades have seen the progress of DRM as one of the emerging contemporary civil rights movements globally. The rights-based outlook to disability has gained recognition at all the relevant fora propelling the disability cause internationally, regionally and nationally. Immediately following the establishment of DPI, the United Nations had declared at least two important documents rendering full recognition to the newly emerged approaches to disability.[34] These documents included: the 1983 *World Programme of Action on Disability*; and the 1993 *UN Standard Rules on the Equalization of Opportunities for PWDs*. Both of these documents were in fact non-binding; in addition, they were often criticized for not being comprehensive enough in some respects. For example, the Standard Rules make no mention of children with disabilities. However, it cannot be denied that these international documents had their respective supportive roles in the struggle against erroneous and stereotypical attitudes towards disability. As a result, we have now witnessed the promulgation of the first binding disability-specific international Convention – *the United Nations Convention on the Rights of PWDs* (CRPD), which is also known to be the first human rights convention of the 21st Century.[35] What about the progress of the disability movements in Africa, in particular?

Briefly, it can be said that Africa has not been immune to the sea-changes that the international DRM has seen over the past two decades. In fact, some African disability activists had a notable role in the initiation and establishment of DPI.[4 (p.3)] At present, we

have various DPOs functioning actively throughout the Continent, including Continental DPOs such as the Pan-African Federation of the Disabled (PAFOD) and its regional wings representing Eastern, Southern and Western Africa. These continental and regional congregations have been of help in terms of bringing about the desired attitudinal changes about disability in Africa, and creating a communication channel amongst national DPOs. In some countries, we are witnessing a progress that has reached the level of setting up specific government ministries (e.g., Malawi and Uganda) and parliamentary seats (e.g. Tanzania, Zambia and South Africa) reserved for PWDs; as well as the consolidation of *Independent Living (IL)* principles.[4] [(p.4)] Furthermore, the declaration and enactment, in 1999, of the African Decade for Persons with Disabilities, and the subsequent establishment of the Secretariat of the African Decade for People with Disabilities (SADPD) is also another milestone development in this regard. The Decade has a continent-wide remit, from the African Union, to implement the Continental Plan of Action, which arose from the Pan-African Conference on the African Decade of Persons with Disabilities held in 2002.[4]

The evolution and current status of the DRM in Ethiopia is detailed in the next section.

2.3. Disability Rights Movements in Ethiopia

There have, since time immemorial, been prevalent cultural beliefs in Ethiopia portraying disability as a direct consequence of curses, witchcraft and bad omens. Persons with disabilities have for a long time been viewed as *sub-humans*, devoid of rights, equality and dignity.[36] Several examples can be mentioned to illustrate this reality; but we can state a few explanatory instances. The way PWDs are described in nearly all of the major legislations and codes governing the country, such as the *Civil Code*, *Penal Code* and *Commercial Code*, is dehumanizing of this group. Most of these legislations were promulgated in the 1960s, and still exist without any modifications to the terminologies they employ in describing PWDs.[36] For example, both the English and Amharic (which is the Ethiopian national language) versions of the Civil Code of Ethiopia use terms such as ‘insane person’ and the ‘feeble minded’ to refer to people with intellectual impairments; ‘cripples’, to refer to persons with physical impairments;

and ‘infirm person’ for people with sensory impairments.[36] To date, some of these expressions are being used as they are without any replacement by presently acceptable disability-friendly terms.

It was in 1971, during the imperial regime of Emperor Haile Sellasie, that the first national policy document dealing with issues of disability came to the fore, with the enactment of an Imperial Order called the *Rehabilitation Agency for the Disabled Order No. 70/71*. Through this Order, the Emperor had established an autonomous entity called *the Rehabilitation Agency for the Disabled* which functioned on the basis of charity-focused and medical rehabilitation models of thinking that were prevalent worldwide at the time. It must be pointed out that although this move could be considered as a breakthrough for disability-focused activities in Ethiopia, the initiative was entirely a government-driven one; it was not influenced by any disability movement as such which did not exist in the country at that time. It was only after the enactment of this piece of legislation that some PWDs, particularly a few blind people who were close to the Emperor, had begun gathering together and forming a group supported by the government and allied with the International Federation of the Blind.[37] This group was later re-established as the *Ethiopian National Association of the Blind (ENAB)* – the first official disability association in Ethiopia.[38]

Order 70/71 and the Rehabilitation Agency were both repealed after only three years due to the overthrow of the imperial regime by a military junta in 1974. No measurable improvements were observed in the disability sector during the military regime (1974-1991).[37] The emergence of a proper disability movement began to be seen in Ethiopia in the early 1990s. As a corollary to the various international and regional disability movements of the 1980s and 1990s, some clusters of DPOs, mainly characterized by a single-disability representation, started to appear in Ethiopia as well. It was also during this timeframe that disability happened to be mentioned, for the first time, in the Constitution of the Federal Democratic Republic of Ethiopia in 1995.[21] This, in turn, gave rise to the formation of other DPOs; as indicated in the next section.

2.3.1. Formation and Representation of DPOs

The formation of one DPO saw the need for the birth of many others, which created a need for a mother body. Thus, the *Federation of Ethiopian National Associations for Persons with Disabilities (FENAPD)*, formerly known as the Ethiopian Federation of Persons with Disabilities (EFPD), became the official umbrella organization of DPOs in Ethiopia.[38] About six major disability-focused national associations had initially formed FENAPD; these were:

- *The Ethiopian National Association for the Blind (ENAB), established in 1960;*
- *The Ethiopian National Association for the Deaf, (ENAD), founded in 1970;*
- *The Ethiopian National Association for the Physically Handicapped (ENAPH);*
- *The Ethiopian National Association for People Affected by Leprosy (ENAPAL)*
- *The Ethiopian National Association on Intellectual Disabilities (ENAID);*
- *And the Ethiopian National Association for the Deaf Blind (ENADB).*

As mentioned above, the establishment of ENAB and ENAD by far precedes all the other DPOs in Ethiopia; most of the member associations of FENAPD were founded only after 1993 following the political regime change in Ethiopia which saw the departure of the socialist-military rule in 1991.

However, even though FENAPD is said to be functioning as a *cross-disability* umbrella organization of DPOs in Ethiopia[38], there are claims that more than 17 organizations officially operating in the country as DPOs have not been included within the FENAPD structure. This scenario stems primarily from the very nature of the FENAPD constitutional document (Memorandum of Association) which allows only *single-disability* organizations to be the regular members of the umbrella Federation.[39] Consequently, actively functioning national multi-disability associations, such as the Ethiopian Women with Disabilities National Association (EWDNA), were included in the Federation only as *associate members* devoid of the right to cast their votes on decisions of the Federation. Similarly, all other organizations and associations that have a *multi-disability* representation are not permitted to be regular constitutive members of FENAPD.[39] Many of these DPOs have presently formed yet another syndicate known

as the *Ethiopian National Disability Action Network (ENDAN)* which allows membership to all and any organization working on the disability cause, irrespective of the type and nature of the organization requesting membership.[40] Hence, there are apparently two consortiums of DPOs presently functioning in Ethiopia.

It was explained earlier in this chapter that such a *uni-disability* oriented approach, like that adopted in FENAPD, was in fact exercised within the international arena as well during the establishment of organizations such as the World Blind Union as far back as the 19th Century[6] (*also see Section 2.2.2: History and Emergence*). Nevertheless, contemporary disability movements worldwide have gradually categorized this approach as an *exclusionary and divisive* trend in the disability movement, especially since the movement demands nothing short of a unified action to curb the limitless injustices against PWDs.[41]

On the side of the government, the office currently responsible for addressing disability-related matters in Ethiopia is known as the *Department of Rehabilitation and the Elderly* – a small bureau running under the auspices of the Federal Ministry of Labour and Social Affairs (MoLSA). Two official policy documents pertaining to disability have been issued by this office since its establishment; and these are:

1. *The 'Developmental Social Welfare Policy' (released in 1997); and,*
2. *The 'National Programme of Action for the Rehabilitation of Persons with Disabilities' (1999).*

An analysis of the contents of these documents unravels the underpinning views on which they were founded. On the one hand, both documents address disability solely from a rehabilitation, social welfare and charity-oriented perspective, which render these policy papers obsolete in light of the aforementioned contemporary approaches to disability.[42]

Furthermore, there is no evidence showing that the preparation of these policies was complemented by the tangible contributions of PWDs and DPOs, none of which were sufficiently consulted by the Ministry during the policy formulation process.[37]

Have things, however, changed in this respect, since the advent of Poverty Reduction Strategy Papers (PRSPs) as globally recognized tools of poverty alleviation in the so called low income countries, including Ethiopia? Carrying out nationwide, broad-based and pro-poor consultations is said to be the foundation block of forming PRSPs in any country.[43 (p.2)] Hence, one may logically anticipate to see the active participation of PWDs, a community often considered as the 'poorest of the poor', in the process of forming PRSPs. Has this been the case in Ethiopia? When did Ethiopia subscribe to the PRSP approach and how has it implemented this approach so far? What is the PRSP? Answers to these relevant questions are provided in the following sections.

2.4. PRSPs in Ethiopia

Ethiopia started the process of formulating PRSPs almost immediately after the decision by the International Monetary Fund (IMF) and the World Bank that countries wishing to secure loans and debt relief privileges must, as a prerequisite, produce and implement poverty reduction strategies or PRSPs.[44] Accordingly, an "extensive, comprehensive and highly participatory course of action" was officially launched by the government of Ethiopia in the year 2000 to formulate the country's first PRSP.[45 (p.2)]

The Ethiopian PRSP process has, to date, journeyed through three consecutive and complementary phases. The first PRSP, launched in 2001/02, was known as the *Sustainable Development and Poverty Reduction Strategy Paper (SDPRP)*. The second one is known as the *Plan of Action for Sustainable Development to End Poverty (PASDEP)*, introduced for a five-year period of 2005 to 2010. The third PRSP, called the *Growth and Transformation Plan (GTP),* is presently undergoing a process of revision and official launching.

The government organ leading the overall PRSP process in Ethiopia is the *Federal Ministry of Finance and Economic Development (MoFED)*.[45] This Office carries out its supervisory role by way of forming specifically designated sub-committees at Federal, Regional and *Woreda*/District levels, running under the auspices of MoFED. The sub-

committees, corresponding respectively to both the Federal and Regional administrative levels are:

- *The PRSP Steering Committee,*
- *The Technical Committee, and*
- *The PRSP Secretariat*

According to the guidelines provided by the World Bank, which is where the PRSP notion originated from, the fundamental stages of a PRSP formulation process are as illustrated in *Figure 2* below:

Fig. 2: Stages in the PRSP Formation Process

Figure 2 demonstrates the standard procedure that should be adhered to in preparing PRSPs. As can be seen, this process involves successive phases of progress which are all required to be fulfilled by the PRSP preparations of any given nation. The process begins with formulating the initial PRSP (usually referred to as the *Interim* PRSP or I-PRSP), the preparation of which should be corroborated by status reports. The input gathered from the I-PRSP would then inform the subsequent *formulation* and *implementation* of the main PRSP document or PRSP I, which again should be corroborated by detailed progress reports. These progress reports are to be disclosed to the general public and to the relevant authorities of the World Bank and the IMF who appraise the documents and determine whether the country qualifies for loans and/or debt relief privileges under the HIPC (Highly Indebted Poor Countries) scheme.[44] The formulation and implementation of one PRSP document takes 3 to 5 years on average.[44] Upon the completion of PRSP I, a review or *monitoring and evaluation* process follows. Then afterwards, a similar process starts all over again to formulate the next PRSP or PRSP II to be followed by PRSP III, PRSP IV and so on.

Nearly all documents providing records of the PRSP process in Ethiopia state that a "broad-based and vibrant public participation at all levels" has been one of the major aspects of the process.[46 (p.3)] Has it, however, really been so in terms of involving PWDs and DPOs in this process? The answer is *'no'* as can be understood from the details in the next section.

2.4.1. Involvement of DPOs

Disability and/or PWDs were not addressed in either of the first two PRSPs which have been effective over the past decade since Ethiopia adopted the PRSP approach. This, in itself, is enough evidence implying that the Ethiopian PRSP consultative process has hardly involved PWDs and their representatives in the preparation of the SDPRP and PASDEP. A review of both of these PRSP documents also reveals that the issue of disability was not given due consideration compared to other matters such as gender, children and the youth.[47; 48]

In situations where disability was said to have been incorporated in the Ethiopian PRSPs, it was alluded to merely in generalized terms such as *vulnerable groups*, *marginalized groups of society*, or *disadvantaged groups* - an approach that undermines the recognition of the specific needs of PWDs.[43 (p.2)] Lately, though, efforts have been made on the part of the disability movement to bring about some changes in this regard. The researcher was informed during this study that FENAPD has presently formed a Task Force, the first of its kind, charged with the responsibility of presenting an evidence-based concept paper to the government requesting the effective inclusion of disability at least in upcoming PRSPs.[49] This Task Force would be composed of representatives of all the member associations of FENAPD, as well as concerned local and international partners such as the International Labour Organization (ILO) and other Civil Society Organizations (CSOs).[49 (p.13)]

In response to these endeavours, the latest and currently under-review PRSP document of Ethiopia – the Growth and Transformation Plan (GTP) - has touched upon some aspects of disability issues under its section dealing with *Social Welfare*.[50] Although the manner disability is addressed in the GTP is *not* as detailed as would have been

preferred and anticipated by the disability movement, this document does manifest a step in the right direction, compared to the previous PRSPs which said nothing about disability. A glimpse at the disability-specific parts of the GTP follows next.

2.4.2. The Growth and Transformation Plan (GTP)

This latest PRSP document, currently being launched (between September and December, 2010) by the Ethiopian government, has in fact alluded to disability only briefly and treats the matter as a *welfare case* alone, instead of a multi-facetted social issue. Nonetheless, the recognition that is now accorded to disability in the Ethiopian PRSP, by virtue of the GTP, should be considered as cornerstone progress paving the way for a more comprehensive disability inclusion in the development endeavours of Ethiopia.

As indicated above, the GTP treats disability and PWDs solely as 'welfare cases' juxtaposed with issues of the elderly in the society.[50 (p.72)] Admittedly, however, the points included in this document do try to adhere to contemporary beliefs about disability; namely, the social and human-rights based outlooks explained earlier in this thesis (*see Section 2.2: The Concept, History and Emergence of the DRM*). A closer look at the relevant paragraphs of the GTP is important to further elaborate where, and how, exactly disability is addressed in the document.

Section 8.3 (Social Welfare section) of the GTP states its main "Strategic Direction" as follows:

> On the course of promoting the economic and social development of the country the social welfare main emphasis lies in protecting rights and facilitating conditions which will enable persons with disability and older people to use their abilities as individuals or in association with others to contribute to the development of society as well as to be self-supporting in the political, economic and social activities of the country…[T]he programs that are implemented for people with disabilities (PWDs) are programs that aim in preventing disability and providing education and training for PWDs and rehabilitating them and have equal access and opportunities as well as by

> providing information about disability and PWD changing the society's attitude towards disability and PWDs positively.[50]

Evidently, it appears that the GTP envisages the active participation and contribution of PWDs, which is something that has not been adequately underlined by other policies so far produced in the country with respect to disability. In stating the principal objectives of this section, the GTP emphasizes the promotion and expansion of social welfare. It says:

> The objective of the sector's plan is … making sure the involvement of all relevant stakeholders in promoting social welfare services in an inclusive manner; identify social welfare problems and take corrective measures, in view of supporting the nation's poverty eradication endeavour to promote activities that will benefit people with disabilities and the elderly.[50]

An outline of implementation strategies is also provided in this section. Of the points jotted down as *mechanisms of implementation*, the following are the ones specifically dealing with disability, as quoted ***directly*** from the document: [50]

- *To expand social welfare services those that are given by the government, the community and NGOs.*
- *To promote PWDs to use their skills on the economic, social and political matters of the country.*
- *To facilitate the implementation of education of children with special needs.*
- *To empower people with disabilities to exercise their right to have equal access and opportunity to be employed.*
- *To put together deliberate effort to prevent hindrances in home and work place, recreational centers, schools, health centers and other places that will limit the mobility of People with disabilities.*
- *To provide physical support materials for the disabled.*
- *To implement and strength rehabilitation, technical and vocational training support and outreach programs for people with disabilities.*
- *To engage and mobilize the community in providing social welfare service.*

- *To conduct research activity regarding social welfare.*
- *To provide education and information services to raise public awareness about disability and people with disabilities.*

These implementation strategies have touched upon several issues that are expected to be included in modern policies pertaining to disability. This list of strategies addresses a range of important issues, such as, the effective integration and empowerment of PWDs, the promotion of equal rights, accessibility and reasonable accommodation, as well as raising the public awareness about disability. It is stated also that the sector will endeavour to boost social welfare services and research regarding welfare; although nothing has been explicitly said on the need and promotion of disability-focused research.

It should be underlined, however, that this document does have certain visible shortcomings. Three elements can be said to be lacking from the GTP, when seen in the light of what a sufficiently disability-inclusive PRSP is supposed to look like:

1. A cross-sectoral inclusion of disability, which is believed to be the most preferred mechanism of disability inclusion in PRSPs, [43] is set aside by the GTP. We do not see disability mentioned in any of the sector-wide plans enumerated and detailed by the document;

2. Similarly, it would have been better if the GTP had not treated disability solely as a 'welfare case', since disability is essentially a multi-faceted socio-economic condition;

3. The specific differences between disability and the issue of the elderly should have been delineated satisfactorily, should the two issues be placed together in the first place.

It must be recalled at this juncture that the *UN Convention on the Rights of Persons with Disabilities (CRPD)*, which Ethiopia has ratified in May 2010, declares the "full and effective participation and inclusion of PWDs in society" as one of its foundational

principles.[51 (p.6)] The Convention demands that State Parties should "closely consult and actively involve PWDs, including children with disabilities, through their representative organizations" in designing and implementing the Convention and in all "other decision-making processes concerning issues relating to PWDs".[51 (p. 6; Art. 4(3))] One of the main pieces of national policy that certainly is of concern to PWDs is the PRSP and decisions related to it, including the implementation of the MDGs which are a part and parcel of the tenets of poverty reduction. Thus, it follows that the full inclusion and effective participation of PWDs and DPOs in the preparation of these documents, from the outset, is not only a fundamental right of PWDs, but it is also the legal duty of the government carrying out these development strategies.

What about the situation in other African countries concerning the inclusion of disability in PRSPs? Are there any lessons that can be learned so as to appraise the relative strengths and weaknesses of the Ethiopian scenario? A brief look at the process and extent of disability inclusion in the PRSPs of a few African countries is provided in the next section.

2.5. Disability Inclusion in the PRSPs of some African Countries

First of all, it should be noted that in looking at the relevant experiences of other countries, one should take due cognizance of the following inevitable variables:

1. Cultural, historical and socio-economic backdrops, in general, may vary for each country;

2. The PRSP approaches and policies too are very country-specific;

3. The competences and capacities of DPOs/DRMs might differ significantly from country to country.

It is with these facts in mind that the researcher has selected a few African countries from East, West and Southern Africa, which, in his opinion, could provide pertinent examples to inform the situation in Ethiopia.

It has been said that the PRSP formation process in any nation comprises three major stages; namely, the *formulation* stage, where a detailed analysis of the poverty of the country is provided; the *implementation* stage, where a broad-based planning and participation of the public and development partners is sought; and the *monitoring and evaluation (M&E)* stage, where M&E units, technical groups and independent evaluators provide detailed progress reports. As a general rule, therefore, ensuring the inclusion of disability in the PRSPs requires that disability issues find their way into each of these phases of the PRSP formation process. Having said that, let's briefly see how the African countries selected in this section have embarked on this matter in their respective contexts.

2.5.1. TANZANIA

The East African nation of Tanzania (mainland and Zanzibar) is reported to have more than three million PWDs, approximately 9 percent of the country's population.[52] According to the latest disability survey from 2008, mainland Tanzania has slightly more PWDs than Zanzibar, and the disability prevalence is said to be higher in the rural areas.[53]

It was mentioned earlier in this study that only a few countries throughout the world have included disability in their interim or first PRSPs. Tanzania was among one of the examples from the African continent in that it had effectively taken lessons from the experiences of the inadequate inclusion of disability in their first PRSPs and fundamentally reversed this situation in their subsequent PRSPs.[54] Records of the DRM in Tanzania show that the movement was a vibrant participant in all the phases of the country's PRSP formulation processes from the very outset, thereby effectively voicing the interests of PWDs in the Tanzanian PRSPs.[49] One of the factors raised as a major initial contributor to this active participation of the Tanzanian disability movement in the PRSP processes was that a leading member of the movement had close connections with officials in charge of the PRSP, and that these officials too were strongly supportive of the idea of disability inclusion in the PRSPs.[49 (p.7)] Another factor was that the donor community in Tanzania exerted its influence with the effect of realizing disability-inclusive PRSPs.[54 (p.2)] Consequently, disability has in fact been significantly included in

the Tanzanian PRSPs with some very specific targets; the National Strategy for Growth and Reduction of Poverty 2005-2010 (also known locally as 'MKUKUTA') expressly recognized disability as the main cause of poverty, a crosscutting issue and a concern considered in all sectors and mentioned in all strategy clusters.[54 (p.3)]

In a bid to increase and broaden the involvement of PWDs in the country's development agenda (in the PRSPs, in particular), the MKUKUTA Disability Network was formed in 2005 embracing the Tanzanian Federation of DPOs (called the SHIVYAWATA), disability NGOs, and key government offices as well; the Network contained 27 member associations and organizations in general.[55] The purpose of this Network was to closely follow-up the implementation of the PRSP.[55 (p.3)] These efforts have not only resulted in a visible and multi-sectoral inclusion of disability in the country's PRSPs, they have also produced tangible results on the ground. For instance, just since 2000, the primary education enrolment of children with disabilities boomed from 0.1 percent in 2000 to 20 percent in 2010.[49 (p.9)] Disability has now become one of the issues that the Tanzanian government recognizes as a vital component of its development agenda and a key contributor in the country's effort to attain the MDGs.[55 (p.1)] Moreover, the disability movement has continued actively engaging in increasing public awareness and the awareness of PWDs about the MKUKUTA (PRSP) and disability inclusion.

Among the challenges facing the Tanzanian disability movement and its efforts with respect to PRSPs is the relatively lower attention given to disability in the PRSP monitoring mechanism.[54 (p.9)] It is expected that this shortcoming will be addressed in the upcoming PRSPs of the country. The need for increased support to DPOs in terms of finances and other resources is also stressed as another challenge.[49 (p.10)]

2.5.2. RWANDA

Although a national census carried out in 2002 has estimated the size of PWDs in Rwanda to be 5 percent of the total population of the country, [56] this number is said to have greatly underestimated the prevalence of disability in this East African nation which has passed through episodes of massive genocide and civil wars in its recent history. Reports show that, as is the case in Ethiopia, poverty reduction efforts in

Rwanda did not initially take disability issues properly into account; the disability movement too had little awareness about the benefits and/or direct impact of PRSP to the disability community.[57]

With the advent, in 2006/07, of its second PRSP document called the Economic Development and Poverty Reduction Strategy (EDPRS), a significant participation of the Rwandan disability movement in the country's PRSP process started to be recorded. The formulation stage of the EDPRS involved the formation of eleven Sector Working Groups (SWGs) composed of local government institutions, District Development Committees, development partners, civil society and the private sector.[57] A special group working on issues categorized as *crosscutting*; namely, gender, HIV/AIDS, environment and 'Social Inclusion' (which involved PWDs, orphans, refugees, the elderly and other vulnerable groups) was also part of the SWG.[57] It was beginning from this formulation phase that a wide range of representatives of PWDs, such as the Rwandan National Decade Steering Committee, the Union of the Blind, the Union of the Deaf, the Association of Physically Disabled and the Parent's Association of Children with Mental Disabilities, were actively and collaboratively involved.[56] There was also a requirement that five disability representatives should be elected in each district as members of the District Development Committees.[49 (p.11)] As it was necessary for the SWG to prioritize the pressing needs that had to be included in the PRSP, DPOs were consulted to provide their list of priorities; hence, education, health and social protection were identified as major priorities by the representatives of PWDs.[49 (p.12)]

The disability movement also took part in designing the logical framework of the EDPRS which enabled the DPOs to contribute in the drafting of the education, health and social protection sector strategies as well as to review and comment on other sector strategies of relevance to PWDs, such as justice, decentralisation and security.[57] Due to the representation and lobbying of DPOs, it is said that the social protection and education sectors have, in particular, included a number of specific targets for PWDs, including special needs education, access to school, vocational training and the Social Fund.[57] Furthermore, the disability movement has been involved in preparing the country's Social Inclusion Checklist to ensure that issues of PWDs are recognised as national

policy issues seeking thorough actions by the different sectors.[56] A number of sectors are reported to have already taken disability issues well into consideration, while some others are yet to do so due to constraints such as funding and human resource deficits.[57]

2.5.3. MALAWI

Located in the Southern Africa region, the Republic of Malawi is one of the only two African countries (the other one being Uganda) that have a specific government ministry established to address disability-related matters. Prior to the establishment, in 1998, of this Ministry (called the Ministry of Social Development and Persons With Disabilities – MSDPWD), disability issues in Malawi, from a governmental point of view, were mostly taken care of by the Ministry of Health (MoH), Ministry of Community Services (MCS) and other ministries.[58] Malawi has a total population of about 13 million, of whom 4 percent are PWDs, according to The Malawi Population and Housing Census of 2008.[59]

Endeavours to ensure the recognition of PWDs in Malawi's development initiatives are spearheaded by the Ministry of Social Development and Persons with Disabilities, together with the Federation of Disability Organizations in Malawi (FEDOMA), which is the umbrella DPO in Malawi, and the Council for Non Governmental Organizations (CONGOMA).[60] The Ministry is vested with the power to oversee the implementation and mainstreaming of disability in policy and development programmes in all other government ministries.[49 (p.19)] Although the country's PRSP did not address disability issues at first, subsequent PRSPs have indeed included disability multi-sectorally as was manifested in the second PRSP known as the Malawi Growth and Development Strategy (MGDS).[49 (p.18)] The broad and long-term development scheme, called Vision 20-20 of Malawi, is also reported to have given due considerations to matters pertaining to disability.[49 (p.18)]

Malawi is regarded as one of the best examples in Africa where a remarkable collaborative effort is seen between and among the disability stakeholders in the country, which in turn has caused an increasing level of attention to be rendered to the disability cause by the government and its development partners.[61] Nonetheless, the

Malawian disability movement still claims that a lot remains to be done both in terms of attaining the full participation of PWDs in development consultations, as well as in magnifying the disability cause in the PRSPs and their implementation.[49 (p.18)] It is also indicated that the disability movement needs to be more proactive in its engagements with the government and other development partners; mainly in terms of presenting clear and concrete plans targeted to better inform upcoming PRSP processes.[58]

2.5.4. SENEGAL

A 1988 National Household Survey conducted in the West African nation of Senegal estimated the number of PWDs in the country at 800,000, amounting to nearly 10 percent of the general population.[62] About 80 percent of the PWDs live in rural areas with no access to basic social services.[63] As in the case of the previous three countries, Senegal's first PRSP document was neither participatory in terms of PWDs, nor did it reflect the disability cause in its contents.[49 (p.16)] Participation of PWDs and DPOs in the Senegalese development agenda and the PRSP, in particular, came to be realized when the second PRSP document (PRSP II) was introduced in 2006/07. Owing to concerted efforts made by the disability movement in Senegal, led by the umbrella DPO known as *Fédération Sénégalaise des Associations de Personnes Handicapées* (FSAPH), PWDs and DPOs have managed to participate in the preparation of PRSP II.[49 (p.19)]

The PRSP II came out with disability clearly mentioned in several sector-specific strategies, including: education; economic empowerment of PWDs where the use of CBR and Social Fund programmes was highlighted; the promotion of a disability law which is currently being drafted; and employment in which the country has a legal requirement reserving 15 percent of new civil service positions to PWDs. [49 (p.16); 64 (p.26)] The increasing role of women with disabilities (WWDs) in Senegal's PRSP process is also often reported as exceptional. DPOs of women with disabilities have formed strong alliances with the general women network in a bid to consolidate their clarion call for a greater inclusion of PWDs, in general, and WWDs in particular.[49] Reports indicate that, once enlightened about the PRSP and its implications, the women have begun working hand-in-hand with their fellow colleagues at grassroots level so as to bring their

common concerns in an organized manner to national PRSP consultations and decision making.[49 (p.17)]

To conclude, it is obvious that all of these countries have adopted disability-inclusive PRSPs immediately after the conclusion of their initial PRSP documents which did not address disability. This, the researcher believes, can be one lesson in itself for Ethiopia which has just begun mentioning disability in its third PRSP document. The relative strength of the disability alliances and collaboration in these four selected countries is also another important feature that the disability movement in Ethiopia can draw lessons from. It can also be observed that in all of the four countries, there is more or less a lack of disability-specific data, the impact of which has been discussed earlier. In addition, one can understand that the major challenges being encountered by the disability movements throughout Africa are almost similar and can be summarized as:

- ✓ Capacity limitations (be they financial or human resource based);
- ✓ Lack of technical expertise on issues of disability, development and the PRSP process, which negatively affects the ability of DPOs to present a clear, measurable and convincing quest for disability inclusion in development initiatives;
- ✓ Lack of disability awareness within the general public, including government officials, especially those at lower levels where policy implementations mainly take place;
- ✓ The tendency, in some cases, to lump disability issues into the category of *vulnerable* and *disadvantaged* groups, which fails to address the specificities of disability issues.

2.6. Chapter Summary

This Chapter provided detailed literature on the philosophical underpinnings of the notion of DRM, including the history and emergence of this notion at international,

regional and national levels. It was explained, based on the DRM conceptual framework, that a movement that aspires to be a disability movement, regardless of where it is located, should involve three basic steps of progress. First, it should clearly define the problem it aims to tackle and the roots of the identified problem. Second, it should provide a list of solutions that the movement desires to bring about. Third, it should set out realistic mechanisms to deal with possible issues that may arise after the solutions it proposed have taken place (otherwise known as *the aftermath* or *post-change* issues). Each of these three steps has been explained in-depth in this Chapter. An account of the disability movement in Ethiopia, its initiation and current status was also provided. As the study is focused on the role of Disability Rights Movements in the Ethiopian Development Agenda, with a particular emphasis on the PRSP process, the Chapter reviewed literature concerning the PRSP process in Ethiopia and the involvement of PWDs and DPOs in the process. The extent of inclusion of disability issues in the Ethiopian PRSPs so far, was also seen in detail. Relevant experiences of four African countries were also briefly discussed in order to be able to compare the situation in Ethiopia with the success *and* failures of these African countries.

CHAPTER THREE

3. METHODOLOGY

3.1. Introduction

This Chapter discusses the research methods employed in line with the objectives of the study. The chapter is divided into the following sub-headings: the objectives of the study; research paradigms; the research design, research setting, sample size, data collection procedures, data analysis and ethical considerations. A brief summary will then conclude the Chapter.

3.2. Objectives of the Study

The objectives of the study are:

1. To describe DRMs and investigate their roles;
2. To explore the involvement of DRMs/DPOs in the Ethiopian development initiatives, specifically in the PRSP process; and,
3. To elucidate factors that facilitated and/or hindered the DRM/DPO activities in Ethiopia, with a particular emphasis on: *(1) the challenges*; *(2) opportunities* and *(3) the way forward*.

3.3. Research Paradigms

There are three basic research paradigms: *positivism* (the quantitative approach), *interpretivism* (the qualitative approach), and the *critical approach*.[65] *Positivism* refers to the systematic empirical investigation of quantitative properties and phenomena and their relationships; the objective of the method being to develop and employ mathematical models, theories and/or hypotheses pertaining to a given phenomenon.[65] *Interpretivism*, or the qualitative approach, which is the method this study adopted, is a way to gain insights through discovering meaning by improving our comprehension of the whole.[65 (p,22)] Qualitative research explores the richness, depth, and complexity of a certain phenomenon; it involves detailed, verbal descriptions of characteristics, cases, settings, people or systems obtained by interacting with, interviewing and observing the subjects. This paradigm typically starts with use of a document review to collect data.

The *Critical Approach*, on the other hand, explores the social world, critiques it, and seeks to empower the individual to overcome problems in the social world; it enables people to understand how society functions and the methods by which unsatisfactory aspects can be changed.[65]

3.4. The Research Design

As stated earlier, this study has employed the *qualitative paradigm*, which is further divided into five main types/designs; namely, the *case study*, the *grounded theory*, *phenomenology*, *ethnography* and the *historical method*. The *qualitative case study design* is specifically what the researcher has used in this study. This is an approach that facilitates the exploration of a phenomenon within its context using a variety of data sources and ensuring that the issue is not explored through one lens, but rather a variety of lenses which allow for multiple facets of the phenomenon to be revealed and understood.[66] It gives a perspective to the understanding of the research question(s) and social contexts of the local population in its natural setting, emphasizing the relationship between events and providing a comprehensive contextual analysis of the issue being researched. It also helps the researcher to examine a wide range of areas in order to have a holistic grasp of the research topic. A disadvantage of this technique is that it is microscopic in nature, as it usually depends on a few particular cases in order to arrive at generalized conclusions.[67]

3.5. The Research Setting

This study was conducted in Addis Ababa, the capital of Ethiopia. In collaboration with FENAPD – the umbrella DPO representing most of the disability activities throughout the nation, DPOs based outside Addis Ababa were contacted and interviewed via teleconferences.

3.6. Sample Size

The number of people originally selected as a sample and contacted by the researcher was 54. While 21 were selected to participate in *key informant interviews (KIIs)*, 33 were selected for three *focus group discussions (FGDs)*, each comprising 8 to 10 people. Of

the 21 people selected to be key informants, the researcher was able to interview 18. Likewise, 26 of the 33 people selected for the FGDs attended the discussions. Participants in both cases were selected from various DPOs, disability activists, disability-focused and other local and international Non Governmental Organizations (NGOs), Community Based Organizations (CBOs), professional associations and other Civil Society Organizations (CSOs). The actual sample size was determined once the researcher was satisfied that the data saturation point had been reached and that there was no further or new information that was coming out during interviews to be added to the study. The following table shows the exact number and distribution of participants of the study.

Key Informant Interviews	***Focus Group Discussions***
8 DPO leaders and disability activists (Based in Addis Ababa) 4 representatives of government offices (MoLSA, MoE, MoFED, MoH) 4 NGOs/CSOs (local and international) leaders and coordinators 1 higher learning institution representatives 1 representative of the donor community	5 representatives of DPOs based in four major regions of Ethiopia (Amhara, Tigay, Southern Ethiopia and Oromia regions) **All contacted via teleconferences* 6 representatives and consultants of DPOs based in Addis Ababa 5 disability activists and university students with disabilities 5 experts in disability and development issues, including PRSPs 5 representatives of disability-focused NGOs and CSOs

Table 1: Number and Representation of Participants

The *purposive sampling method* was used to recruit knowledgeable informants who were best situated to provide sufficient insights into the study. Through this sampling method, the researcher was able to access important primary sources which provided an input that would otherwise be unlikely to be obtained from secondary sources.

Snowball sampling method was also employed to identify respondents who participated in the three FGDs. Snowball sampling involves asking key informants to nominate new individuals who should be interviewed to add further insights into the research questions.[68] One advantage of this sampling technique is that it helps the researcher to utilize the social network of the key informants to recruit possibly hidden people who may have the potential to contribute to the study.[68] Its limitation is, however, that sometimes the informants may nominate individuals with whom they share common views; hence, it may be difficult to have a candid distribution of views within the targeted population.

3.7. Data Collection Procedure

The main data collection methods employed in this study are: *key informant interviews (KIIs)* and *focus group discussions (FGDs)*. *Semi-Structured Interview Guides* (*see Appendix III: Page 128*) were used as data collection tools for the study. The key informant interview and focus group discussion methods are explained as follows:

3.7.1. Key Informant Interviews (KIIs)

These are qualitative in-depth interviews with people who are well versed in and have actual information on the research questions raised by the study.[69] The key informant interviews are expected to reveal potentially useful and in-depth information on the subject at hand in a manner that may be easy to understand and provide guidance on the process. The voice of the *silent minority* could be explored with this method. These interviews also allow the researcher to further develop strong relationships with key people in society. Interactions with informants raise the awareness and interest of stakeholders in the agenda of the study. The drawback of this technique is that sometimes it is difficult to get hold of the key informants, as most of them are very busy

people. The method may also tend to be subjective because of the relationship between the researcher and the informant. Moreover, it is a complex challenge to develop trust and confidence in the informants as some may reflect biased views.[70]

Procedure: Prior to commencing the interviews, the researcher chose a conducive environment for the interview; at times, some of the key informants had access to quiet and comfortable rooms of their preference for this purpose. The researcher would then introduce himself and explain the aim of the study to each informant. Participants were assured of confidentiality and informed that they had the right to withdraw from the study at any moment, should they feel uncomfortable, with no consequences to them. Permission was sought to tape-record the interviews; and each interview took 30 to 60 minutes. Where necessary, the interviews were conducted through telephone calls. Probes were used to elicit more information from the participants. Field notes were also taken during the interviews to supplement the tape-recorded data. Interviews were transcribed verbatim and the transcripts were returned to key informants for verification.

3.7.2. Focus Group Discussions (FGDs)

A focus group discussion is a qualitative interview of a homogeneous group of six to ten people that interact to discuss a specific topic under the guidance of a leader.[71] Its advantage lies in the flexibility it offers for participants to interact. It also allows the researcher to closely investigate and obtain more information, as well as seek clarification on pertinent issues. The weakness of this method is that it is susceptible to biases by the researcher, who is flexible and has the freedom to choose what information to transcribe or not. In addition, participants who are vocal tend to dominate the discussion, thereby preventing others from sharing their views. The researcher needs to have skills in group dynamics and knowledge in conducting successful focus group interviews.[72]

Procedure: Three FGDs, each attended by 8 to 10 participants, were conducted during the study. The participants consisted of representatives of relevant institutions/offices such as FENAPD and all the major DPOs in the country; pertinent government

authorities, like the Ministry of Finance and Economic Development (MoFED), Ministry of Labour and Social Affairs (MoLSA), Ministry of Health (MoH) and Ministry of Education (MoE); academics and activists in the disability field; national and international CSOs and NGOs. Prior to commencing each FGD, the researcher chose a quiet and comfortable environment which was accessible to all participants. He then introduced himself and explained the aim of the study to the participants; assuring them of confidentiality and their right to withdraw from the study at any moment should they feel uncomfortable, with no consequences to them. Here again, permission was sought to tape-record the interviews and it was made clear to the participants that during the course of the study, the recorded interviews would be securely stored in a manner that *only the researcher* could access. Upon completion of the research, the recorded interviews would be destroyed. Each FGD lasted 90 to 120 minutes, and the discussions were carried out in English and Amharic, depending on the participants' preference (Amharic is the national and official language of Ethiopia, and English is the second official language). Where applicable, the researcher translated the data from Amharic to English and asked an independent person to check that all the translations were accurate. Probes were used to elicit more information from the participants. All participants were given the same opportunity to express their views, which were respected. Field notes were also taken during the FGDs to supplement the tape-recorded data.

Finally, interviews were transcribed verbatim; and, where necessary, the transcripts were taken back to the participants for verification. Such a process is also known as *Member Checking*.[72] Information obtained from participants of the three FGDs was triangulated with one another in order to consolidate the breadth and quality of the data gathered. *Triangulation* is a method used to complement the gaps in the information received from one person or group with supplementary information obtained from another person or group.[73] The following figure depicts the data collection process employed in the study.

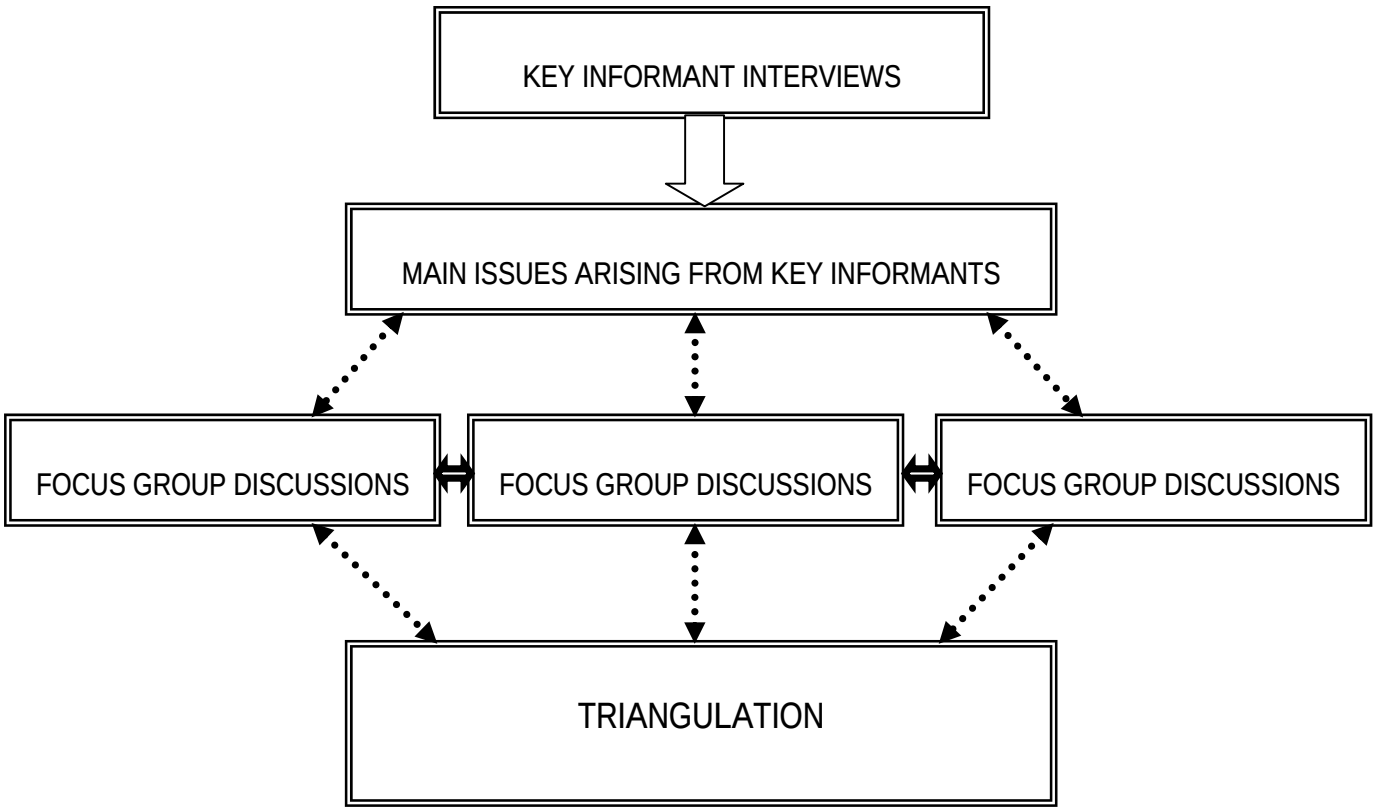

Fig. 3: Data Collection Flow Chart

Figure 3 illustrates the data collection process whereby the main issues that emerged from key informant interviews were taken to each of the three focus group discussions. The information obtained from the focus group discussions was then consolidated through the triangulation method as shown in the diagram.

3.8. Data Analysis

All transcripts were read several times, until the researcher was satisfied that he was well acquainted with the main issues raised in the interviews. A thematic content analysis was done by identifying common patterns through the *colour coding* of data in terms of frequently raised issues. The codes with common meaning were then grouped into categories from which the main themes and sub-themes were generated to explain the findings, as illustrated in Chapter Four below.

3.9. Limitation and Delimitation of the Study

Ethiopia is a Federal republic with nine regions and two metropolitan city administrations. The average distance between the capital, Addis Ababa, and the nine regional states ranges between 100 and 1000 kilometres. A research undertaking that claims to study a certain nationwide phenomenon in Ethiopia should, therefore, ensure that it is adequately representative of all, or most, of the regions constituting the nation.

Due to budget limitations, the researcher of this study had to be based mainly in Addis Ababa while conducting the research. In an effort to redress this situation, attempts were made to obtain as much input as possible from the four main regions of the country (namely; Oromia, Amhara, Tigray and Southern Ethiopia) through the use of teleconferences and email communications. Even though the under-developed communication infrastructure in Ethiopia posed its own challenges on this effort, the teleconferences with leaders and representatives of DPOs from the four regions were eventually successfully conducted.

3.10. Ethical Considerations

Prior to the commencement of this study, permission was requested and granted from Stellenbosch University Ethics Committee. Further permission was also sought from Addis Ababa University (AAU) Department of Special Needs Education which is currently the main tertiary education and research Institute working on disability studies in the country. Participants in the research were given information sheets to read beforehand and consent forms to sign, should they agree to participate in the study.

They were also assured of their right to withdraw from the study at any time without being required to give reasons, and without any consequences. Anonymity and confidentiality were ensured in order to protect the identity of the key informants. Participants of the focus group discussions were assured also of confidentiality and told that information gained from this study would be used only for research purposes.

3.11. Chapter Summary

This Chapter described the methods applied during this research. It indicated the objectives of the study, which determined the research paradigms, design, setting, sample size and the data analysis methods applied in the research. It ensured also that all the necessary ethical requirements were fulfilled by the researcher, prior to the commencement of the study.

CHAPTER FOUR

4. PRESENTATION OF RESULTS

4.1. Introduction

In this Chapter, the findings of the study are presented, focusing on the Disability Movement in Ethiopia and its role in development initiatives, including the challenges and opportunities that it faces. The findings also describe the context within which the involvement of PWDs in national poverty reduction efforts should be investigated. The data analysis was guided by the main objectives of the study which were outlined in the previous chapter (*see Chapter Three, Section 3.2: Objectives of the Study*).

Pseudonyms are used to represent key Informants. In addition, letters of the alphabet are used to represent participants from the three focus group discussions as follows: members of first group will be referred to as *FGD A-1 to A-9*; those of the second group will be *FGD B-1 to B-9*; and members of the third group will be referred to as *FGD C-1 to C-9*.

The thematic diagram in *Figure 3* below provides a summary outline of the themes and sub-themes that emerged from the key informant interviews and focus group discussions.

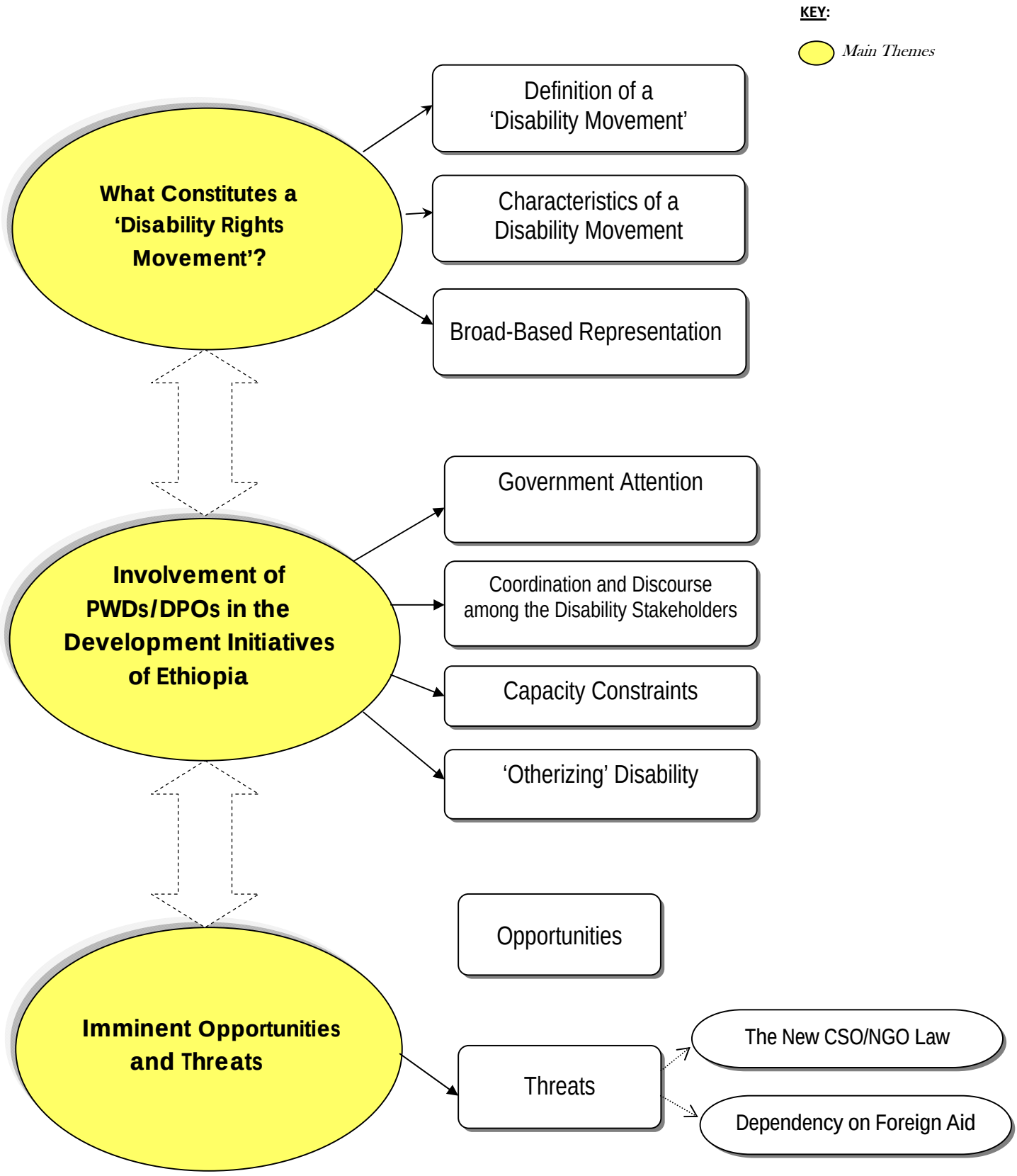

Fig. 4: Themes Emerged - A Diagrammatic Illustration

The above diagram shows that three main themes emerged from the findings of the study; and these are contained in the three circles located vertically one after the other in order of priority. The circles are also connected to one another with dashed arrows to indicate that the themes emerged, though separate, are tacitly intertwined. Accordingly, the emerged main themes are presented as:

1. *What constitutes a 'Disability Movement'?*
2. *The involvement of PWDs/DPOs in the development initiatives of Ethiopia; and,*
3. *The imminent opportunities and threats facing the disability movement in Ethiopia.*

Each one of the main themes in the yellow circles then points to the sub-themes that emanated from it (which are enclosed in rectangular boxes). A similar pattern is followed in cases where additional themes came out of the sub-themes as well.

Presentation of the data analysed in this way follows next.

4.2. What Constitutes a 'Disability Rights Movement'?

On the basis of the first objective of the study (namely, *describing Disability Rights Movements and investigating their roles*), the question "what constitutes a 'disability movement'?" and a discussion of the ideal roles of such a movement emerged as one of the three main themes of the study. The participants' responses to this theme were further sub-divided into three other sub-themes, all informing the main theme as illustrated in the analysis below.

4.2.1. Definition of a 'Disability Movement'

In describing a 'disability movement', it was found to be necessary to first of all define the term 'disability movement' in the context of this study. Key informants were asked to share their understanding of this term, and their responses were passed on to the FGDs to solicit more views.

As stated by key informants, it is important that any discussion on the status and contribution of PWDs in a given nation should clarify what exactly a ‘movement’ is as it applies to the subject at hand, and then look at the phrase ‘disability movement’ against the defining elements of a ‘movement’:

> **Kebede:** It is very relevant, as we go along in this discussion, that we clearly establish the main components that a ‘movement’, in general, and a ‘disability movement’, in particular, should fulfil as a matter of fact. And then we need to see if there even exists a real disability movement in our country based on the evidence at hand.

Affirming the preceding view on the importance of providing relevant definitions, another key informant said:

> **Abraham:** The ‘Disability Rights Movement’ is nowadays becoming one of the major rights movements of our time, increasingly joining the rank of the likes of Feminism and various minority rights movements. It is, therefore, with this underlying fact at hand that we should identify at least the most important elements that constitute such a movement

This issue was carried forward to all the three FGDs, of which a participant of FGD A suggested the following definition of a ‘movement’ and, by implication, a ‘disability movement’. Note that in some of the views of the participants, the terms ‘movement’ and ‘rights based movement’, on the one hand; and ‘disability movement’ and ‘Disability Rights Movement’, on the other, were used interchangeably.

> **Participant A-1:** In my opinion, a rights-based movement is there when several people sharing similar concerns, views and goals [pertaining to certain rights] exert different forms of efforts to have their voices heard, and their issues addressed in a society. These efforts mainly include forming organizations that represent the cause in question [disability]; opposing the existing situation in various ways such as waging a series of well-informed critiques, demonstrations and solution-oriented recommendations aimed at achieving the desired goal.

The above definition provided by Participant A-1 was shared and agreed upon by all the participants of the other FGDs and the key informants alike. In agreement with this definition, another participant of a different FGD added:

> **Participant C-1:** A movement is basically preceded by the presence of a certain oppression, violation of rights or a phenomena of some sort victimizing a certain section of society [in our case, persons with disabilities] who would then organize themselves to fight against that phenomena in one way or another with a goal of modifying or getting rid of the situation for the better.

In consideration of the above opinions, which were concurred with by all key informants and members of the FGDs, it can be concluded that it is essential to provide a clear definition of a 'movement', in general, and a 'disability movement', in particular, prior to evaluating the existence and expected roles of such a movement. It was stated that this concept basically represents a situation wherein victims of a certain societal phenomenon or system gather collectively in order to try and change that phenomenon in various ways that could lead them to the desired goal(s).

4.2.2. Characteristics of a Disability Movement

In the light of what was generally agreed as a definition of a 'movement' (*see views of Participants A-1 and C-1: Section 4.2.1*), key informants and members of the FGDs went on to reflecting on the basic aspects against which a 'disability movement' should particularly be measured.

A key informant said the following as to what a 'disability movement' should principally target:

> **Abraham:** A disability movement in a certain country should be one which targets, as a rule of thumb, the respect and equality of PWDs in a society, thereby ensuring that they do have their say on all matters that affect them in one way or another; most importantly, for example, the fundamental rights to equal participation and development.

It was also stated that the effectiveness of such a movement primarily depends on the effectiveness of its internal strength. As one DPO representative who participated in FGD C said:

> **Participant C-4:** Based on my experiences, to be inward looking is, I think, another element that a disability movement must fulfil. What I mean by this is that, before making any claims against the outlooks of the society out there, a disability movement must have an internal strength of its own first; a strength wherein it sufficiently sensitized the community it represents, aiming to create a situation where every person with disability can stand for her/his own right and becomes an active advocate of the cause. That is where it should all start with.

Another participant strengthened this view and further commented:

> **Participant B-4:** I believe that a 'movement' and especially a 'disability movement' should be all about advocacy and bringing about an all-out change to the system it fights against. This begins with enlightening the very members of the movement and making persistent and vibrant attempts, in various ways, to interact with the society at large; to keep knocking and knocking hard until the movement is convinced that the societal system it challenges has profoundly changed in favour of the movement.

Accordingly, it was established that *advocacy*, *internal strength* and *adequate sensitization* of PWDs and the public at large should altogether be seen as the primary characteristic features expected of a disability movement.

4.2.3. Broad-Based Representation

Representation was another notion that was placed high on the agenda in discussing the elements constituting a disability movement. One key informant underlined that the extent to which a movement represents the group it stands for is an inevitable component determining the nature of the movement:

> **Sebeta:** 'Movement' and representation are inevitably mutually inclusive; one cannot exist without the other. Where there is genuine representation, you would find the kid with a disability way down there in the small rural village, or his family, talking enthusiastically about a better tomorrow ahead of them,

trusting that there is some entity out there that would share and echo their concerns.

Consistent with the preceding observation, it was underlined that a movement claiming to stand *for* PWDs should ensure that it sufficiently represents PWDs at grassroots levels, and that it has a broad-based representation as a result. A participant with disability from FGD A stated:

> **Participant A-7:** If I don't feel like my basic, inherent needs as a human being are respected; if I keep being inhumanly hidden in my small, shanty room, let alone knowing what is happening out there in the name of a 'disability movement', how on earth can anyone even dare say that they represent me? Despite what some people might try to tell us about such things like a 'broadening representation', 'mass participation', etc., I strongly believe that a proper representation depends essentially on locating and amplifying the oppressed voice of the poor family in the small village..

While participants expressed the need for a comprehensive self-representation of all PWDs without distinction, it was also emphasized that the notion of representation should *not* be too narrowly defined to mean that no one, but PWDs only, should advocate for the disability cause.

> **Participant A-7:** 'Nothing About Us Without Us' means that 'we must be there whenever you talk about anything that mentions us'. It does not, and should not, mean that it is only us who should talk about issues that concern us. Obviously, it just doesn't work that way. But I've practically witnessed that some disability activists get very irritated when they see a 'non-disabled' person talking on behalf of PWDs. These activists have a point too, since we do have some people misrepresenting us for their own little benefits. So, yes, a balance has to be stricken between both of these extremes.

As the preceding comment emphasized, it should be noted that a lot of disability work and advocacy within the movement can be achieved with joint efforts by PWDs and their fellow 'non-disabled' colleagues. In fact, disability mainstreaming in itself can be said to be best realized in the sense that the two groups work together as equal partners respecting each other's needs and spaces. A disability movement should,

therefore, work in such a manner as to ensure the effective representation of PWDs in all relevant socio-economic and political spheres.

The level of participation by PWDs and the disability movement as a whole in development initiatives, with particular reference to Ethiopia, is discussed in the next section.

4.3. Involvement of PWDs/DPOs in the Development Initiatives of Ethiopia

The findings in this section were based on the second objective of the study, which is: *to explore the Involvement of DRMs/DPOs in the Ethiopian development Initiatives, specifically in the PRSP process*. It was admitted that Ethiopia, though one of the least developed countries in the world, has been undergoing a substantial process of development, particularly over the past decade. Acknowledging this fact, a question was raised as to *if* and *how* PWDs have actually been recognized and involved in these national socio-economic development initiatives taking place in the country. Participants responded vigorously to this question addressing the matter from various perspectives and citing several practical instances as follows.

4.3.1. Government Attention

The recognition that the Ethiopian government renders to disability and PWDs in its development agenda is one of the focal themes that emanated from the data analysed in the study. Participants expressed their views based on certain facts which, in their opinion, would demonstrate how serious the Ethiopian government is concerning disability issues.

A participant with disability, from FGD C, stated her views on the basis of her practical experiences as well as voicing the views of her association. She mentioned instances manifesting the prevalence of both *direct* and *indirect discriminations* at various administrative levels of government, particularly at the lower levels where the broad majority of PWDs are located.

> **Participant C-2:** Well, we do hear that there are certain development activities going on in all corners of the country, especially these days. But we certainly do not see us [PWDs] partaking actively or benefitting in this famous development; we do not see PWDs being given equal chance to be part of this as citizens. There are problems; the authorities seem to see only our disabilities, instead of thinking that we can work. Thus, they don't provide us with things such as 'revolving loans' which they provide everybody with; because they don't think that we can properly work and return the loans. Also, the government says 'Education for All', but this is being hardly realized when it comes to children with disabilities. Look at all these school buildings that are being constructed everywhere in large magnitude; are these buildings being made accessible to us, to PWDs? The answer is a big NO! Is this education for all? In fact, this is an indirect way of telling us to remain in our homes, hidden and locked up in the dark with our families. They say 'inclusive education', but what does that mean if a student with physical disability can't go upstairs to attend his classes? In that case, the old system of separate schools, boarding schools, would be much better. Like, for instance, our Association has its own boarding school, and it is implementing integration. But are other public schools emulating this example? No, that's not what we're witnessing. We hear that Ethiopia is one of the first 30 signatories if the Convention on the Rights of Children. That's good. But when did that happen, and what changes have occurred since then? I don't have the answer. All I know is that we always shout for our rights, but usually, or almost always, remain in vain. That's it!

As administrative officials are obviously the products of the society that brought them up, it follows that these officials would mostly portray the beliefs and attitudes they grew up with. The preceding comment expressed by participant C-2, showing the exclusion of PWDs (intentionally or otherwise) by relevant government offices and programmes, clearly exemplifies this scenario. Another participant, also representing a DPO, looked at the matter in terms of the importance of having an organized government entity that can be entrusted with handling disability-related issues. The absence of parliamentary representation of PWDs was also mentioned. He criticized the existing situation in this regard:

> **Participant A-3:** This country has ministries for the youth and gender issues, but there's no ministerial representation for PWDs who constitute at least 10% of the population, about 7 or 8 million people, which is a big number.

> And this brings about its own major problems when it comes to implementation of policies, especially in the promulgation of legislations. The only government representation that we have is as a tiny sub-department at the Ministry of Labour and Social Affairs. This has a huge negative impact; it would have been better if we at least had some desk at the Office of the Prime Minister. It is indeed a big problem that there's no one exclusively entrusted to see to it that disability is being properly addressed. Moreover, there is no parliamentary representation of PWDs, as is the case even in countries near us, like Uganda, Tanzania and Kenya.

Concerning the bureau that is mandated to deal with disability issues; namely, the *Department of Rehabilitation and the Elderly* at the Ministry of Labour and Social Affairs (MoLSA), participants said that this office has hardly been active, and that the reasons often given for this are budget limitations and lack of efficient strategies. A *change of attitude* is needed at MoLSA as well, said one participant:

> **Participant B-3:** The Department at MoLSA has not so far brought any major paradigm shift as such. We still see them concentrating too much on rehabilitation and the medical model in general, instead of delving into the much needed socio-economic transformation of PWDs. In addition, this Department seems to do almost all of what it does based on foreign or external funding, if and when that is available. There is no budget that the government exclusively allocates for disability; or if there is, it is probably a little more than none.

A representative of MoLSA, however, differs to the above view and says:

> **Dereje:** MoLSA is doing what it can, I think. I recognize that we are far from getting to the level of achievement that we would like to arrive at. But we are doing what is possible. MoLSA, together with its international partners like the ICRC, has established various rehabilitation centres in different corners of the country. It is continuing this effort. We believe that this contributes a lot to the improvement of the lives of PWDs in the country. So, in general, MoLSA is carrying out its responsibilities, even though there is still so much to do and though there are some real constraints such as budget constraints stemming from the country's poverty.

Some participants did not agree with most of the points in the preceding comment, and implied that there is an evident need for a *fundamental restructuring* of MoLSA in line

with the current demands of the models and proper representation of disability. One participant argued:

> **Participant A-7:** Even the name of the Department tells you what this small office is all about. It's all about 'rehabilitation'. Yes, there sure are rehabilitation centres established by MoLSA and the ICRC. We know that, and it is good. But what we are saying is that that's not the major solution to the problem. Such a view misses the big picture and it shows where MoLSA's attitude still is concerning the models of disability. They need to be action-oriented; and bring PWDs themselves onboard to enunciate their voices to the government and society. I don't think that they're doing this. All that we're seeing is what can be called a 'proxy' representation of disability; representation by people who actually may not know that much about disability in the first place.

Another participant with disability opposed the trend of mentioning budget shortages and the nation's lack of adequate financial resources as one of the problems affecting the government's focus on disability. She asks:

> **Participant C-2:** The excuse we usually hear from government entities is lack of budget and funding. But if I am considered a citizen just like everyone else, why am I not being taken into account when other issues and sections of society are budgeted for? Why is it that roads, constructions and public transportations ignore my needs when they are planned? I was counted as a citizen when the government did its population census, right? So, if I am a citizen, then why are my needs being neglected?

The continued focus by MoLSA on the concept of *rehabilitation* rather than on the *habilitation* of PWDs; and the limited role being played by the Department of Rehabilitation have, in fact, been evidence of the insufficient attention rendered to PWDs by the Ethiopian government. Even if the scarcity of resources, attributed to the country's poverty, is sometimes a real challenge justifying the insufficient emphasis given to disability, participants argued that this does not warrant the existing considerable preclusion of disability from the economic plans and budgeting schemes of the government. Hence, the call for a more coordinated or, as some participants suggested, a *restructured*, entity that efficiently addresses the disability cause in

Ethiopia is valid. In talking about development, issues specifically pertaining to PRSPs often take centre stage, as can be seen from the discussions below.

4.3.1.1. Disability and PRSPs in Ethiopia

A good number of the remarks of participants on the subject of government attention particularly referred to the Ethiopian PRSP process and its features. At the time when most of these interviews were conducted, the Ethiopian PRSP in force was known as the PASDEP (the Plan of Action for Sustainable Development to End Poverty) – the second PRSP of Ethiopia. Therefore, note that the comments of the participants frequently cited the PRSP as PASDEP, although the PASDEP has now been replaced, as of September 2010, by the GTP – the Growth and Transformation Plan (the third PRSP) which has to a certain extent included a disability component. The researcher believes that most of the participants' views on the PASDEP apply as they are to the GTP and to the overall PRSP process in Ethiopia.

Prior to reflecting on how disability-inclusive the Ethiopian PRSP has been, key informants explained some general facts about how the PRSP consultation process actually took place in the Ethiopia.

> **Kaleb:** The process of preparing the PASDEP began with a consultation at grassroots level. By grassroots level, I mean the local administrative level. In our case, it is what we locally call the *'Kebele'* or community level; that is the lowest administrative structure and the area where you find the largest population. So, that was what they did; the consultation begins at that point. It's all over the country that consultations took place. I don't think all the districts throughout the country were involved. I think it is carried out on a sample basis. There are over 500 districts or *"Woredas"* in Ethiopia. So obviously, I don't think the discussions would take place at all districts in the country. But, the popular participation would be definitely sought at those structures, particularly at district and local administrative structure discussions. Otherwise, you cannot say that we have involved the people in the preparation of the document. The very concept, PRSP, also requires such a broad consultation as a primary requirement of the process.

Specifically elaborating on the efforts exerted by DPOs in this process, FENAPD representatives underlined the attempts made hitherto to ensure the participation of PWDs at different levels, Regional and Federal, in the PRSP consultative fora. Also mentioned were the challenges posed by the vastness of the country, which was another factor that limited the representation of PWDs in the consultative processes due to distances and inaccessibility issues.

> **Kaleb:** In fact, we didn't mobilize many PWDs to participate in those grassroots level or community level discussions in previous preparations of the PRSP. What we did was that we just assigned some people to attend. And that was just in Addis Ababa, the capital, not in the regions. So, that's what I mean by grassroots level discussions. This time, though, what we are doing, despite all the obvious hurdles such as inaccessibility of the discussion forums to PWDs, is that we have already agreed with some organizations and DPOs to have regional level committees comprising members from each DPO exclusively to work on this issue. And that committee, that team, is supposed to work with government line-ministry representatives. Once this regional process is over, when it comes to the Federal level discussions and consultations, then organizations and DPOs at the Federal level, like FENAPD, would intervene and they take the process from there up to the top level conferences, and what have you. So, that was the latest plan.

It was stated that although various promises were made on different occasions by government officials to include disability in the PASDEP, in reality these promises were not kept despite the assertions by DPOs that a PRSP that excludes disability is similar to one that excludes poverty itself.

> **Kaleb:** You see, just to mention one instance, we sent the President, the previous President of the Federation, to a meeting held at ECA [the Economic Commission for Africa], where all the representatives of civil society and other organizations were present to discuss macro-economic issues of the PASDEP. And the President addressed that conference on disability matters. He practically said 'unless we include the issue of disability, this document will not be a document that talks about poverty'. And as usual, the people at the chair and all said 'oh no problem, we will include it!'. But the PASDEP came out without mentioning disability. All those who were responsible for the preparation of the document were taking note of the issue of disability when the Federation President made that speech. They promised, but failed to

include it once again. So definitely they omitted it intentionally. That was what we have come to conclude.

On this very issue of 'false promises', one key informant commented that this scenario 'puzzles' his mind. He backed his observation with a recent study done by Inclusion International which mentioned a situation where governments make pledges that they often fail to keep regarding disability inclusion in the PRSP.

Abebe: This thing puzzles my mind, you know. A report from Inclusion International this October, 2009 said that, concerning this PRSP, 67 percent of the countries in our world promise to include disability issues in PRSP. But only 20 percent of them would actually include disability in their PRSP. Why?

It was mentioned that the civil society in the Ethiopian PRSP process, including DPOs, was grouped under a consortium called the Poverty Action Network of Ethiopia (PANE), which engaged directly with the government on behalf of multiple CSOs, CBOs and NGOs. According to some key informants, this in itself might actually conceal disability matters since the consortium is composed of many organizations, all of which would like to see their respective causes addressed in the PRSP.

Feleke: PANE is the official arm of the civil society organizations, the CSOs, in this PRSP, and they are the ones with the power of negotiating with the government representing CSOs in the PRSP. They were attempting to carry out their duty of representation; we could see that. But I think as far as disability is concerned, even if PANE has been trying to do something, the disability cause should not be forced to grapple with all the other issues that PANE deals with. Unlike many other sectors, the disability sector has so far been repeatedly precluded from the PRSP. So it should get the space to stand on its own and be seen in all PRSP talks with the government.

It was also stated that various PRSP-awareness raising workshops have been organized by FENAPD, together with other NGOs and CSOs interested in this particular matter; again, PANE has been the main CSO working with the Federation in this respect. However, most of these meetings happened to be unattended by pertinent officials of the key ministry overseeing the PRSP process in Ethiopia – the Ministry of Finance and Economic Development (MoFED).

> **Melaku:** Okay, you might have heard that the Federation has organized several workshops with PANE to some of the sector ministries' planning department experts; so that this disability inclusion effort in the PRSP could be heard. We always call upon MoFED to come to these meetings, and they do send some representatives. But the key people that we would like to have in the workshops from MoFED don't usually appear.

A key informant briefed the researcher about the main aspects of the efforts thus far made by PANE, the Federation and other CBOs to realize what they call a "Disability Inclusive PASDEP" (DIP). According to this key informant, these efforts mainly have a sporadic flow; some of them are still going on; some of them have disappeared or have not shown their results, and some were interrupted altogether.

> **Meaza:** PANE, FENAPD and CBM have tried to do some research on Disability Inclusive PASDEP (DIP); we tried to touch upon some areas. A few relevant government offices also participated, like MoLSA and MoFED. It was definitely not enough but it would give some clue. We also formed a Task Force to facilitate this. The Task Force was composed of different government offices; Ministry of Education, MoLSA, MoFED and other NGOs were also members. I think the Task Force is still working and we believe that it would contribute something for this process. This is the major thing that we're doing so far. There was also an initiative chaired by MoLSA to have a working group on DIP, kind of similar to the Task Force. That didn't continue for reasons unclear.

It was argued, nonetheless, that ensuring the inclusion of disability inevitably requires much more than organizing workshops and making calls to the ministry offices. It demands organized lobbying, and even *personalized lobbying* focusing on the main government ministry and the few relevant official(s) having the 'real power' on the matter. One participant said the following, citing an example of how the disability-PRSP lobbying ought to have been carried out.

> **Participant C-3:** I think there need to be some serious discussions with one or two key people at MoFED. MoFED is the key ministry. It is not MoLSA. That key person with the real power at MoFED should be exclusively followed up by at least one consultant. For example, what was done in the Ministry of Education in order to realize the effective recognition of Special Needs Education Strategy was that a full-time special disability consultant was

> assigned at the Ministry; the Finland government sponsored that, and things are going very well in that regard. Therefore, there is a need for a disability-focused 'watchdog' at MoFED. Because every time, everybody, every sector has an interest in the PASDEP. Everybody wants to have a stake in there; everybody wants a piece of this big cake called PRSP. So this thing needs a personalized lobbying. You don't effectively penetrate the relevant organs through organizing a series of public workshops.

Another key informant supported the preceding view and reiterated what she described as an "articulate and time-effective role" expected of PWDs themselves which, in her opinion, has not yet been happening for one reason or another. She believes that there is some government commitment, and that the government might need clear specifics on what should actually be stated in the document. Providing concise, articulate and satisfactory information on this is expected of the disability movement.

> **Bekelech:** The people themselves, people with disability... how do they enforce this, push their cause to be included in the PASDEP? Asking for the mere inclusion should not be the last target. What should be included where? What is our target? What do we really want to achieve ultimately? How should we be included? These are the points that we have to identify and clearly articulate. By now, for example, government ministries are preparing their own plans. And they will submit it to MoFED. MoFED will then finalize the last PASDEP. PWDs, DPOs and their partners can also submit what they want to be included in there. By the way, if they [the DPOs] are to produce that sort of document, I don't think it should be a wide one. It should be very concise and eye-catching for the evaluators of the document. If they produce that sort of articulate concept note, it could well be included through these sectoral-ministries.

The influence and support of the donor community in Ethiopia was also brought up as a major potential contributor to a meaningful incorporation of disability in the PRSPs.

> **Tessema:** Major donors in Ethiopia, as represented by the Development Assistance Group (DAG), can generate a real impact on this. They can make a strong recommendation to the government to this effect. That would be quite an impetus, with a great possibility of producing something visible and very meaningful.

In a rather rare and brief interview that it held with the researcher of this study, MoFED explained its take on the subject. Their comment, which of course was a constructive one, appears to somewhat suggest that the 'ball is on MoLSA's pitch', as the latter is the lead government ministry mandated to address disability issues. They said:

> **MoFED:** We do know about the tasks that CSOs and other stakeholders in the disability field are carrying out. And we certainly appreciate these endeavours and our representatives have been partaking in many of these engagements. It is also evident that some concrete progress is being recorded in the area, although not enough compared to the existing need. We have recognized the fact that disability should indeed be incorporated in the PRSP, preferably via sector ministries. Our expectation is that MoLSA has been handling this, and that it would continue to channel the relevant input to us. MoLSA is the one mandated to do these things.

What has also been explored is that there are, at times, certain differing views among the parties working towards disability inclusion themselves; as to whether the required inclusion should be a *multi-sectoral* one or whether it should be *an exclusive and separate inclusion* that addresses disability as a separate topic. According to participants who attended those debates, a consensus was finally reached to pursue the notion of *sector-wide/multi-sectoral* inclusion of disability. A key informant who took part in most of the deliberations on this matter stated:

> **Abebe:** During our meetings with PANE concerning this PASDEP, what we have discussed was which way we are going; can we introduce the issue of disability through the concerned ministries? Or can we simply prepare a Concept Paper and submit it for MoLSA or MoFED. I think the person who came from MoFED at that meeting said that, it was impossible to add something from the top to bottom; plans can't be trickled down from MoFED to the various sector ministries. It necessarily has to follow a 'bottom-up' approach. Plans need to be submitted to MoFED from the line ministries; not vice versa. So, based on this explanation we got, a decision was made to continue our fight to introduce the issue of disability through each ministry's PASDEP preparation. But even this decision has not been changed into a practice as yet.

Expressing his reservation concerning the occurrence of any such debates on conceptual frameworks, another key informant argued that getting disability in the PRSP should be the only priority at this stage. All other details can come at a later point, once the first and immediate priority is fulfilled, said this key informant.

> **Ziad:** You know, first thing is first. This conceptual analysis, as important as it may be, should be done once we have at least a small portion of disability in the PASDEP. We can then build on this in the future. At the moment, we are trying to just get entry and we should be satisfied with whatever entry point we can have, because if we have that entry point, then the ideas of each ministry having a desk, a disability desk, and handling disability issues within our ministries, etc., can come later. But at the moment, it is crucial that disability finds its way in that document.

It was pointed out that Ethiopia is presently one of the fastest growing economies in Africa and that the Ethiopian government is very much preoccupied with pursuing various ambitious macro-economic plans. One key informant underlined that, although PWDs too would benefit from the development effect of this growth, the fact remains that the macro-economic focus should not set aside other important social dimensions, such as disability.

> **Brian:** The government is so much geared towards very macro-economic initiatives; in terms of infrastructure, power plants, roads, electric, rural electrification, a lot of emphasis on health, education, etc. So all of the investments are into these very macro things. This country is rapidly transforming through major investments with recorded GDP growth rate of 10% last year, for instance. The ruling party has very big ambitions to pull up Ethiopia into a middle-income country in ten, fifteen years through a very rapid economic growth. All this is so very good. And we do believe that the plans, especially on education and health, would at the end of the day benefit PWDs. The government is going to continue to focus on the macro-economy development. But this shouldn't be at the expense of social services and other things; that's the point here. We still don't expect to have a specific chapter on disability in the PRSP, even in the next PRSPs. Nor would that necessarily be desirable, as long as other sections of the document take disability into account.

In slight contrast to the views of the above key informant, a participant of FGD B said that the development impact on disability is even greater when the government's focus is on such extensive and macro-economic programmes:

> **Participant B-4:** In my opinion, the fact that our government is focused on such big, macro-economic plans is an opportunity to the disability movement. The problem again, I think, is that the relevant government authorities are either unaware or not sufficiently sensitized to take cognizance of disability when planning and implementing the intensive macro-economic plans of the government.

Both of the above views do have a point. On the one hand, it is necessary to note that an exclusive emphasis on the macro-economy *could* lead to setting aside important social issues like disability. On the other hand, however, such broad economic plans could be utilized to have a wide constructive impact on disability as well, through convincing the government about the productive potentials and value of PWDs.

Key informants once again emphasized that the need for PRSP-focused disability research in Ethiopia is evident, for reasons including creating awareness within the disability community about what the PRSP is and its implications. Participants also highlighted that the sources of the PRSP notion, the World Bank and the IMF, should see to it that such informative studies are conducted to the extent possible, and that PWDs are getting the relevant knowledge on PRSPs. Furthermore, it was suggested that relevant ministries like MoFED should sub-contract such studies that would provide them with strong research evidence, which is what they say they need. A key informant said:

> **Yamrot:** I think the IMF, the World Bank and institutions related to those have the duty to make sure that information about PRSPs is reaching PWDs and DPOs in countries like Ethiopia. Plus, since this government is so much evidence-based, they rightly require research evidences for any development claim that you might want to make. The key persons and ministry need evidence in order to appreciate the relevance of our request. We need to provide that. Even the few so called researches that we so far have on disability either don't talk about the PRSP or they are not as elaborate as is required. MoFED itself should encourage and work with such studies as well.

In summing up this section, it was noted that participants agreed on most of the essential matters concerning the inclusion of disability in the Ethiopian PRSPs. It was asserted, almost unanimously, by all FGD participants and key informants that the PRSP consultative forums in Ethiopia have hardly involved PWDs, as can be understood from the PRSP documents themselves which have not given due consideration to disability. A collaborative (and not competitive) effort by the disability movement; sufficient understanding of the disability cause by government officials and an increased influence from the donor community were pinpointed as the major interventions required to realize a disability-friendly PRSP in Ethiopia.

The coordination required among and between stakeholders in the disability sector was further discussed and explicated, as can be seen in the next section.

4.3.2. Coordination and Discourse among the Disability Stakeholders

One of the core themes that surfaced in the course of this study was the question of *coordination and cooperation* amongst the disability stakeholders operating in Ethiopia. It was stated that this issue plays an inevitable part in shaping the nature, strengths and weaknesses that define a disability movement and its impact in a country. It is a manifestation of the 'culture of collaboration' in the sector, said one key informant.

> **Brian:** This is obviously a vehicle to do what we would like to achieve in the disability movement in Ethiopia. Coordination, coalitions and strong partnerships in the sector are of vital importance. It is all about developing a culture of collaboration between everybody who is working in this area.

Concurring with the necessity of promoting the culture of collaboration mentioned above, participants conveyed their perceptions of the prevailing scenario in Ethiopia in this regard. They said that lack of coordination dominates most, if not all, of the disability-related activities in Ethiopia; and as one key informant said, this particular factor has been the main cause of some bottlenecks in the Ethiopian disability movement:

> **Abebe:** Although it is reiterated time and again that there is lack of resources and funding in the Ethiopian disability movement, I definitely don't agree with most of these claims. There are lots of scattered activities here and there; there are lots of organizations who would like to support disability initiatives in Ethiopia. Even the government seems to have the commitment to work on important matters like the inclusion of disability in the PRSP. But since there is no actively functioning and well-organized coordinating body, we see widely dispersed moves in different corners of the country. That brings about a considerable wastage of time and resources which could have been used far better and brought momentous changes, if there was an effective coordination.

In adding to this view, another key informant stated that these problems of coordination stem principally from some inflexible attitudes prevailing in the disability movement itself. It was observed that some DPOs, as one key informant described it, "literally consider it a threat" to make their doors open to broader and common fora representing the disability cause throughout the country. Participants said that, in these cases, the belief is apparently that there must be only a handful of prominent disability activists who should control the disability sector, and that all other players in the field should answer to those few. Thus, said some key informants, there is an evident need for a change of attitude in such cases where there is a noticeable resistance to harmony and coalition within the movement.

> **Brian:** Some DPOs, including the Federation, are still operating in what can be called 'the old fashion way'; as if disability is their issue and only they can work on it. They don't know how to do coalitions and partnerships with other organizations. And we know from experience in other countries that unless you build a strong coalition of stakeholders, you don't have much influence. Unfortunately, some DPO leaders are operating in the 'old mode'; that the pie is only so large that if you involved other people it would take resources away from them. The truth of the matter, however, dictates otherwise. The pie can be infinitely enlarged if you act in a transparent, trustworthy manner in partnership. So there is an issue, there is a problem here.

The foregoing observation basically implies that there is a tendency in the disability movement to maintain a vertical and hierarchical relationship, instead of a horizontal one; while an effective and modernized method of coordination requires the opposite.

As a result of this, there is evidently an inadequate communication within the movement, as the following participant with disability underlined:

> **Participant A-7:** I don't have much knowledge even about what my own DPO is doing. If we, the members, aren't aware of what is happening within our DPO, how can it be expected that others would know about us, or vice versa?

The other factor pointed out as producing an exacerbating impact on the current milieu was the way FENAPD's Constitution (Memorandum of Association) was drawn up. It was explained that this Constitution was written in such a way that regular membership rights are denied to cross-disability DPOs or other disability-focused organizations that may want to join the Federation. Instead, such membership is allowed only to what are called 'single-disability' associations.

> **Yamrot:** The Federation is a network of DPOs; DPOs in essence not all DPOs. There are a lot of DPOs which are not part of the Federation; because the way the Federation is organized is based on a Constitution; and the Constitution only allows DPOs to be a member of the Federation only if they are 'uni-disability', one type of disability DPOs. For example, the Ethiopian National Association of the Blind, Ethiopian National Association of the Deaf-blind, Ethiopian National Association of the Physically Handicapped, Ethiopian National Association on Intellectual Disabilities, Ethiopian National Association on Persons affected by 'Hensen's disease' or Leprosy, and Ethiopian National Association of the deaf. I think these are all. These have been the six only members of the Federation. This is the traditional way of organizing DPOs. Nowadays cross-disability groups are appearing in the country; for example, there is the Ethiopian Woman with Disabilities National Association which is a very strong and gender-focused cross-disability DPO; but they are not regular members of the Federation, they are only 'Associate Members' because the Constitution does not allow them to be regular members with voting rights. Then comes the Tigray Disabled Veterans Association (TDVA), and there are quite a lot of DPOs who are not members of the Federation because of this reason.

It is reasonable to say that the Federation's Constitution should not be as restrictive of membership as it is now, since such prohibitions could only harm the tenacity and voice of the disability movement. According to some participants, lessons can and should be learnt from the disability movements in other countries or even from other 'minority

movements' within Ethiopia, such as the Network of Ethiopian Women Associations (NEWA). It was stated that all focus in the disability movement should be geared towards creating *broad-based coalitions*, instead of moving away from that, as a participant from FGD-C asserted:

> **Participant C-3:** Basically, the issue is that the Federation is constructed on a rather traditional model. Many countries have now gone way ahead of us on this; such as in NUDIPU [the Federation in Uganda], any disability group can be a member; UDPK in Kenya, any DPO can be members. If we look at the formation of the Americans with Disabilities Act (ADA) which was/is a fundamental legislation, there were the Democrats, there were the Republicans, parents, veterans (disabled veterans). There was such a broad representation and they were all pressing Congress for this legislation. We don't see that here. We have model examples even locally, such as the Network of Ethiopian Women Associations (NEWA), which is a wide, broad-based network. Of course, eventually that's going to have to happen in the disability movement too. But I think we're in kind of a transition and there is... kind of... still a conservative leadership. Until the younger generation comes up, there is still going to be this resistance to change.

The divisive impact of such trends is what was reflected above. It was also said that, partly because of these prevailing circumstances within the movement, many DPOs and disability-focused organizations have now established another disability-specific consortium known as the Ethiopian National Disability Action Network (ENDAN). This newer entity, as one key informant explained, permits all and any interested organization to be its member. The key informant explained the formation and nature of ENDAN as follows:

> **Brian:** ENDAN or the Ethiopian National Disability Action Network was a creation of many years ago of the ILO and MoLSA; initially with the government's idea to create a network of everybody working on disability in Ethiopia; schools, NGOs, and as I said, even the government. It used to be called the 'Disability Forum'; and then the Forum decided to legally register as a Network. When it came time to register as a Network, the Ministry of Justice said 'no, you cannot have government entities as part of the Network; it has to be an NGO/CSO Network'. So it was re-formed as an NGO/CSO Network. And it has been quite active in sharing information; the purpose of a network,

like all networks, is sharing information and working to strengthen the members, the member organizations of the network. It is now working in partnership with an Italian NGO known as the CCM which helps in building the capacity of ENDAN. The nature of ENDAN is that it involves all DPOs, including the Federation members (all of the Federation members are members of ENDAN), and also the disability NGOs, plus the cross-disability ones, like the Tigray Disabled Veterans Association (TDVA), the Ethiopian Women with Disability National Association (EWDNA), etc. All these have been members.

In tandem with the above explanation, another key informant added the following, emphasizing the disadvantages of limited coordination and coalition in the disability movement:

Yamrot: Even in cases where there happen to be commitments from the part of the government offices, in order to practice, to realize those commitments; in order to bring them to the ground, there is a need for coordination. I mean, we can't achieve anything concrete without including all; because if we say that disability is an issue for all, we have to practically bring all onboard. We cannot and should not say 'no, this is a DPO thing, the others should not be directly involved; it's not a concern for the others'. Disability is a concern for everybody; it's a crosscutting issue.

As explicated above, the prevailing lack of concerted efforts in the disability sector could be both a factor and good excuse for the inadequate attention being accorded to disability by the relevant government authorities. One key informant expressed the major ramifications resulting from uncoordinated and, at times, dissected moves amongst organizations claiming to work for the same cause. He said:

Abebe: Well, this visible lack of cooperation, coordination within organizations that are working for and with PWDs has deeper ramifications. As long as we don't have that, usually the government or anybody else out there would say, and rightly so, 'well, you have to put your own house in order first before you can tell as what to do'. So that is one big and perhaps embarrassing obstacle to the disability movement.

While the forgoing opinions stressed the coordination problems between and among DPOs, some key informants wanted to allude to similar problems seen within

government departments as well which are supposed to address disability efficiently. *Genuine political will* and *commitment* were underlined as the requisite necessities in this regard, as this key informant said:

> **Dr Sileshi:** MoLSA is indeed the main government Ministry that is supposed to extensively handle disability matters. But some other ministries too should be embarking on disability issues. Even in the few cases where some ministries address disability, like the Ministry of Health and Ministry of Education, these ministries don't seem to know anything about who is doing what. There has to be an unyielding willingness and commitment to work together for a better impact. Isn't that obvious? The practical experiences so far don't seem to prove any effective coordination taking place among the relevant government offices on matters of disability. This is a major weakness with multi-faceted implications.

Another key informant representing the Ministry of Education (MoE) mentioned an additional example demonstrating the lack of coordination on disability matters within government departments.

> **Abebe:** For example, if we see school accessibility issues in Addis Ababa, of course 4-storey school buildings are being built. That's good, but they're all inaccessible to students with disabilities. What the Addis Ababa Education Bureau said on this was that the Bureau and the body that constructs these schools are different; they're two different bodies. The builders don't know what we mean by schooling and the necessary ingredients in schools; they simply construct the buildings. So there is no connection or coordination between the two bodies, both of which are working in the same sector. That is the major problem that we have seen.

It was finally conceded that, in the face of such drawbacks of coordination and coalition seen in the disability sector and movement, it cannot be claimed that adequate groundwork was or could be done to realize a worthwhile recognition of disability in national development initiatives. A matter that is directly related to this and discussed in detail by participants was the issue of *capacity constraints* seen in the disability movement. The next section presents the findings in this respect.

4.3.3. Capacity Constraints

Capacity, said participants, is a key factor determining the extent of involvement by PWDs in the development endeavours of a nation. One key informant wanted to capitalize on a broader understanding of capacity, in relation to PWDs and DPOs:

> **Solomon:** Capacity is usually understood as meaning funds or financial resources. This, I think, is a very narrow interpretation of capacity. As important as financial capacity is, the most important things that come to my mind when we talk about the capacity of PWDs and DPOs are education, information and awareness, of both PWDs and the society at large. An educated and informed group can be said to have passed the first and very basic phase of being capacitated.

In support of the view that capacity should be about education, information and awareness within the disability movement, more than it is about financial capabilities, another key informant representing a government ministry stated the following:

> **Bekelech:** This word is mentioned so repeatedly in almost all discussions concerning disability and DPOs. But when you ask them [the DPOs and PWDs] what exactly they mean by capacity, their immediate and perhaps only response would often be ‘we don’t have the financial ability to pursue our goals’. When we talk of bringing PWDs into discussions concerning development, it should not be just about simply bringing people with disabilities together; they have to also know what to do. Ok why are we gathering? What is the meeting we are going to about? What are they going to do? It sometimes does not hold water to merely say ‘you have to include us’; the people at the podium, the chairs, the meeting facilitators may certainly ask ‘how?’ Then the PWDs and DPOs should elaborately answer this question. Otherwise, we will have no option, but to continue complaining about the exclusion of disability from development talks in the country. Capacity should therefore mean knowledge and education in the first place.

A participant with disability from FGD C concurred with the preceding views on the link between capacity, education and information; and the indispensible role these elements play in determining the inclusion or otherwise of PWDs from relevant development fora. In adding her comments, this participant stated some practical experiences relating to

what she considers the 'root issue' connected to the capacity of PWDs within the Ethiopian context:

> **Participant C-2:** The whole oppression and incapacitating attitude begins with our own families, where there is a huge lack of awareness. Except in few exceptional cases, our families don't really think of us as children who can grow into being future supporters of our family like their other kids; they don't think that we can be educated and be self-sustaining. Due to some backward views of the society, disability is still predominantly attached to curse, witchcraft or sin; we are not going out of our homes, and we don't have enough education. And such an attitude continues to permeate into schools, etc. Like, for example, if a child with disabilities is taken to school, the school might well decline to admit the child. We faced these kinds of real experiences even in our Association, the National Association for the Blind. There were instances where we took some blind kids to school, and the school said 'no, we can't accept them, because the other kids in the school might get frustrated and stressed when they see these disabled children amongst them in the school'. Due to root causes like these, the disability community remains largely uneducated, and so we are definitely living within an indescribable level of poverty. No education, huge poverty, no capacity.

Per the foregoing comment, the capacity problems that PWDs continuously suffer from, whether it is that of knowledge and education or that of financial resources, originate from the root problem of societal prejudice and misconceptions about PWDs. In line with this comment, another participant representing the Ministry of Education (MoE) said the following, citing some data specifically pertaining to the education of PWDs:

> **Participant A-2:** You know, about 58 percent of the Ethiopian population is illiterate. So due to this, these people with disability are pushed to accept that they are not useful. Because of the society and the culture, there are so many ways of demoralizing expressions and so on; the attitudinal or awareness problem is too much. So due to this, most of these people [PWDs] are in their homes. For example, if you take the World Bank assumption, from the school age population worldwide, 10-12 percent of children with school age are children with disability. In 2008/9, we had about 70 million children of school age globally, which means about 1.7 million children with disabilities according to this study. But only 41,300 of them were at school. In Ethiopia, only 2.5 percent of the overall primary school age children in the country are children with disabilities; and less than 1 percent among secondary school

> students. So what we are thinking is that, our main problem is attitude; our main problem is limited awareness. We should inform and educate families, the society, educational officials at different levels as well as PWDs and their organizations themselves. Without some significant achievement in this, I do not think we can say, in full confidence, that we are doing well on our overarching goal of EFA (Education For All), which is what we [the Ministry of Education] are basing all our efforts on.

The above feedback from the MoE representative clarifies the direct negative impact that societal misconceptions have on the education of PWDs. Due to widely prevalent attitudes that PWDs cannot be productive, the society often disregards its duty to ensure the basic right to education that PWDs deserve just as their fellow compatriots do. As rightly said, such discriminatory attitudes in turn arise from the fact that there is a deeply-entrenched ignorance and lack of disability awareness in the society at large.

Highlighting the other aspect of capacity constraint, apart from education and awareness, a representative of the Ethiopian National Association for the Deaf Blind (ENADB) shared the routine concern encountered by her colleagues at ENADB as they tried to participate in various national socio-economic discussions:

> **Participant B-1:** When it comes to this issue of capacity and our involvement in national deliberations, for example our group, the deaf-blind people, I don't think they have in any way participated in such meetings; mainly because they don't have the kind of communication means that would enable them participate in those meetings. Their communication needs are not at all taken into account; like for instance, they need to have personal assistance; they need to have, you know, a peculiar communication method that helps them understand what is being talked about. But these meetings are not organized in such a way. Or at least, they should have given us the discussion agenda beforehand, so we can take time and have a look at it. Otherwise, we do go to these meetings and be there physically, but only to remain literally unnoticed. It's only when you are allowed to speak about your needs in a very strong way that people can hear you and then, you know, such problems related directly to capacity would begin to be addressed.

Thus, even in cases where PWDs make attempts to break all the prejudices and partake in nationwide deliberations that matter to them, they remain unnoticed in these

meetings which do not take the accessibility needs of PWDs into account. In other words, the specific needs of PWDs necessary to ensure their participation in such meetings are frequently disregarded, thereby making it difficult or impossible for PWDs to be involved in these important talks. Hence, another aspect of capacitating PWDs is to make such forums as open and fitting as possible to the needs of PWDs.

In contrast to some of the previous views which stated that lack of financial resources is not the major issue at stake affecting the capacity of PWDs, a participant of FGD A expressed his comment emphasizing that money is the main issue underlying capacity:

> **Participant A-7:** Of course money is the very core of the major capacity problems that we are facing. It is because we do not have money that we can't educate people belonging to our community [of PWDs]; and that we can't facilitate our participation at all the relevant forums in such a vast country like Ethiopia. No one can mention of a government budget allocated to capacitate PWDs and DPOs and ensure their active role in this country. I have never seen any so far. Even in order to be able to solicit funds from other sources, you need the capacity to do so, which we do not have. There might be many organizations who would like to help, but we have not been able to reach them as yet, because we need the organizational capacity to do so. In cases where some support was extended from such sources, we see a big lack of proper utilization of these funds. This too is because the capacity of DPOs isn't built in a manner that enables us to utilize our resources efficiently. So yes, it all boils down to the fact that we lack the money that empowers us to actively do what we are supposed to do.

It is true that both financial resources and education or information are vital components leading to the desired level of capacity. In most cases, one produces the other, and vice versa. However, given the predominant issue of lack of awareness, in the society as well as within the disability movement itself, which has for long been negatively affecting the overall role and capacity of PWDs, it seems fair to conclude that more weight should be accorded to education and awareness in efforts to build the capacity of PWDs.

The availability of disability-specific research and data were also underlined as forming an 'intrinsic element' of the capacity of PWDs. A key informant claimed:

> **Kebede:** I think it's when there is sufficient research and data on disability that such important matters like capacity problems get to be evidently explicated. On many other crucial issues too [concerning disability], you just don't find data that support the many legitimate claims that PWDs have. Because of this, the cries of PWDs and DPOs appear to be filled with mere, un-researched complaints. Research, therefore, does form an intrinsic element of the capacity matters which have been pronounced by PWDs for decades.

Another key informant backed the previous view and added:

> **Kaleb:** Whenever we go to workshops and meetings, people talk about lack of data that demonstrates the situation of people with disabilities, and as a result, policies favouring PWDs cannot be effectively made; because policy making requires data and information. The consequence of this has been that even disability development programmes are not being effectively designed and implemented.

Both key informants bemoaned the absence of disability-specific data in Ethiopia and its ramifications on the capacity of PWDs, DPOs and the disability sector in general. It is when there is detailed research evidence concerning the level and extent of a problem that solutions to that problem begin to be properly explored. Since there is a significant lack of data on disability in Ethiopia, there is also an evident lack of efficient disability policies and strategies in the country, hence hampering the contribution, capacity and participation of PWDs.

However, one participant contested the foregoing assertions and argued that numerous studies have been carried out on disability in Ethiopia, and that this issue should not be mentioned as a shortcoming as such. In the views of this participant, if one says that there is no adequate research done in Ethiopia on disability issues, then the 'culprits' should be those who have repeatedly approached PWDs and DPOs with proposals to do research, while they actually produced nothing of much value to the community. Her full comments read:

> **Participant B-1:** We have indeed been contacted and interviewed many times by individuals and organizations who told us that they were conducting disability research. We never hesitated to cooperate with these people. We

have also seen the results of some of these studies; they are publicized. If one tells me that all these studies are not adequate, I wouldn't really understand that. I don't think research should be mentioned as one justification for the immense problems of capacity that we are undergoing both as individuals and organizations of PWDs.

Several other opinions countered most of the observations of Participant B-1, while concurring with some of her points. It was admitted that a few institutions or individuals might have approached some DPOs and PWDs with a claim that they were conducting disability research; but producing nothing in effect. Nevertheless, such rare instances cannot obliterate the other reality at hand; that is, disability research is hardly available in Ethiopia, and that this has been another hurdle holding the disability movement back for years. One key informant who is known to be well versed on disability research issues in Ethiopia said:

> **Yamrot:** To the best of my knowledge, there has not been any strong research on disability in this country. I mean, it's true that some people might have claimed at different times that they conducted and produced research on disability. But all that we have seen so far are nothing more than minor workshop papers or concept notes, at best. Those are not what we mean by 'research', properly so called. All the workshop papers that they present are just simply, you know, a kind of compilation of rather shallow studies and things like that. I haven't seen any in-depth, well-detailed and documented kind of research as such.

A participant representing MoLSA weighed in with the following comments concerning this matter:

> **Participant B-2:** With regard to research, it is not questionable. It's absolutely necessary. Different [disability] researches do have different purposes; the coverage also differs; the content also differs. We cannot limit research, saying that 'from now onwards no research' or something like that. We don't say like that, we just can't say like that. We do have lack of information on disability. That is why the number of people with disability is sometimes so minimized; sometimes it might be overestimated. So research, both quantitative and qualitative, is necessary; no doubt about this one.

Another key informant, on behalf of a disability-focused NGO, stated his opinion underlining the scarcity of disability studies in Ethiopia and its implications. He also alluded to the ripple effects of the lack of data by mentioning the recently conducted nationwide Census in Ethiopia which has understated the number of PWDs. He said:

> **Brian:** Look, we have to get serious now. What has been done in the past, except one or two exceptions, has just been real superficial kind of stuff. We desperately need empirical research. This government is very much evidence-based; this government likes to have empirical data, not just 'bla bla bla, you should include disabled people'; no no no, show us, give us the numbers. Unfortunately, the recent, not so recent now, Census has greatly undercounted the number of disabled people in the country; and it's so embarrassing that the Census Agency has not yet officially released the data. But we know that it puts the number of PWDs in the country at less than 1 percent. This is patently impossible. In a country so poor, with a history of violent conflicts and all... no, no, it's just not possible. So anyway, there is a big need for more and more research.

In a nutshell, most of the participants have underlined the lack of education and information, lack of financial resources, issues of accessibility and the absence of disability-specific research as the main capacity constraints that have restricted the active involvement of PWDs in the development endeavours of the nation.

It was also argued that, PWDs should not be considered as negligible segments of society; and hence, should *not* be referred to as the 'few others' in important policy documents. The next section dwells on this particular point.

4.3.4. 'Otherizing' Disability

The word 'otherize' was first employed by key informants to express the trend, seen in many development policy and strategic documents, of putting disability in vague and all-inclusive terminologies. Such a tendency of mentioning disability and PWDs as 'the others' is still continuing, instead of showing any sign of diminishing, said one participant with disability:

> **Participant A-4:** Even though we are of course 'disadvantaged' and 'vulnerable', as we are often referred to, we do have our own specific needs that may not relate in any way with other 'vulnerable groups'. It is these specific needs that are being blatantly circumvented through the use of very generalized and ambiguous terms such as 'the others' and the 'vulnerable'. In no way can someone convince me that I'm included in a plan that categorizes me as 'the other'. How do I know how many thousands of things are in fact assumed to exist under this term? How do I know where my exact place is within the myriad of things that this term represents? The only impression that this term gives me is that I am considered as literally insignificant, and hence, that I'm 'otherized'.

In line with the foregoing remark, key informants asserted the socio-economic impacts of such a categorization of PWDs. They also said that this approach to disability is tantamount to the exclusion of disability altogether, and is thus discriminatory by and large.

> **Yamrot:** Yes there's no explicit prohibition that forbids PWDs from being part of socio-economic plans and participation. But the reality dictates otherwise. I think the fact that PWDs are usually referred in many important strategies and forums as 'the others' indirectly instructs a systematic exclusion of PWDs, as can be seen in many routine, practical experiences of the latter. You know, even basic societal services in this country, most of them, don't seem to consider PWDs as citizens or primary clients and beneficiaries. It is a real challenge for an individual with disability to go to her locality, like what we call the *'Kebele'* in this country, and get the services which are provided there for citizens. Because most of these *'Kebele'* buildings are constructed and organized in such a manner that does not take the specific needs of PWDs into account. And many a times, their attitude is also 'inaccessible'. So these *'Kebeles'*, which are the core bases of government structure, don't make it possible for PWDs to comfortably use such fundamental services. Why? Because PWDs are just 'the others' and come at the very bottom of all concerns. The same thing is true with many health institutions, schools, recreational places and what have you. PWDs are not considered as one of the legitimate, primary clients with full citizenship rights. This is an implication that could well emanate from the very categorization of PWDs as no more than 'the others' and the 'disadvantaged' - an outdated approach that necessarily has to change for good in this 21st Century.

As correctly elaborated in the above observation, mentioning PWDs only as 'the others' and 'the disadvantaged' would often end up concealing disability issues; it disregards the specificities pertaining to PWDs. As a result, PWDs might reasonably consider this trend as another tool of discrimination in itself. It is believed that important policy documents, such as the PRSPs, should take the lead in alleviating, and gradually doing away with, the mentioning of disability in such unwarrantedly wide and ambiguous phrases.

Imminent opportunities and challenges facing the disability movement in Ethiopia, which were among the main findings of the study, are presented in the following section.

4.4. Imminent Opportunities and Threats

The findings in this section were analysed in line with the third main objective of the study; that is: *to elucidate factors that facilitated and/or hindered the DRM/DPO activities in Ethiopia with a particular emphasis on: (1) the opportunities; (2) challenges and (3) the way forward.*

Current opportunities and threats facing the disability movement in Ethiopia were among the major topics raised by participants of this study with a view to providing a complete picture of the existing scenario. These opportunities and threats need to be identified and clearly spelled out, not only to draw a full picture of the present situation, but also because they could serve as a springboard from which to indicate the way ahead.

4.4.1. Opportunities

Participants stated that there are some current and upcoming opportunities that should be highlighted in discussing the disability movement in Ethiopia. A key informant outlined most of these opportunities as follows:

> **Yamrot:** Of course, there are some opportunities that can be mentioned. There are some encouraging disability policy frameworks coming on board; like for example, there is the Building Code enacted last year at the Federal

> level; this code calls for a compulsory implementation of accessibility of buildings in Addis Ababa. We heard that they [the City Administration] are going to come up with a detailed regulation and directives on this Code, because it's only two or three articles in the Code that mentioned disability. There is also a very nice Employment Proclamation on the employment rights of persons with disabilities; it's called Proclamation 568/2008. So, I think, at the higher level there is a commitment, and the government is aware. There is also the Special Needs Education Strategy which was designed, I think, in 2006. Right now, ENDAN, the Ethiopia National Disability Action Network is working with the Ministry of Education to produce a draft framework on the special needs education on Technical and Vocational Education Training. So there are some encouraging developments.

The aforementioned remark underlined some present and upcoming changes in terms of designing a better policy framework on disability; such as the introduction of anti-discriminatory legislations, accessibility laws and improvements in the education sector. The progress seen in the education sector, in particular, was mentioned by participants as a 'role model' that should be emulated by other sector-ministries. A key informant, who was involved in designing most of the disability-inclusive programmes at the Ministry of Education, gave a detailed account of the ongoing positive developments seen in terms of introducing disability as a crosscutting issue in the education sector:

> **Gelan:** Well, in the case of the Ministry of Education (MoE), there's what is called the Education Sector Development Program (ESDP) that we formulate every five years. The purpose of the ESDP is translating the policy issues into action; that is the main goal of the ESDP. So, for example, in the current ESDP, which is ESDP III (from 2005 to 2010), Special Needs Education is considered as a crosscutting issue to be included in all the education curriculum of teacher's education. All teachers heading to primary, secondary, TVET [Technical and Vocational Training] and higher education streams are exposed to Special Needs Education before their graduation. About two million Birr was allocated in the ESDP III for Special Needs Education only. Moreover, there are, again for example, about 714 teachers, blind teachers, who have diploma and Bachelor's degree teaching in schools. Together with the government of Finland, which backs most of the Special Needs Education efforts at the MoE, some teachers got advanced education in Scandinavian countries and returned back to provide their expertise. Nowadays, some government universities have opened Special Needs Education departments

> and they are training teachers in that specialty. At diploma level, for example, we now have 5 colleges; at B.A. level we have 3 universities, at M.A. level one university and at Ph.D. level one university. So I would say that these are really great achievements. But, of course, we do acknowledge that there is a long way to go.

Admiring the strides that the MoE is making, some participants also suggested that the training about disability should not be limited to would-be teachers only. Instead, just as the issue of gender is being addressed nowadays, disability too should be a part and parcel of the regular education system; included as a subject matter on its own all the way from primary up to tertiary and post-tertiary levels of education throughout the country.

> **Etagu:** The Ministry of Education should now plan to pave the way where someone could design a disability module that can be taught or tailored to be taught at all levels of the education system, so that preschool, primary school, secondary, college and universities and all give everybody a compulsory disability module. That is basically how it is now as far as gender issues are concerned, for instance. This is obviously because these schools are the ones producing the economists that are leading the country; they are producing the teachers, the lawyers; everybody passes through the university, and they don't know anything about disability. They only confront it when they come to the workplace, behind the desk, and surely it's just one of those things that they push aside. But if people are sensitized from primary school and they're aware of this, then they wouldn't create walls when they hear the word 'disability'. That's the way it should be, we believe.

The other progress highlighted as a 'breakthrough' was the fact that disability happened to be mentioned, for the first time, in the presently under-review latest PRSP document of Ethiopia; namely, the Growth and Transformation Plan (GTP). Participants said that, even though disability is mentioned in the GTP only as a 'social welfare' issue and far less than what was hoped for, the GTP should be considered as another step forward in the right direction. One key informant reflected on this matter as follows:

> **Etagu:** The recent Ethiopian PRSP, also known as the GTP, has touched upon disability in its sub-section dealing with social welfare. Although the mentioning of disability in this important document was only brief and

> considers disability merely as a 'social welfare' issue, this is quite an improvement, especially when compared with the previous PRSPs which almost didn't say a word about disability, despite all the efforts exerted to change that situation. I think we should be really encouraged by this step forward, and continue our push. As the nice Chinese proverb says, 'a thousand kilometres journey begins with an inch of a walk'.

Other FGD participants and key informants have fully concurred with the views expressed in preceding comment.

In May, 2010, the government of Ethiopia ratified the UN Convention on the Rights of People with Disabilities (CRPD), which is also another cornerstone development, as participants added:

> **Participant A-7:** I believe that the signing and recent ratification of the CRPD by our government is a big thing for the disability movement in Ethiopia. We should continue the fight with these glimmers of hope that we are witnessing. We should make sure that these initiatives do come to the ground and produce some effective, visible change. That is the main task at hand now.

While the opportunities *in* and *for* the disability movement were highlighted as seen in the foregoing views, it was also underscored that there are current challenges facing the movement which need to be brought up. The next section looks at those.

4.4.2. Current Threats

4.4.2.1. The New CSOs/NGOs Law

A point emphasized, time and again, by participants as an 'imminent threat' that the Ethiopian disability movement is now facing was the new law passed, in 2009, by the Ethiopian government to regulate the operation of CSOs and NGOs functioning in Ethiopia. This new law, which is officially known as the Charities and Societies Proclamation No. 621/2009, basically declares that all local CSOs and NGOs in Ethiopia that aim to work on rights advocacy (and this includes DPOs) cannot operate with the support of financial means emanating from outside the country. A participant

from FGD C elaborated on the exact requirements of this law and why it poses, in her words, a 'peril' to the disability movement:

> **Participant C-6:** The letters of this law state, in clear terms, that if an organization opts to work on issues of advocacy of any kind, very much including advocating for the rights of people with disabilities, 90% of its operating budget must be generated locally, and only 10% can be obtained from an international financial backing. In a country that is so poor, with a significant portion of its people living well below the absolute poverty line, it is obvious that demanding CSOs, including DPOs, to work solely based on funds locally unavailable, is only an indirect way of telling this organizations to halt their activities altogether. This is a real peril to DPOs and the disability movement in general.

A supplementary explanation was given by a key informant who focused specifically on what this law does *not* prohibit. According to this key informant, the said restriction does not apply to a CSO or an NGO that prefers to be engaged in a 'relief and development-oriented work', as long as the organization does not touch upon matters pertaining to rights advocacy.

> **Yamrot:** The thing is that, relief and development works, such as various activities in the health and education sectors, human resource development and all that, can be carried out by any NGO without limitations on how much funding they may get from outside sources. But when it comes to addressing issues of advocacy, human rights and the like, the rule is that such an organization must operate only by financial means coming from within the nation, and nowhere else. Apparently, the justification behind this law is that, if you opt to advocate for the rights of citizens, then it should become an entirely domestic affair, and you should not get the money to do this, possibly together with other instructions, from foreign sources. It is pretty much the politics of the day, you know; 'safeguarding sovereignty'.

Due to the fact that most DPOs in Ethiopia, the Federation included, have been obtaining their basic operational budgets from international financial partnerships and grants, the enactment of this new law has posed a *clear and present* danger to their survival. What is more, this phenomenon has already begun creating further splits within the movement. On the one hand, some DPOs chose to continue their advocacy work on

behalf of disability, hence giving up any international funding in accordance with the new law. Some other DPOs, on the other hand, have opted to abandon their disability advocacy and keep themselves alive, because quitting foreign support would automatically result in their complete closure. One key informant described this as a 'real dilemma':

> **Kebede:** It is a real dilemma. The members of the Federation have decreased just since this law was passed. The Federation made a decision to register as a 'development NGO'. But some DPOs that were members of the Federation disagreed with the decision taken by the Federation and declined to register as a development NGO. Instead they said 'no, we are an association of our members, and therefore, we will continue advocating for the rights of our members, regardless of potential financial constraints'.

Pursuant to these comments, it can be concluded that that this law should have made some exceptions to make sure that rights-based movements, such as the disability movement which is only beginning to emerge, would not be aborted because of the repercussions of the law. A participant with disability stressed this point as follows:

> **Participant B-5:** We were just beginning to grow as a movement and community. There are lots of continued injustices and misconceptions in our society about disability and PWDs. There is a colossal task ahead of us to transform the entrenched attitudes in the society. As a movement, we are in a progress of maturing through various challenges and difficulties. We should not at all be compelled to relinquish advocating for our rights. It is obvious that we can't locally solicit operating budgets for this movement; we may of course get to such a level gradually. But at the moment, we just can't. Firstly, we do not have the capacity to do extensive fundraisings locally. Secondly, the society at large is not in a position to provide funding to such rights-based movements; both the economic capacity and the understanding is lacking at the moment. Also, there is no specific budget allocation by the government itself to support the disability cause. Because of all these convincing reasons, the government should have certainly made some exceptions in this law to continue encouraging the advocacy for minority rights, especially the rights of the poorest of the poor - the rights of PWDs.

4.4.2.2. Dependency on Foreign Aid

One participant expressed an argument contrary to most of the preceding views concerning the funding restrictions posed by the new law. He argued that, the disability movement is, in his words, "suffering from an extensive dependency syndrome" on foreign funding. This, he added, is the main reason which has proliferated most of the current concerns about the financial consequences of the new law. His views read in full as follows:

> **Participant A-6:** Yes, I do see that this new law is to some extent repressive. But I also believe strongly that the Ethiopian society is very much cooperative for causes that it believes in. If the society was aware that there is an active movement standing for the rights of the disabled, and if it was made crystal clear that this movement needs the support of the society, the people would definitely help. I have no doubt about that. In my opinion, the main problem is that there is an extensive dependency in the disability movement on foreign financing; that's called a 'dependency syndrome'. It is this syndrome which we have to do away with in order to be able to see the real potential resources we have at hand locally. So, I say, the issue falls back onto the movement itself. We should learn to look inward, rather than outward. A lot can and will be done without the need to look outside.

All in all, the new law and the existing dependence on foreign aid were emphasized as the main current predicaments faced by the disability movement in Ethiopia.

In recapping the discussion on present opportunities and threats, it may be concluded that the Ethiopian disability movement should be motivated by all the aforementioned improvements being recorded in the field. At the same time, however, the struggle should continue in order to remove, or at least ameliorate, the highlighted potential threats in a bid to realize an improved situation in this regard.

4.5. Chapter Summary

In this Chapter, it was discovered that participants of the study have identified a number of themes describing the Disability Rights Movement (DRM) in Ethiopia and its existing role in the country's development initiatives. Participants explained the essential

elements which, in their opinion, should constitute a disability movement in a given nation, thereby indicating what they would like to see happening in Ethiopia as well. In their discussions addressing the extent of involvement by DPOs and PWDs in national socio-economic fora, particularly the PRSP formulation process carried out thus far, participants revealed that the progress in this respect has generally been less than satisfactory. It was highlighted that *key factors*, such as inadequate government attention to the disability cause; capacity constraints within the disability movement; the lack of coordination and coalition in the sector; and the consideration of disability as an issue of *'the few others'* have been hampering the active participation of DPOs and PWDs in the Ethiopian development agenda.

Present opportunities and *threats* faced by the disability movement in Ethiopia were also raised and discussed. The mentioning of disability, for the first time, in the presently under-review PRSP document of Ethiopia (known as the *Growth and Transformation Plan - GTP*) was underscored as a 'great achievement', despite the fact that the GTP mentions disability only briefly and as a s*ocial welfare* subject alone. The recent ratification of the UN Convention on the Rights of PWDs (CRPD) by the Ethiopian government was also commended by participants as another step forward. Some current challenges were also pinpointed by participants. A law recently promulgated in Ethiopia with the potential effect of restricting activities of rights-based advocacy by local CSOs and NGOs, including DPOs, was mentioned as a 'looming danger' faced by the DRM in Ethiopia. Persistent dependency on foreign aid was also underlined as another threatening situation in the disability movement. .

CHAPTER FIVE

5. DISCUSSION OF THE RESEARCH RESULTS

5.1. Introduction

This Chapter provides a detailed, literature-based discussion of the major themes identified in the previous Chapter, so as to enable readers to broadly understand those issues discovered in the study pursuant to its objectives. The pages to follow will discuss the research results under these main headings: A) the concept of 'Disability Rights Movement' needs to be better understood and implemented; B) the involvement of DPOs and PWDs in the Ethiopian development agenda is inadequate; C) the GTP's failure to integrate disability multi-sectorally; and D) a 'new challenge' to the Ethiopian disability movement.

The chapter will finally conclude with a Chapter Summary.

5.2. The Concept of 'Disability Rights Movement' Needs to be Better Understood and Implemented

Participants of the study provided fairly detailed remarks about what they consider as a 'movement', in general, and a 'Disability Rights Movement' (DRM), in particular. According to the views of key informants and participants of the FGDs in this study, a DRM should primarily be comprised of *indispensable* elements, such as *efficient and vibrant disability advocacy* as well as *broad-based representation of the grassroots*, in order to have an effective socio-economic impact.

In line with these views, Jane Campbell and Mike Oliver (1996) suggest that the success or failure of any social movement, including DRMs and/or DPOs, must be judged against the following four essential parameters: [3 (p.168)]

1. *Whether any new political or economic changes have resulted from the activities of the movement;*

2. *Whether any specific legislation or policy measure has happened;*
3. *What changes in public opinion and behavior have been produced? And,*
4. *Whether any new organization has been created as a result of the movement in question.*

In addition to the preceding four measuring points, some argue that three additional yardsticks must also be employed in investigating a *disability movement*, in particular. These are: [3 (p.169)]

1. *The extent of consciousness raising and empowerment reached amongst PWDs;*
2. *The extent to which disability issues are raised nationally, regionally and internationally; and,*
3. *The promotion of disability as a human and civil rights issue*.

Similarly, Jerry Alan Winter (*cited in* Peter Blanck, 2005) underlined that, like any other social and civil-rights movement, a Disability Rights Movement entails certain phases of progress in a bid to produce a meaningful impact on the system that it intends to influence and ensure the recognition of PWDs.[74 (p.148)] Although PWDs in different countries might have different levels of concerns and challenges due to evident socio-economic and political variations, it is believed that a disability movement in any society should go through three major phases of development, irrespective of where the movement might be located. The *first phase* is where the movement is expected to provide a clear definition of the problem that is targeted, as well as the root causes of the identified problem(s).[74] Having clarified the problem and its sources sufficiently, the movement should then outline the corresponding solutions that it deems relevant and acceptable in line with its ideologies. This includes, but is not limited to, the enactment of appropriate legal and policy frameworks and/or the modification of existing ones.[74;3] The realization of these solutions, however, may not be adequate to signify the success of a disability movement. There may still happen to be certain issues that the movement needs to deal with even after the changes it proposed are introduced. These issues are generally referred to as the *'aftermath'* of change or *'post-change challenges'*; and

include issues such as the insufficient enforceability of laws and policies; and remnants of the modified or replaced system. The third phase is supposed to deal with these aftermaths of change.[74] It is, therefore, in going through these phases of progress that a movement eventually turns out to be a full-fledged disability movement capable of ensuring the effective recognition of disability matters in relevant socio-economic endeavours of a nation.

This study has shown that, when the disability movement in Ethiopia is seen in the light of the above measuring points, it can hardly be concluded that the movement has been satisfactorily active in bringing about the desired changes to the country's disability sector. Participants emphasized that factors, such as capacity constraints in the movement, inadequate government attention and lack of efficient coordination within the disability movement, are the main reasons for the relatively inactive role of the disability movement in Ethiopia. Thus, it is suggested that the concerned stakeholders in the movement, including the government, should re-organize the movement based on the benchmarks mentioned above, as well as the principles underlining the notion of DRM (*see Chapter Two, Section 2.2: the Concept, History and Emergence of the DRM*).

5.3. The Participation of DPOs and PWDs in the Ethiopian Development Agenda is Inadequate

It was observed from the views expressed by participants of this study that there is a unanimous response regarding the question of PWD's practical involvement in the development affairs of Ethiopia. Two rather contradictory realities emerged. On the one hand, it was admitted that Ethiopia has been undergoing a considerable process of development, particularly over the past decade. This fact was also affirmed by international commentators credible with regard to gauging the development situation of countries. These commentators stated, based on the 2010 Human Development Report (HDR), that, although Ethiopia is still one of the least developed countries in the world, its progress over the past ten years makes it one of the top ten 'movers' in Sub-Saharan Africa.[75] Additional literature shows that most, if not all, of the ongoing Ethiopian development policies, including the country's implementation of the *Millennium Development Goals (MDGs)*, are said to be underpinned by a pro-poor orientation.[76; 43]

On the other hand, however, it is equally evident that these pro-poor policies have time and again excluded a segment of society that is said to constitute a substantial portion of the poor – namely, PWDs. This is exactly the point at which the factual paradox becomes apparent: pro-poor policies of poverty eradication that do not take the poorest of the poor (PWDs) properly into account.

Participants reiterated that there is little empirical evidence demonstrating whether PWDs constitute the poorest of the poor; and whether there is a *direct link* between poverty and disability in Ethiopia. Actually, many argue that this lack of empirical evidence (i.e. the absence of a disability dimension in national censuses and surveys; or the lack of statistical exploitation of collected data) in itself is both a manifestation and result of the marginalization of PWDs. At the beginning of this thesis, we alluded to some statistical facts suggested by the few studies available in this regard (*see Chapter One, Section 1.1: Background of the Study*) These studies disclosed that PWDs are disproportionately represented among the poor in both developed and developing countries; and that in developing countries, in particular, PWDs constitute one in five of those who live below less than a dollar a day - the absolute poverty threshold.[15] The studies also claimed that the bi-directional link between poverty and disability is strong. Some articles (*e.g.* Marcel Fafchamps & Bereket Kebede, 2008) have further elaborated on this point as follows, underlining that the link between poverty and disability is even stronger in developing economies.

> Poverty may cause disability through malnutrition, poor health care and dangerous living conditions. Case studies in developing countries show that higher disability rates are associated with higher rates of illiteracy, poor nutritional status, lower immunization coverage, lower birth weight, higher rates of unemployment and underemployment, and lower occupational mobility. In turn, disability can cause poverty by preventing the full participation of persons with disabilities in the economic and social life of their communities, especially if the appropriate supports and accommodations are not available. This effect is likely to be worse in developing economies because of the reliance on physical labor for income generation – for example, in farming. [77 (p.2);]

In spite of the absence of corroborative empirical evidence, the proportion of PWDs who are poor, as well as the link between poverty and disability, is believed to be even higher and stronger in Ethiopia.[78 (p.18)]

By the same token, data on the proportion or size of PWDs in many developing countries is difficult to find, if it exists at all in the first place. Ethiopia is one example where this fact remains true to date, as was also emphasized by the key informants and participants of this study. A factor that is usually mentioned as a 'major contributor' to the absence of disability-specific data in developing countries is the relatively high cost of collecting thorough and fully representative data.[78 (p.21)] This justification, however, is often refuted by representatives of PWDs who argue that a government has the duty to carry out a periodic and nationwide census of its citizens, including PWDs. That is why disability activists consider the lack of relevant data as yet another demonstration of discrimination against PWDs.[43]

Be that as it may, estimates provided by the United Nations suggest that there are approximately 650 million PWDs worldwide, or 10 percent of the global population; an estimated 80 percent of these living in developing countries.[15] Another widely accepted figure is that of the World Health Organization (WHO), according to which PWDs make up some 10 percent of the population of any nation.[79] Obviously, these figures are believed to be much higher in countries affected by a series of armed conflicts or other natural or social disasters. Moreover, it is claimed that the aforementioned conservative figures do not take into account the ripple effects that disability inflicts on the extended family of the PWD and the community at large. When all these variables are given due consideration, it becomes evident that PWDs are not a marginal minority at all; in fact, they are sometimes referred to as the *majority of minorities* in many countries.[63]

With these facts in mind, a look at the census results disclosed by the Ethiopian Central Statistics Authority (CSA) over the past two decades proves that the CSA has barely provided reliable data on disability and PWDs in Ethiopia. While the 1984 Population and Housing Census (PHC) estimated the number of PWDs in Ethiopia at 3.6 percent of the total population, that of 1994 stated its estimate as only 1.8 percent.[80] Although not

officially published yet, the latest PHC (2007) is also said to have estimated the number of PWDs at less than 1 percent. Observably, these figures are unrepresentative of the reality, especially when seen in the light of the fact that Ethiopia has been going through numerous episodes of civil wars and natural calamities, such as recurrent famine, which are all factors known to greatly increase the number of PWDs. On top of that, the scope, standard and quality of the disability-specific data hitherto gathered by the CSA have also been widely questioned. Apart from the narrow and erroneous disability concepts employed in the surveys, it was reported also that the methodologies applied were not up-to-standard; this includes the survey instruments and the personnel who collected the data.[81] Consequently, taking the UN and WHO estimates as a springboard, it is reasonable to conclude, until better evidences come to the fore, that the number of PWDs in Ethiopia amounts to at least 10 percent of the general population. Note that the current population of Ethiopia is estimated to be about 74 million, according to the CSA Census conducted in 2007.

It is, therefore, with the foregoing realities at hand that one may find it difficult to acknowledge as complete the current development ventures of Ethiopia which, by and large, have conferred a noticeably shallow glance at matters pertaining to disability, as also underlined by the participants of this study. This can further be explored by an analysis of the country's PRSP documents – the main growth packages of the nation.

It was explained earlier in this thesis that Ethiopia was one of the first subscribers to the PRSP since the very onset of this mechanism (*see Chapter Two, Section 2.4: PRSPs in Ethiopia*). It was explained also that the PRSP process should, by definition, be essentially predicated on broad-based consultations of all layers of society, involving the poor themselves as its integral part.[43] However, the interviews with participants of this study, as well as a reading of the substance of all of the PRSP regimes so far formulated and implemented by Ethiopia, show that disability has hardly been addressed in these important documents. As mentioned above in Chapter Two, three PRSP documents have so far been formulated by the Ethiopian government (again, *see Chapter Two, Section 2.4: PRSPs in Ethiopia*). Representatives of PWDs interviewed in this study have all provided accounts of the level of involvement that was accorded to

PWDs in the formulation process and subsequent adoptions of these three PRSP documents.

As for the first PRSP, also called the *SDPRP (the Sustainable Development and Poverty Reduction Plan)* which was released for the 2000/01 through 2005/06 time period, it was conceded that the disability movement was not adequately aware of the existence of the PRSP process, which was a fairly new concept at the time. Consequently, DPOs had barely pursued the idea of partaking in that process, mainly because of the then lack of awareness about PRSPs. Put otherwise, those years were, as one of the participants described, "completely missed years", for the disability movement and its interest in the SDPRP. A somewhat similar phenomenon was recorded in other countries as well concerning the incorporation of disability in their respective first PRSPs.[43 (p.2)]

When the second Ethiopian PRSP was introduced in 2005/06, a more active and concerted initiative on the part of the disability stakeholders came to be seen, so as to ensure the insertion of disability issues in this second document known as the *PASDEP (the Plan of Action for Sustainable Development to End Poverty)*. DPOs and other disability-focused CSOs and NGOs did attempt to have their voices heard at various levels of the PASDEP formulation process. These efforts also included the establishment of a Task Force composed of all the disability stakeholders and relevant government departments in order to influence the pertinent authorities, primarily the Ministry of Finance and Economic Development (MoFED) which is in charge of the PRSP process in Ethiopia. In response to these efforts, official promises were said to have been made by the concerned government officials to the effect that the PASDEP would include disability issues. However, disability once again remained literally unrecognized in the second Ethiopian PRSP, while similar documents developed in other African countries within this time frame had incorporated disability drawing lessons from the failures and experiences of their first PRSPs (*see, for example,* A.K. Dube, 2005).[82]

In the views of the key informants and participants of this study, the main reasons attached to the successive exclusion of disability matters from the first and second PRSPs of Ethiopia were, among others:

- The low level of awareness both within the disability movement as well as pertinent government offices about PRSPs and disability inclusion;
- Lack of coordination, again both within the disability movement and relevant government offices, in efforts to realize a disability-inclusive PRSP;
- Inaccessibility of most of the PRSP discussion venues, which made it difficult for PWDs to effectively engage in these forums even in cases where they were invited to attend.

A PRSP Discussion Paper produced in 2002 by the International Labour Organization (ILO) outlined some other factors generally leading to the exclusion of disability from PRSPs (ILO, 2002). The researcher of this study believes that these factors mentioned by the ILO Discussion Paper apply directly to the Ethiopian situation as well, in addition to the factors mentioned above. According to the ILO, it might be concluded that the absence or inadequate treatment of disability issues in PRSPs is a reflection of some or all of the following:

> It might be that PWDs have not been able to formulate their needs and/or they were overruled by more powerful or vocal stakeholders when it came to negotiating a consensus. It might also be that they have not succeeded in convincing the government that practical solutions for socio-economic integration of PWDs are possible. [43 (p. 1)]

When these factors are summed up, they imply that *voicelessness* is the most important dimension of the poverty of PWDs, and that empowerment strategies for PWDs are essential.

It has to be recalled, however, that the newest and third PRSP document of Ethiopia, called the *Growth and Transformation Plan (GTP)*, has mentioned disability issues for

the first time since the country started using the PRSP approach. This recent progress is being perceived by the disability movement in Ethiopia as an encouraging move in the right direction, despite the delays seen in getting to this stage. The parts of the GTP specifically pertaining to disability were quoted and explained in detail in Chapter Two above (*see Chapter Two, Section 2.4.2: The Growth and Transformation Plan (GTP)*); thus, those parts will not be repeated here. Nonetheless, there was an issue underscored by the participants of this study as a *major limitation* of the GTP in terms of the way it addressed disability and PWDs. This limitation is that, the document mentioned disability only in its section dealing with matters of *'social welfare'*, thereby categorizing disability as a *social welfare case* alone; instead of applying a *multi-sectoral integration* of disability in the sector-strategies outlined by the document. However, one may ask at this juncture, why did the participants of this study, as well as other disability activists, assert that disability should be recognized in the PRSP as a crosscutting and multi-faceted issue? Why should disability be integrated as a component of each sector strategy in the PRSP? The next section expounds on this particular point.

5.4. The GTP's Failure to Integrate Disability Multi-sectorally

Participants have rightly emphasized that the needs of PWDs cut across multiple sectors like the needs of anybody else: education, health, employment, urban planning, housing and culture can be mentioned, among other sectors. If it is accepted that the needs of PWDs cut across all sectors just like the needs of everyone else, and that *special* or *welfare services* for PWDs are only tools to facilitate access to ordinary sector policies and programmes, it follows that the needs of PWDs should be taken into account in each of these sectoral policies and programmes themselves. Setting up the institutional framework for such a multi-sectoral disability inclusion should be a key element of any poverty reduction strategy addressing PWDs.

Literature hints that this concept of multi-sectoral integration of disability is one of the implications of the vast conceptual revolutions which have taken place in the understanding of disability in recent years.[43] It is believed to have been initiated by the

international organizations of and for PWDs and has gradually influenced national policies as well as the thinking of international development organizations. This vital notion may roughly be summarized as follows: *policy and programs in favour of PWDs should no longer be viewed as a means to rehabilitate and adapt the individual with disability to society, but to adapt society to the needs of the individual with disability;* furthermore, the concept of *rehabilitation* should give way to the concept of *creating an enabling environment*; and the concept of *social assistance* to the one of *respect of society for the rights of her minorities*.[43] The fundamental changes that this shift of attitude implies need to be properly understood, and replace pre-existing concepts such as *special treatment*, *centre for the handicapped* or even ideologies viewing disability as a *social welfare* scenario and nothing more, when it is actually much more than that. In other words, in cases where special measures need to be introduced concerning disability, it should *only* be with an underlying purpose of *offsetting* the systematic discrimination that the individual with disability might have been subjected to and to give the person access to *ordinary* policies, programmes, services and opportunities, no more and no less.

Current evidence show that such a socio-economic integration of PWDs is not only a question of social justice and a right, but the best and most prudent solution in terms of a *social cost-benefit analysis* as well. For instance, a study by the World Bank revealed that the annual loss of GDP globally, due to having so many PWDs out of active work and socio-economic involvement, ranged between 1.37 trillion and 1.94 trillion US Dollars.[83] No doubt, therefore, that economic rationality and human rights go hand in hand in this case; and that a sufficiently comprehensive PRSP addressing disability should be designed in view of this perspective. It is also important to reckon that multi-sectoral integration of PWDs means more than the reduction of social costs, because for many individuals with disabilities, socio-economic integration means a *direct participation in economic growth.*[43] It is asserted that the overarching goal of a poverty reduction programme with respect to PWDs should be to reduce the poverty of PWDs by, in the words of Simon Zadek, *'unlocking their economic potentials'*, and not by re-distributive, welfare policies (Simon Zadek & Susan Scott-Parker, 2001).[84] In the

majority of cases, therefore, costs in terms of accessibility, technical/assistive devices, and other accommodations should be seen as *investments* and not as unproductive social welfare expenditures.[84 (p.14)]

In addition, in view of the forgoing outlook, a decisive *national structural policy change* that the multi-sectoral approach calls for is the cessation or minimization of the traditional trend in which all disability-specific matters fall entirely within the ambit of a *social affair* policy and/or ministry. A departure from this trend is required for most or all of the following reasons, according to advocates of the multi-sectoral integration approach: [43]

- *The personnel of the social affairs ministry cannot be specialists in all relevant sectors concerning disability (education, employment, health, accessibility issues and the like). As a result, such services provided by social affairs personnel to PWDs would be inadequate or "second class services", at the most;*[43 (p.7)]

- *As social affairs are already in charge of sectoral services to individuals with disabilities, other competent line ministries would easily pass-off their respective responsibilities towards PWDs, thereby creating a visible gap in the implementation of programmes relating to disability; and,*

- *More often than not, extensive national macroeconomic plans happen to be strategized and implemented with little emphasis on social policies, so much so that the financial and personnel resources of the ministry of social affairs usually remain stagnant or even diminished. Eventually, ministries of social affairs end up dealing with often increasing social problems with reduced resources.*

All of these repercussions of the absence of cross-sectoral inclusion of disability were also reported by the participants of this study. It was observed in this study that the Department of Rehabilitation at the Ministry of Labor and Social Affairs (MoLSA), which is the only office in charge of disability matters in Ethiopia, has not been active enough

to meet the increasing needs of PWDs. We have also seen that Ethiopia's current rapid and macroeconomic development trajectory has set aside important social dimensions, such as disability; which, in turn, affected the allocation of operational budgets to the ministry authorized to handle social affairs. An effective introduction of the multi-sectoral integration of disability in the PRSP, it is believed, would provide sustainable solutions to these problems. On the one hand, it ensures that PWDs would be able to meaningfully avail themselves of each sector in accordance with their respective needs. This means, for instance, that a DPO seeking the modification of a certain new road structure to fit to the needs of PWDs would no longer have to go to MoLSA looking for remedies; but instead to a pertinent department specializing in disability matters at the Ethiopian Roads Authority. On the other hand, this method would also relieve MoLSA of the overwhelming technical and budgetary pressure stemming from being the only government office in charge of such a broad crosscutting issue like disability, on top of several other social issues.

Creating a disability-specific ministry can be another helpful and complementary measure in this process in a bid to make sure that the needs and interests of PWDs are properly taken into account in all sectoral policies. The essential qualification required of such a ministry is to be knowledgeable about the different sector policies and programmes relevant to disability, so as to be able to firmly advocate for the interests of its target group (PWDs) in negotiations with line ministries as well as the government as a whole.[43 (p.8)] Hence, instead of being the specialist solely of disability matters, this ministry has to be *the 'all-round connoisseur'* of a whole set of sectoral policies and programmes; it must have both competency and the necessary access to all the relevant information channels that would allow it to closely follow up on sector policies.[43 (p.8)] It is, therefore, suggested that one of the actions of a PRSP document that adequately appreciates the crosscutting nature of disability should be the redefinition of the mandate and the consolidation of the competencies of the office(s) in charge of disability; or, indeed, the creation of one.

It must be noted, nonetheless, that the quest for a cross-sectoral integration of disability does not intend giving the impression that such an approach is easy to carry out.

Proponents of this method, including some participants of this study who were proposing the same, acknowledge the practical challenges of implementing the method, and yet assert that a *strong political will and vision* can realize the effective strategizing and implementation of a sector-wide inclusion of disability; and that the PRSP is a great opportunity to do so. The following quote summarizes this point:

> [The multi-sectoral integration of disability] requires political will and vision and the capacity to defend the (re)-allocation of scarce resources against competing demands. But… it *is possible*, and that technical solutions and adequate strategies exist. The PRSP exercise is a unique opportunity to mobilize financial and political support, if only there is the will among key stakeholders to do so. It should also be clear that the final benefit for a country will be more social justice, cohesion, tolerance, diversity and peace.[43 (p.11)]

In general, a disability-inclusive PRSP makes sense only as a *comprehensive and coherent whole* of different sectoral parts that incorporate disability. The interrelation and systematic aspect is decisive here: programmes designed to ensure access to education for PWDs would remain futile if the provision of assistive devices and appliances, the accessibility of schools, public and private facilities, and the employability of PWDs are not simultaneously ensured in a coherent manner. Each element depends on all the others, and all of them are directly or indirectly elements of the PRSP and its strategies. Introducing one or the other element into the PRSP is almost of no use without a comprehensive and coherent whole. It is of course true that in poor and developing economies like Ethiopia, it might be inevitable to add another important dimension into the multi-sectoral ideology; and that is the *prioritization* of the needs of PWDs. Given the various widespread socio-economic challenges that Ethiopia faces, one should not expect a situation where all the needs of PWDs would be met simultaneously. However, the country's PRSP should endeavor to serve as a *progressive tool* to both recognizing and prioritizing the needs of PWDs in the development agenda, with the ultimate goal of ensuring a fully-fledged inclusion of PWDs.[78]

While the GTP was mentioned by the participants of this study as a new positive development in the Ethiopian disability sector, new challenges facing the sector and

movement were also revealed, as discussed in the next and last section of the findings of this study.

5.5. A 'New Challenge' to the Ethiopian Disability Movement

As discovered in this study, in a move that created some real concern about the survival and functioning of DPOs in Ethiopia, the government has recently passed legislation that could cause a fundamental reformation of all non-governmental organizations and civil society initiatives operating in the country. In the opinions of most of the participants of this study, this new development is apparently an *imminent challenge* facing the Ethiopian disability movement.

This recently enacted law (called the Ethiopian Charities and Societies Proclamation No. 621/2009) declares that if a CSO opts to work on issues concerning rights advocacy, and this clearly includes disability advocacy, it should generate 90 percent of its budgets *only* locally, and not from international funding of any sort.[97] Organizations which would prefer procuring more than 10 percent of their budgets from foreign sources can only work as 'Resident Charities' or 'Societies' focusing only on 'relief and development' work without any involvement in acts of advocacy.[85]

Knowing that most, or all, DPOs in Ethiopia have been operating by virtue of various international working partnerships and the financial support resulting from those, the aforementioned new legal restrictions would surely curtail their overall work on advocating for the rights of PWDs. The researcher has learnt that this impact has already begun to be felt within the Ethiopian disability movement in different forms. A case in point is the split currently occurring within FENAPD itself between the members wanting to stick to their advocacy work, and those considering their reformation as 'development NGOs' since they cannot exist without some external funding. FENAPD is now re-registered as a 'Resident Charity' deciding to become more of a relief and development organization; and its member associations that have decided to follow this same path have continued to remain within the Federation. Whereas, some of the founding members of FENAPD who refused to abandon their work on advocacy for

disability rights are leaving the Federation, hence notably reducing the size and influence of the latter.[39]

Advocating for the rights of PWDs is considered to be an *intrinsic element* of the activities of DPOs in any country. In a country like Ethiopia, in particular, where the rights, dignity and equal socio-economic participation of PWDs is still far from being adequately recognized, there is no doubt that an increasingly larger scale of disability advocacy is indispensable. The CRPD, which, as said above, has been ratified by Ethiopia, also underlines the need for an increased advocacy for the rights of PWDs.[51]

Thus, it is rightly suggested that the said new legal restraint should be revisited by the Ethiopian government in a manner that pre-empts the deterioration of the disability movement, which is only evolving in the country.

5.6. Chapter Summary

This Chapter discussed the main findings of the study consulting relevant literature in-depth based on the issues which surfaced in Chapter Four of the study. It was highlighted that the disability movement in Ethiopia is not sufficiently active for reasons attributable to capacity constraints, inadequate government attention and lack of harmony within the disability movement itself. A suggestion was also made to the effect that the movement should function with due cognizance of the notion, philosophies and framework of the DRM ideology which are applicable worldwide. The other main finding discussed in this chapter was based on the premise that the involvement of DPOs and PWDs in the Ethiopian development agenda is inadequate. It was explained that, although Ethiopia had excluded disability from its two successive PRSP documents; namely, the SDPRP and PASDEP, it has now accorded the issue some level of recognition in its latest PRSP called the Growth and Transformation Plan (GTP). The GTP has mentioned disability only as a social welfare issue, instead of a multi-sectoral, multi-faceted matter. A legislative challenge that was reiterated by participants as an 'imminent threat' to the disability movement in Ethiopia was also discussed in this chapter.

CHAPTER SIX

6. CONCLUSION AND RECOMMENDATIONS

6.1. Introduction

This Chapter aims to conclude this study by looking at each of the research questions raised at the beginning of the thesis and recapping how these questions have been answered by the findings of the study. Outlined below are the main research questions on which the conclusions provided in this Chapter will be based:

1. *What constitutes a 'Disability Rights Movement' (DRM)?*
2. *What roles have DPOs in Ethiopia played so far in terms of realizing the effective inclusion of disability in the country's socio-economic programmes, most importantly in the PRSPs?*
3. *What factors have facilitated and/or hindered the involvement of DPOs in the Ethiopian development agenda?*

Following the conclusions, the researcher will present a set of recommendations that he believes should be taken into account by the concerned authorities and stakeholders in paving the way forward for an increased role of the Ethiopian disability movement in the nation's development initiatives.

6.2. Conclusions

6.2.1. What constitutes a 'Disability Rights Movement' (DRM)?

This study has established that any discussion concerning a disability movement should, first of all, clarify what exactly constitutes the notion of *Disability Rights Movement (DRM)*, and investigate the disability movement in a certain country (in this case, Ethiopia) in light of such a clarification. Accordingly, it was stated that the DRM

has now become one of the emerging contemporary civil rights movements of the 21st Century and was, in fact, initially encouraged by previously emerged prominent civil rights movements such as Feminism and anti-racism ideals. It was also mentioned that scholars in the disability field refer to the disability movement as a *liberation movement* since it is basically about liberating PWDs from various forms of socio-economic and political exclusions in a given society. Like any other social and civil-rights movement, a DRM entails certain phases of progress so as to become effective in its role as a movement. Although PWDs in different countries might certainly have different levels of concerns and challenges due to inevitable socio-economic variations, it is believed that a disability movement in any society should go through these common phases of development and include the DRM ideologies detailed in Chapter One of this study. What is more, participants of the study have identified some characteristic features which, in their views, a successful Disability Rights Movement should manifest; namely, efficient advocacy, internal strength (coordination/harmony within the movement) and broad-based representation of PWDs at grassroots level.

6.2.2. What roles have DPOs in Ethiopia played so far in terms of realizing the effective inclusion of disability in the country's socio-economic programmes, most importantly in the PRSPs?

Having discussed the constituents of the notion of DRM, the study went on to assess the Ethiopian disability movement and the role it has played hitherto in realizing the recognition and inclusion of disability in the country's socio-economic development agenda, especially in the PRSPs. The study explained that DPOs began to be formed in Ethiopia in the 1960s, with the establishment of the Ethiopian National Association for the Blind (ENAB) as the first DPO in the country, followed by the Ethiopian National Association of the Deaf (ENAD). However, it was only since the 1990s that the disability movement in Ethiopia began intensifying dramatically because of some internal and external factors; such as, political changes within the country and the UN declaration of the International Year of Disabled Persons (IYDP) in the 1980s, which resulted in the creation of DPI. Several DPOs were formed in the country in the 1990s, and an

umbrella organization of DPOs, called the Federation of Ethiopian National Associations of Persons with Disabilities (FENAPD), was also founded. Interestingly, though, not all DPOs operating in Ethiopia can be a part of FENAPD, the Constitution of which requires that only single-disability, and not cross-disability, DPOs can be regular (voting) members of the umbrella organization. It was argued that the policy reflected in the FENAPD Constitution needs to be modified in such a way as to allow regular memberships to all DPOs and disability-focused organizations in the country thereby strengthening the solidarity of the disability movement as such.

It was asserted that in spite of the fact that Ethiopia is currently embarking on considerable development initiatives, the recognition accorded to disability and PWDs in these initiatives has so far been very minimal. This also holds true when one looks into the country's PRSP documents (and, by extension, the Millennium Development Goals) which have for long given little or no consideration to disability matters. The study indicated that Ethiopia has formed and implemented two PRSP regimes, the SDPRP and PASDEP, between 2002 and 2010, both of which had literally excluded disability from their respective ambits. The involvement of PWDs and DPOs in the formulation, implementation and monitoring phases of both of these documents was also reported to have been nearly nonexistent. In fact, when the first PRSP (the SDPRP) was introduced, DPOs were in general unaware of the document and the PRSP concept as a whole; hence, they did not exert any effort to participate in the process of forming the SDPRP. However, when the second PRSP (the PASDEP) was initiated, visible and repeated attempts were reported to have been made by DPOs and other stakeholders of the disability movement to ensure the participation of PWDs in the process and the ultimate inclusion of disability in the PASDEP. Interviewees representing some DPOs also recalled that, government officials had made official promises to work towards including disability matters in the PASDEP. However, to the dismay of the disability activists, this second PRSP document too came out without addressing disability issues in its contents. This outcome, the study concluded, was attributable to both the lack of attention by the Ethiopian government to disability issues and the insufficiency of the efforts made by the disability movement as well. It was also underlined that the

experiences of some African countries clearly show that most have effectively included disability beginning from their second PRSP documents, unlike the case in Ethiopia.
The third PRSP document – the Growth and Transformation Plan (GTP), which is presently being reviewed and launched by the Ethiopian government to cover a period of five years between 2010 to 2015, is considered to be an exception when compared to its predecessors. This document has, for the first time, mentioned disability explicitly in its section dealing with 'social welfare'. The study found that this latest move is considered by the Ethiopian disability movement as an encouraging step in the right direction; even if the GTP categorized disability only as an issue of social welfare, instead of a crosscutting, multi-faceted matter that should have been integrated in each of the main sections of the plan. It was also emphasized that the recognition of disability as a multi-sectoral issue, and that of PWDs as productive citizens, is not only a matter of ensuring the rights of PWDs as enshrined in the Convention on the Rights of PWDs (CRPD), but is the best and most prudent solution in terms of a social cost-benefit analysis as well. A recent study of the World Bank was mentioned as a pertinent reference in this respect; this study revealed that the annual loss of GDP globally, due to having so many PWDs out of active duty and socio-economic involvement, ranged between 1.37 trillion and 1.94 trillion US Dollars!

The Ministry of Education was repeatedly mentioned as a role model in terms of its participatory efforts to intensify and integrate special needs education at all levels ranging from primary to tertiary education by developing a national Special Needs Education Programme Strategy (SNEPS). It was underlined that this example should be emulated by all the other sectors and facilitate the way to develop a comprehensive and coherent disability-inclusive PRSP in Ethiopia.

Another recent move admired by participants of this study was the ratification of the CRPD by the Ethiopian government in May, 2010. The study reflected the hope that these recent constructive steps would also be corroborated by an increased *political will and commitment* to bring about concrete changes on the ground. Meanwhile, it was also stated that the coordination and harmony between and among stakeholders within the disability movement itself needs to be much stronger than it presently is.

6.2.3. What factors have facilitated and/or hindered the involvement of DPOs in the Ethiopian development agenda?

As pointed out in answering the preceding research question, the involvement of DPOs in the Ethiopian development agenda has generally been too low. This, in turn, logically implies that the hindrances against the participation of DPOs have outweighed the factors that might be considered as facilitative: but *both* factors did exist, according to the findings of this study.

The following were identified as the major factors that have hindered the role and involvement of DPOs in the development endeavours of Ethiopia:

- Capacity limitations: human, financial, knowledge;
- Lack of disability awareness within the general public, including government officials, especially those at lower levels where policy implementation mostly takes place;
- Inadequate government attention to the disability cause and to the empowerment of DPOs;
- A major absence of research and data on disability. This also involves the failure of national census/surveys to accurately collect and report disability data;
- Insufficient coordination and solidarity within the disability movement, as well as within the relevant government departments, which has adversely affected the effectiveness of the unilateral efforts scattered here and there;
- Lack of technical expertise on issues of disability, development and the PRSP process; hence the inability of DPOs to present a clear, measurable and convincing quest for disability inclusion in development initiatives;

- The prevalent tendency to lump disability issues into ambiguous categories such as *'vulnerable'*, *'disadvantaged groups'*, and the *'others'*, all of which fail to address the specificities of disability matters; and,

- The law recently passed by the Ethiopian government to regulate the operation of NGOs and CSOs in the country. This law requires that all organizations, including DPOs, opting to work on issues of rights advocacy must solicit 90 percent of their operating budgets solely from local sources. Participants of this study underlined, on the one hand, that the said requirement is difficult for DPOs to realize since soliciting funds locally for disability advocacy is unlikely to be effective, at least with the present socio-economic realities of the country. On the other hand, it was also suggested that the Ethiopian disability movement needs to work on ways of ensuring its continuity without a profound reliance on foreign funding.

Due to some recent constructive steps being seen in terms of the recognition accorded to disability in Ethiopia, the findings of the study indicated that there are also positive factors, though few, which should be highlighted. These are:

- The ratification of the CRPD by the Ethiopian government. The Convention demands, among other things, that PWDs participate equally in all discussions concerning the socio-economic development of signatory states and in all "decision-making processes concerning issues relating to PWDs" *(CRPD: Article 4(3)*);

- The inclusion of disability in the latest PRSP document called the Growth and Transformation Plan (GTP). It was argued that, although the GTP mentioned disability only briefly and as a social welfare issue alone, it did and will encourage further efforts and involvement of DPOs.

The study has, therefore, exhaustively answered each of the research questions it raised, as can be seen in this concluding chapter. But, what recommendations would

the researcher suggest based on the findings of this study? An answer to this last question is provided in the section to follow.

6.3. Recommendations

The researcher would like to make the following recommendations based on his findings in this study, and in line with the objectives of the research. The recommendations are categorized in terms of the specific target groups they are addressed to; namely, the disability movement in Ethiopia (i.e., DPOs, PWDs and disability-focused NGOs, CSOs and CBOs); the government; researchers and society at large.

6.3.1. The Disability Movement

The findings of this study clearly stated that the success or failure of a disability movement is determined *primarily* by the strength and vigour within the movement itself. Thus, the researcher suggests the points outlined below as steps that should be contemplated and applied by the disability movement in Ethiopia so as to attain better results in efforts to ensure the meaningful consideration of disability in the Ethiopian development agenda:

I) The creation of a harmonized, collective and collaborative disability movement that curbs the current absence of coordination seen within the movement. Such a harmony and collaborative culture would not only result in concerted actions and unified lobbying for the disability cause; it would also prevent the unnecessary wastage of resources (human, financial and time) emanating from scattered and uncoordinated activities. It also increases the possibility of exploring a variety of cost-effective, complementary mechanisms and action plans, thereby avoiding the *'reinvention of the wheel'* (the repetition of similar methods/activities by one organization after another and so forth).

II) The researcher recommends that the presently in-force FENAPD Constitution (Memorandum of Association), which does not allow cross-disability

organizations to be regular members of the Federation, be modified as soon as possible. Contemporary philosophies of Disability Rights Movements (DRMs) require, and rightly so, that a tendency whereby 'single-disability' organizations exclude cross-disability ones from their circles can only be harmful to the overall effectiveness of the disability movement as a whole.

III) Increased participation of PWDs themselves is also another important aspect that the disability movement in Ethiopia should work towards achieving. Findings of the study pointed that, there are many PWDs in Ethiopia who would like to be actively involved in the movement, but are either wondering about how they can do so, or are simply not given adequate forum from which to make their contributions. The motto *'Nothing About Us Without Us'* resonates here.

6.3.2. The Government

Based on his findings, the researcher believes that the Ethiopian government should implement the following measures in order to practically carry out its duty of guaranteeing that PWDs do partake in the country's development endeavours, equally alongside all other citizens:

I) Resolve the considerable challenge of the lack of disability-specific data which has, for a long time, negatively affected the inclusion of disability issues in socio-economic planning and implementation. This problem could be alleviated by, among other measures, improving the breadth and standard (quality) of the surveys of the Central Statistics Agency (CSA) so as to make them more inclusive of disability data. Providing the relevant training about disability to the staff and field workers of the CSA would also help a great deal in this regard.

II) It was mentioned in the study that some recent steps being taken by the government, such as the ratification of the CRPD and the inclusion of disability for the first time in the country's newest PRSP document (the GTP) are in fact commendable moves. Nonetheless, there is still a need for a visible paradigm

shift towards a comprehensive and coherent *multi-sectoral inclusion* of disability, instead of the current apparent trend of viewing disability merely as a *social welfare* case. As thoroughly explained in the study, the needs of PWDs, like those of every other section of society, are multi-faceted and do cut across all sectors of development. It is believed that implementing the cross-sectoral integration of disability in development strategies (the PRSPs, in particular) amounts both to the increase in the recognition of the *social* and *rights-based* models of disability, as well as the empowerment of PWDs and the disability movement in general.

III) In line with the preceding recommendation, the duty to address disability matters should spread across all sector-ministries, and not remain stagnant at a small department in the Ministry of Labour and Social Affairs (MoLSA). The PRSP should set a leading example in promoting this view. It was reported that the role played by MoLSA concerning disability issues has so far been minimal for reasons related to capacity, lack of resources and, most importantly, the overburdening of this Ministry by various social issues other than disability.

IV) In time, the establishment of a ministry dealing specifically and broadly with disability matters, as is already the case with issues of women, the youth and children, is strongly recommended. Such a ministry would be able to efficiently initiate, closely supervise and significantly assist socio-economic activities relating to PWDs, who constitute 10 percent of the Ethiopian population.

V) It is also recommended that the new NGO/CSO law, which requires that organizations working on rights advocacy in Ethiopia (including disability rights) must solicit their operational funds from local sources only, be applied reasonably when it comes to DPOs. Since DPOs in Ethiopia mainly depend, at present, on financial sources emanating from partnerships with similar organizations based aboard, the government should see to it that this new law would not ultimately result in the disappearance of DPOs; hence leading to the deterioration of the disability movement which has only begun emerging in the country.

6.3.3. Researchers

The study also calls upon researchers to confer due attention to disability-focused research, which is evidently lacking in Ethiopia. There is a substantial need for research evidence on matters pertaining to disability and development; and, therefore, an increased emphasis on this is obviously necessary.

6.3.4. The Public At Large

It was underlined in this study that PWDs in Ethiopia have suffered much more from societal disabling conditions (mainly marked by attitudinal misconceptions leading to prejudices, stereotypes and discrimination) than the actual 'medical' impact of the impairment itself. That is why clear distinctions had to be made between *'disability'* and *'impairments'*, on the one hand, and the *'social'* and *'medical'* models of disability, on the other. Accordingly, the society should progressively adopt the belief that PWDs can be productive; can be enabled, if only the prevalent prejudices and misconceptions in the society are effectively replaced by an enabling environment. The full participation of PWDs in socio-economic and political affairs of the country benefits not only PWDs, but the overall society and the nation as a whole; because this section of society, though it is a minority, represents a significant, potentially productive minority. Moreover, as one disability activist interviewed in this study asserted, a poverty reduction plan that does not include PWDs cannot be claimed to be a poverty reduction as such. Rightly, national development initiatives which exclude disability issues can hardly attain the MDGs as a development target.

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ADDENDA

Addendum I

List of Participants and Organizations Contacted:

Person's Name	***Organization Represented***
Mr. Kassahun Yibeltal	*Former President, FENAPD*
Mr. Memberu Tequame	*General Manager, FENAPD*
Mr. Mesfin Jonfa	*Consultant, FENAPD*
Mr. Tekalign Bayissa	*ENAPH*
Mr. Zemedkun Ayele	*ENAPH*
Mahlet Tigneh	*The Poverty Action Network of Civil Societies in Ethiopia (PANE)*
Aster Masresha	*ENAB*
Ms. Roman	*President, ENADB*
Ms. Mekdim Mengistu	*ENADB*
Mr. Eskinder Dessalegn	*ENAD*
Mr. Mamo G. Tsadik	*ENAID*
Mr. Lulseged Birhane	*Chair, ENAPAL*
Mr. Sileshi Yaregu	*Researcher*
Mr. Daniel Abreha	*FENAPD, Mekele, Tigray Region*
Mr. Demewoz	*FENAPD, Mekelle, Tigray Region*
Mr. Wondimagegn	*FENAPD, Awassa, Southern Region*
Mr. Hussien Urketo	*FENAPD, Awassa, Southern Region*
Mr. Bizualem Tayachew	*FENAPD, Bahir Dar, Amhara Region*
Mr. Asrat	*DPO based in the Oromia Region*

Mr. Alemayehu W. Kirkos	*Ministry of Education (MoE)*
Mrs. Abebech Asfaw	*Ministry of Labour and Social Affairs (MoLSA)*
Mr. Damtew Alemu	*Awareness & Advocacy Expert, MoLSA*
Ms. Genet	*PRSP Directorate Director, MoFED*
Mr. Espen Villanger	*Researcher, World Bank Office, Addis Ababa*
Mr. Fidel Sarasoro	*Head, International Development Assistance Forum: UNDP, Addis Ababa*
Ms. Laura Leonard	*Development Specialist, Irish Aid Ethiopia*
Mr. Fantahun Melles	*National Program Coordinator on Disability, ILO Regional Office, Addis Ababa*
Mr. Eshetu Bekele	*Executive Director, PANE*
Mr. Naod Mekonnen	*PRSP Research Expert, the Ethiopian Economic Professionals Research Institute (EEPRI)*
Mr. Alemayehu T. Mariam	*Dean, Special Needs Education Department, Addis Ababa University (AAU)*
Dr. Brook Lemma	*Deputy Director, Research and Graduate Programs Office, AAU*
Prof. Tirussew Tessema	*Disability Researcher; Dean, Education Faculty, AAU*
Mr. Bob Ransom	*Director, the Ethiopian Centre for Disability and Development (ECDD)*
Ms. Yetnebersh Negussie	*Program Manager, ECDD*
Ms. Hannah Nebiy	*The Federal Institute of the Ombudsman, Addis Ababa*
Mr. Getachew Adem **(CURRENTLY REPLACED)**	*Head, Economic Policy & Planning, Ministry of Finance and Economic Development (MoFED)*
Francesca Guzzo	*Project Coordinator, Comitao Collaborazione Medica, International Development*
Betelhem Abebe	*A/General Manager, Ethiopian Disability Action Network (ENDAN)*
Ms. Helen Tilahun	*Association of Students with Disabilities, Addis Ababa University (AAU)*

Mr. Habtamu Kebede	*AAU post-graduate student and Disability Advocate*
Mr. Bimrew Ambaye	*IT Specialist and Disability Advocate, Addis Ababa City Admin.*
Mr. Alemayehu Teferi	*Newly elected President, FENAPD*
Mrs. Etenesh W. Agegnehu	*Director, Handicap National (Ethiopia)*
Dr. Shewaminale Yohannes	*Curative and Rehabilitative Service Directorate, Ministry of Health (MoH)*
Mr. Abebaw	*ENAB*
Mr. Deresse Tadesse	*Media and Communications , FENAPD*
Mr. Tesfaye G. Mariam	*Journalist and Disability Activist*
Mr. Menberu Adane	*Consultant, ENAPAL*
Mr. Tagay Mecha	*ENAPH*
Mr. Bahiru	*ENAPH*
Alemtsehay Shimelis	*Ethiopian Women with Disabilities National Association (EWDNA)*
Dibabe Bacha	*EWDNA*
Hannan Endale	*ECDD*
Ms. Tetsenf Asmaf	*Disability Activist*

Addendum II

Semi-Structured Interview Guides:

SEMI-STRUCTURED INTERVIEW GUIDE FOR KEY INFORMANTS

This guide points to broad issues that meet the objectives of this study. However, the interviews will be broadened by the use of probes as well as using one method of data collection technique to inform and complement the next one. For example, the main issues that will arise from key-informant interviews will be explored further in focus group discussions for clarity, depth and breadth of the discussions.

Questions:

1. How would you describe the Disability Rights Movement (DRM) in Ethiopia; its strengths, weaknesses and challenges?
2. How would you describe the participation of PWDs and DPOs in the development initiatives of Ethiopia?
3. Can you please mention some individuals or organisations that were involved in the formation of the Poverty Reduction Strategy Papers (PRSPs) in Ethiopia?
4. Please explain what was involved in the process of forming the PRSPs.
5. Has the process achieved its intended goals?
6. In what ways were people with disabilities (PWDs) represented in this process?
7. Was the contribution of Disabled People's Organisations (DPOs), PWDs and other stakeholders collaborative or competitive? Please explain.
8. In your opinion, what should the role of DPOs be in the PRSP formulation process?
9. What would you consider the drivers for inclusion of disability in the PRSPs?
10. Similarly, what are the restrainers against the inclusion of disability in the PRSPs?
11. What should be done to include disability in the PRSPs?

12. How would you describe disability related services in Ethiopia, including access to employment and community support?

13. In what ways has the inclusion of disability in the PRSPs influenced policy changes in the functions of DPOs or the lives and situation of PWDs?

14. In what ways has the PRSPs influenced country level development policy initiatives associated with disability issues?

15. What is the role of the Constitution of Ethiopia in the formation of the PRSPs?

16. Can you think of a Critical Incident or incidents that contributed to the inclusion or exclusion of disability, and to the involvement of DPOs in the PRSP process?

17. Please explain the associated process skills that were learnt through this exercise.

SEMI-STRUCTURED INTERVIEW GUIDE FOR FGDs

This guide points to broad issues that meet the objectives of this study. However, the discussions will be broadened by the use of probes as well as using one method of data collection technique to inform and complement the next one. For example, the main issues that will arise from one focus group discussion (FGD) will be explored further in other focus group discussions or key informant interviews for clarity, depth and breadth of the discussions.

Questions:

1. How would you describe the Disability Rights Movement (DRM) in Ethiopia; its strengths, weaknesses and challenges?

2. To what extent have Disabled People's Organizations (DPOs) and persons with disabilities (PWDs) been involved in the Ethiopian PRSP process?

3. What are the factors that facilitated and/or hindered the participation of persons with disabilities (PWDs) in the Ethiopian development agenda, particularly in the PRSP formation process?

Addendum III

Letter to Participants:

.....

February 12, 2010

Dear Sir/Madam

The Role of Disability Right Movements in the Ethiopian Development Agenda

RE: REQUEST FOR YOUR PARTICIPATION

My name is Dagnachew B. Wakenè – a master's student at the University of Stellenbosch, Centre for Rehabilitation Studies (CRS) which is based in Cape Town, South Africa. I am currently working on my master's thesis with the topic mentioned above in fulfilment of the Degree of Masters majoring in Rehabilitation (M.Phil).

I hereby would like to request your (or your Organization's) cooperation in providing me with information concerning the role of the Disability Rights Movement (DRM) in the Ethiopian development agenda. I will be conducting key informant interviews and focus group discussions on this subject; hence would like your participation in one or both of these forums depending on your availability.

Should you require further details regarding my request, please do not hesitate to contact me or my supervisor at the addresses indicated below.

Many thanks in advance for your consideration of this request.

Yours sincerely,
Dagnachew B. Wakenè

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Dagnachew B. Wakenè, LL.B.
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Supervisor:
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Addendum IV

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT: The Role of Disability Right Movements in the Ethiopian Development Agenda

REFERENCE NUMBER: N10/07/229

PRINCIPAL INVESTIGATOR: Dagnachew B. Wakenè (Centre for Rehabilitation Studies, Stellenbosch University)

ADDRESS: 1. Centre for Rehabilitation Studies (CRS), Stellenbosch University. P.O. Box 19063, Tygerberg 7505, RSA

2. In Ethiopia:
P.O.Box: 56230, Addis Ababa
Cell Phone Number: +251(0) 911 133 3659

CONTACT NUMBER: +251(0) 911 133 3659 (Cell Phone)

Email: dagnacheww@yahoo.com

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the researcher any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied and that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you have agreed to take part.

This study has been approved by the **Committee for Human Research at Stellenbosch University (Ethics Approval No. N10/07/229)** and will be conducted according to the ethical guidelines and principles of the International Declaration of Helsinki; South African Ethical Guidelines for Research; and the Research Ethics frameworks within the Office of Graduate Studies at the Addis Ababa University in Ethiopia where the research takes place.

What is this research study all about?

- *The study will be conducted in Addis Ababa, the capital of Ethiopia; and is expected to involve all the relevant stakeholders located throughout Ethiopia, in cooperation with the Federation of Ethiopian National Associations for PWDs (FENAPD). Institutions/offices such as FENAPD, all the major DPOs in the country; pertinent government authorities, like the Ministry of Finance and Economic Development (MoFED), Ministry of Labour and Social Affairs (MoLSA), the Ministry of Health (MoH); academics and activists in the disability field; national and international CSOs represented by the ILO, UNDP and the World Bank are among the list of key informants in the project. It is expected that +/- 60 stakeholders will participate in the study.*

- *This research aims at analyzing the role, involvement and impact of people with disabilities (PWDs) and Disability Rights Movements (DRMs) in Ethiopia in terms of realizing the effective inclusion of disability in the development agenda of the country, with a particular emphasis on Poverty Reduction Strategy Papers (PRSPs). The research will make a thorough assessment of the prevailing scenario in Ethiopia, its strengths, challenges and opportunities, based on concrete research evidence. The study also investigates the major causes and determinants that have impacted the role of DRMs and Disabled People's Organizations (DPOs) in the Ethiopian PRSP process thus far.*

- *The study will involve conducting semi-structured Interviews with at least 10 key informants from the above institutions/offices, followed by Focus Group Discussions identified through the key informants (snowballing technique).*

Why have you been invited to participate?

- *You have been invited to participate in this study because of your experience and/or that of your organisation in the Ethiopian disability movement; and in the formulation of development policies in the country, particularly the PRSPs.*

What will your responsibilities be?

- *You will be expected to participate in interviews individually or in a group or both depending on the amount of information you have to offer.*

Will your interviews be recorded and what will happen to such recordings?

- *Yes, the interviews that you provide for this research will be recorded, on condition that the researcher has your express permission to do so. During the course of this study, the recorded interviews will be stored in a manner that only the researcher can access. Upon the finalization of the research, these recoded interviews will be destroyed altogether.*

Will you benefit from taking part in this research?

- *There are no material benefits to you personally, but your information will assist in the recognition and inclusion of disability in the Ethiopian development agenda.*

Are there any risks involved in your taking part in this research?

- *No, there are no risks involved in your participation in this study. Confidentiality will be ensured and your name will not be associated with the information you provide. Nonetheless, some information that you give us representing your organization might be stated in the final research output as the view points of the represented organization.*

If you do not agree to take part, what alternatives do you have?

- *You have the right to withdraw from this study at any point, should you feel uncomfortable. Such a decision will have no consequences whatsoever to you.*

Will you be paid to take part in this study and are there any costs involved?

- *You will not be paid to take part in the study, but your transport and refreshment costs will be covered for each study visit. There will be no costs involved for you, if you do take part.*

Is there anything else that you should know or do?

- *If you have any questions please contact the researcher,* ***Dagnachew B. Wakenè*** *on:* ***dagnacheww@yahoo.com****. Or use the contact details provided above.*

- *You will receive a copy of this information and consent form for your own records.*

Declaration by participant:

By signing below, I …… agree to take part in a research study entitled "*The Role of Disability Right Movements in the Ethiopian Development Agenda***"**.

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.

- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) .....…..…….. on (*date*) ……..…….. 2010.

....
Signature of participant **Signature of witness**

Declaration by investigator

I *(name)* ……..……. declare that:

- I explained the information in this document to ……..
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter. (*If an interpreter is used then the interpreter must sign the declaration below.*

Signed at (*place*) .....…..…….. on (*date*) ……..…….. 2010.

....
Signature of investigator **Signature of witness**

Declaration by interpreter

I *(name)* ……..……. declare that:

- I assisted the investigator (*name*) …… to explain the information in this document to (*name of participant*) …….…….. using the language medium of English/Amharic/sign language.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (*place*) .....…..…….. on (*date*) ……...…….. 2010

....

Signature of interpreter **Signature of witness**

Addendum V

Letter to Stellenbosch University, Ethics Committee:

…….....

July 10, 2010

Ms Carli Sager
Research Development and Support
Tel: +27 21 938 9140
Fax: +27 21 931 3352
Email: carlis@sun.ac.za
Stellenbosch University

Dear Ms Sager,

The Role of Disability Right Movements in the Ethiopian Development Agenda

RE: REQUEST FOR ETHICS APPROVAL

My name is Dagnachew B. Wakenè – a master's student at the University of Stellenbosch, Centre for Rehabilitation Studies (CRS). I am currently preparing to work on my master's thesis with the topic mentioned above in fulfilment of the Degree of Masters majoring in Rehabilitation (M.Phil).

I hereby would like to request an Ethics Approval from your Office for the proposed thesis, which is focused on role of the Disability Rights Movement (DRM) in the Ethiopian development initiatives, with a particular emphasis on the PRSP. The study will be conducted in Addis Ababa, the capital of Ethiopia.

Should you require further details regarding my request, please do not hesitate to contact me or my supervisor at the addresses indicated below.

Many thanks in advance for your consideration of this request.

Yours sincerely,

Dagnachew B. Wakenè
Contact Details:

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Addendum VI

Investigator's Declaration:

STELLENBOSCH UNIVERSITY

FACULTY OF HEALTH SCIENCES

HEALTH RESEARCH ETHICS COMMITTEE
INVESTIGATOR'S DECLARATION

The principal investigator, as well as all sub- & co-investigators must each sign a separate declaration.

A. RESEARCHER

Surname	WAKENE			**Initials**	D.B.	**Title**	MR.
Capacity	**Principal investigator**	X	**Sub-investigator**		**Co-investigator**		
Department	CENTRE FOR REHABILITATION STUDIES (CRS)						
Present position	MPHIL STUDENT			**E-mail**	dagnacheww@yahoo.com		
Telephone no.	**(w)**		**Cell**	+251(0)-911-133659		**Fax**	

B. PROJECT TITLE (MAXIMUM OF 250 CHARACTERS FOR DATABASE PURPOSES**)**

THE ROLE OF DISABILITY RIGHTS MOVEMENTS IN THE ETHIOPIAN DEVELOPMENT AGENDA

I, MR. DAGNACHEW BOGALE WAKENE, declare that

- **I have read through the submitted version of the research protocol and all supporting documents and am satisfied with their contents.**
- I am **suitably qualified and experienced** to perform and/or supervise the above research study.
- I agree to conduct or supervise the described study **personally** in accordance with the relevant, current protocol and will only change the protocol after approval by the **CHR**, except when urgently necessary to protect the safety, rights, or welfare of subjects. In such a case, I am aware that I should notify the CHR without delay.
- I agree to timeously report to the CHR **serious adverse events** that may occur in the course of the investigation.
- I agree to maintain **adequate and accurate records** and to make those records available for inspection by the appropriate authorised agents when and if necessary.
- I agree to comply with all other requirements regarding the obligations of clinical investigators and all other pertinent requirements in the Declaration of Helsinki, as well as South African and ICH GCP Guidelines and the Ethical Guidelines of the Department of Health as well as applicable regulations pertaining to health research.
- I agree to comply with all regulatory and monitoring requirements of the CHR.
- I agree that I am conversant with the above **guidelines**.
- I will ensure that every patient (or other involved persons, such as relatives), shall at all times be **treated in a dignified manner and with respect**.
- I will submit all required reports within the stipulated **time frames**.

Principal/Sub- / Co-investigator /Supervisor: DAGNACHEW B. WAKENE

Signature:

Date: 10 July 2010

CONFLICT OF INTEREST DECLARATION (OBLIGATORY)

I **DAGNACHEW B. WAKENE** declare that I have no **financial or non-financial interests**, which may inappropriately influence me in the conduct of this research study.

OR

 I do have the following financial or other competing interests with respect to this project, which may present a potential conflict of interest: (Please attach a separate detailed statement)

Signature: **Date: 10 July 2010**