

Places of Participation
– The Lived Experience of Persons with Disabilities in
Kampala/Uganda

Mette Strømsø

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Department of Geography

Norwegian University of Science and Technology - NTNU

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Abstract

This thesis explores the commonalities and differences of the lived experience of persons with disabilities (PWDs) in Kampala, Uganda. The endeavor of this study has been to create new references for understanding the lived experience of the embodied selves of PWDs. The thesis has identified various barriers and opportunities to participation for persons with visual and walking impairments in the mainstream society. Secondly, it has assessed how various agents at different levels of the society: macro, meso and micro negotiate access to participation for PWDs in Kampala. Finally, it has assessed how barriers are overcome in the everyday lives of PWDs, and also how it affects the lived experience of their embodied selves.

The theoretical framework that has been applied to this study is Giddens' structuration theory and Agnew's complementary approach to place; place as location, place as locale and place as sense of place. The analytical framework of this thesis is the social model of disability, although with modifications. The nature of this study is exploratory. The information collection consisted of self-selection of informants with four informal conversations, nine in-depth interviews, seven key informant interviews, and observation was as method applied throughout the fieldwork. However, limited understanding of the local context and culture, limited access to informants and a restricted selection of type of impairment are some of the methodological weaknesses of this study.

The study was conducted in Kampala. Kampala is an urban area creating particular barriers and opportunities for PWDs. However, most of Uganda's population lives in rural areas representing other barriers and opportunities to participation. The political place of participation has to a large extent been opened for PWDs albeit the implementation of laws and policies is lacking behind. Despite the inclusion of PWDs, they need information about their rights, and they also need to feel themselves capable to participate. The negotiation of access to participation appears to focus upward in the hierarchy of power rather than down to the micro level, in particular in urban areas. It seems to be the norm rather than the exception for the PWD informants, at the micro level, to avoid or adapt to the hegemonic cultural power rather than to challenge it. Women with impairments are further down on the hierarchal pecking order than men. Within the sense of place, there are individual differences of tendencies of attribution, implying that some informants internalize external oppression while others appear to have more power from within. Hence, they have more power to challenge the hegemonic cultural power.

A major limitation to this study performed in a poor African country is that most of the literature applied is produced in a Western context which might result in a Eurocentric approach and understanding of disability in Kampala.

Key concepts: Commonalities, differences, structure, agency, places of participation, power, negotiation, embodiment, impairment, disability, intersectionality, lived experience.

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Table of Contents

Abstract	i
Acknowledgements	ii
List of Figures	viii
List of Tables	viii
Acronyms and Abbreviations	ix
Chapter 1	1
Introduction	1
1.1 Global Prevalence of Disability.....	2
1.2 Approaches to Disability.....	2
1.3 Research Objectives.....	3
1.3.1 Research Questions.....	4
1.4 Significance of the Study.....	4
1.5 Limitations of the Study.....	4
1.6 Organization of the Thesis.....	5
Chapter 2	6
Theoretical, Conceptual and Analytical Framework	6
2.1 Structuration Theory.....	6
2.1.1 Human Agency.....	7
2.1.2 Social Structures.....	8
2.1.3 Contextuality, Position and Power.....	8
2.1.4 Social Action versus Social Practice.....	9
2.1.5 Persons with Disabilities – Competent Social Agents?.....	9
2.2 Linking Structuration Theory with Space and Place.....	9
2.2.1 Place as Location.....	11
2.2.2 Place as Locale.....	11
2.2.3 Place as Sense of Place.....	12
2.2.4 ‘In Place’/’Out of Place’.....	13
2.2.5 A City – A Place in the World?.....	13
2.3 Poverty and Disability.....	14
2.3.1 Poverty as Capability Failure – A Concept of the Capability Approach.....	14

2.4 Participation	15
2.4.1 Power, Empowerment and Place.....	16
2.5 Identity	17
2.5.1 Processes of Categorization and the Destabilization of the Categories.....	18
2.5.2 Intersectionality	19
2.6 The Body and its Embodiment.....	20
2.6.1 Body and Space.....	21
2.6.2 The ‘Normal’ versus the ‘Abnormal’ Body	21
2.7 Disability and the Disabled Body.....	22
2.7.1 Approaches to Disability – Two Models.....	22
2.7.2 Defining Impairment and Disability – The Terminology.....	24
Chapter 3.....	27
Methodological Approaches and the Research Process.....	27
3.1 Methods and Choice of Informants	28
3.1.1 Primary Information Collection	28
3.1.1.1 Informal Conversations	28
3.1.1.2 In-Depth Interviews.....	29
3.1.1.3 Key Informant Interviews.....	33
3.2 Assistant	35
3.3 Focus-Group Discussions.....	36
3.4 Observation	36
3.5 Researcher`s Position and Reflexivity.....	37
3.5.1 Field Relations and Negotiation of Power.....	38
3.6 Collection of Secondary Information	39
3.7 The Process of Information Analysis	40
3.8 Limitations	41
3.9 Ethical Considerations.....	42
3.10 Criteria for Good Research Practice.....	44
3.10.1 Trustworthiness	44
3.10.2 Replication.....	45
3.12.3 Transferability	45

Chapter 4	46
Study Area – Uganda, Kampala and Disability	46
4.1 Uganda	46
4.2.1 Political Structures – System of Governance	47
4.2.2 Defining Disability in Uganda.....	48
4.2.3 The Disability Movement in Uganda	49
4.3 Kampala – A Capital City	49
4.3.1 Socio-Economic and Socio-Cultural Structures	50
4.3.2 Physical and Built-Up Environment of Kampala.....	51
Chapter 5	53
Barriers and Opportunities to Participation in the Mainstream Society of	53
Kampala, Uganda	53
5.1 Political Participation	53
5.1.1 Legal framework	54
5.1.2 Information of Political Opportunities	55
5.2 Socio-economic and Socio-cultural Participation	56
5.2.1 Attitudes	57
5.2.2 Gender	58
5.2.3 Education.....	59
5.2.4 Health Care Services	61
5.2.5 Employment	62
5.2.6 Access to Land	64
5.2.7 Information.....	65
5.3 The Physical and the Built-up Environment	65
5.3.1 Mobility and Assistive Devices.....	66
5.3.2 Buildings	66
5.3.3 Transport	67
5.3.3.1 Traffic and Pedestrians	68
5.3.4 Safety and Security.....	68
5.3.5 Financial Security: The New Taxi Park and the Kampala City Council.....	69
5.4 Summary	70

Chapter 6	72
Negotiation of Places and Power	72
6.1 Agents of Negotiation	73
6.1.1 Macro Level	73
6.1.2 Meso Level.....	73
6.1.3 Micro	74
6.2 Places of Negotiation.....	74
6.2.1 Negotiation of Political Participation	75
6.2.1.1 Negotiation of Access to Information of Political Opportunities.....	76
6.2.2 Negotiation of Socio-Cultural and Attitudinal Barriers	77
6.2.2.1 Negotiation of the Disabled Body as the Negatively ‘Other’ – Macro and Meso Level.....	77
6.2.2.2 Negotiation of the Disabled Body as the Negatively ‘Other’ – Micro Level.....	78
6.2.2.3 Negotiation of Expected Daily Activities.....	79
6.2.2.4 Negotiation of Patriarchal Structures	80
6.2.3 Negotiation of Socio-Economic Barriers	80
6.2.3.1 Negotiation of Access to Education	81
6.2.3.2 Negotiation of Access to Health Care and Preventive Measures	81
6.2.3.3 Negotiation of Access to Employment.....	82
6.2.3.4 Negotiation of Access to Land	83
6.2.3.5 Negotiation of Access to Information	84
6.2.4 Negotiation of Access to the Physical and the Built-Up Environment	84
6.2.4.1 Mobility and Assistive Devices.....	85
6.2.4.2 Negotiation of Physical Barriers and the Built-Up Environment.....	86
6.2.4.3 Negotiating and Living in the Streets of Kampala	86
6.3 Summary	87
Chapter 7	88
Overcoming the Barriers - The Embodied Experience of Self in Kampala	88
7.1 More than a Label? Identity Formation and Intersectionality	89
7.2 Life Events	92
7.2.1 Traditional Belief Systems – Disability and Witchcraft.....	93
7.2.2 Education – An Object of Value	94
7.2.3 Friendship – A Place as Locale	95
7.2.4 Marriage – Another Place as Locale and an Object of Value.....	95

7.3 Living in Kampala – A Sense of Place.....	97
7.4 Disability – A Tragedy?	98
7.5 Body Perfect?	100
7.6 Empowerment	102
7.7 Summary	104
Chapter 8.....	106
Summaries, Conclusions and Recommendations	106
8.1 Barriers and Opportunities to Participation in the Mainstream Society	106
8.1.1 Summary and Conclusion	107
8.2 Negotiation of Places and Power.....	108
8.2.1 Summary and Conclusions	108
8.3 Overcoming the Barriers – The Embodied Experience of Self in Kampala.....	109
8.3.1 Summary and Conclusions	110
8.4 Recommendations	111
8.5 Limitations	112
8.6 Recommendations for Further Research	113
References	114
Appendices	131

List of Figures

Figure 2.1 Linking Structuration Theory and Place.....	10
Figure 2.2 Intersectionality.....	19
Figure 2.3 Causality in the Two Sets of Disability Definitions.....	25
Figure 4.1 Map of Uganda.....	46
Figure 4.2 Administrative Divisions in Kampala.....	46
Figure 5.1 Old Taxi Park, Kampala 2007.....	70
Figure 5.2 Market Street, New Taxi Park, Kampala 2007.....	70
Figure 7.1 Example of Elizabeth’s Intersectionality.....	90

List of Tables

Table 3.1 Number of ‘Basic’ Informants Aged 20-30 Years by Type of Impairment and Gender in Kampala 2007.....	32
Table 3.2 Number of Key Informants at Macro and Meso Level by Position.....	35

Acronyms and Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
CHOGM	Commonwealth Heads of Government Meeting
DPI	Disabled People's International
HDI	Human Development Index
HIV	Human Immunodeficiency Virus
ICIDH-1	International Classification of Impairments, Disabilities and Handicap
ICIDH-2	International Classification on Functioning, Disability and Health
IMF	International Monetary Fund
KCC	Kampala City Council
LC	Local Council
MP	Member of Parliament
NAD	Norwegian Association of Disabled
NAG	National Agriculture Services
NCD	National Council for Disability
NGO	Non-Governmental Organization
NRM	National Resistance Movement
NUDIPU	National Union of Disabled Persons in Uganda
NUWODU	National Union of Women with Disabilities in Uganda
PEAP	Poverty Eradication Action Plan
PRSP	Poverty Reduction Strategy Plan
PWD	Person with Disability
Polio	Poliomyelitis
SAPs	Structural Adjustment Programs
UN	United Nations
UNAB	Uganda National Association of the Blind
UPE	Universal Primary Education
WB	World Bank
WHO	World Health Organization

Chapter 1

Introduction

'All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood' (UDHR 1948: Art. 1). Everyone is therefore *'entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status'* (UDHR 1948: Art. 2). These two articles are the outset of the Universal Declaration of Human Rights, and they state that all people are equal through birth and that all people have the same universal and indivisible rights. However, it has become clear that all people do not benefit from the human rights, in particular as most human rights are based on the idea of autonomous individuals. All people are not in a position to demand for their rights, such as many *persons with disabilities* (PWDs) (Kälin 2004). It has been acknowledged that in order to establish *de facto* equality for PWDs, it is first necessary to abolish structural discrimination. With regard to PWDs, the United Nations (UN) Convention on the Rights of Persons with Disabilities and its Optional Protocols was adopted by the UN General Assembly in December 2006. This Convention aims to ensure that PWDs enjoy human rights on equal terms as others (UN Enable 2008). The Convention is influential albeit it has still not been ratified. In Uganda for example, the Persons with Disabilities Act was introduced in 2006. This Act focuses on the elimination of discrimination of PWDs on the ground of their disabilities and on the promotion of dignity and equal opportunities for PWDs (Act 3: a, d).

The UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities (UN Standard Rules) was adopted by the UN General Assembly in December 1993. The UN Standard Rules (1993) was launched as a result of experience gained during the UN Decade of Disabled Persons between 1983 and 1992. The political and moral foundation for the UN Standard Rules is, among some, the Universal Declaration of Human Rights and its covenants. The UN Standard Rules are not compulsory. However, they imply a strong moral and political commitment on behalf of the states to take action for the equalization of opportunities for PWDs. The purpose of the UN Standard Rules is to ensure that all members of a society may exercise the same rights and obligations as others. In all societies of the world there exists barriers preventing particularly PWDs to participate in the activities of their societies, and it is the responsibility of the states to take action in order to remove such

barriers. It is also emphasized that PWDs themselves as well as their interest organizations are opted for to play an active role in this process.

1.1 Global Prevalence of Disability

Numbers from the High Commissioner for Human Rights show that over 600 million people, or approximately 10 per cent of the world's population, are impaired in one form or another. Even though different causes and contexts vary, they share the experience of being exposed to various forms of discrimination and social exclusion (OHCHR 2008). In Africa, disability is perceived as a major public health problem with about 35 million PWDs, constituting around 7 per cent of the total African population (WHO-Afro 2008). The latest data possible to procure from Uganda is the 2002 National Housing and Population Census (UBOS 2006). In a population of approximately 24 million people in 2002, about 3.5 per cent are impaired. The disability rate in Uganda has increased from the 1.1 per cent obtained in the 1991 National Housing and Population Census. However, this increase may be partly due to improvements in methods of data collection (ibid.).

1.2 Approaches to Disability

Within the field of geography, *disability* is the study of societies' interactions with people with physical and/or mental impairments. It also focuses on the effects of such interactions on the capacities of PWDs to lead independent lives (Gleeson 1999). Different traditions have each their own interpretation of disability. The *medical, or individual, model of disability* presents disability as a condition which can be overcome by medical knowledge and rehabilitation. PWDs are perceived as the 'not normal' (Oliver 1996a). The *social model of disability*, on the other hand, sees disability not as individual limitations, but rather as society's failure to meet the needs of PWDs. This may systematically lead to discrimination throughout society through prejudicial social attitudes, values and practices (ibid.). Accordingly, PWDs throughout the world endure social oppression and spatial marginalization (Gleeson 1999). Further elaborations of the two models in Chapter 2 section 2.7.1. The social model of disability provides the analytical framework of this study, although with modifications. According to Oliver (1996a) and Sheldon (1999), the social model and the disability movement should only focus on the *commonalities* of PWDs in order to provide a strong and unified voice in the negotiation of their common issues. However, for several reasons this study also focuses on the *differences* of the *lived experience* of PWDs. Disability is not a homogenous category. Hence, persons with various impairments and other variables,

such as gender, may encounter different structural barriers in the lived experience of their *embodied selves*. Furthermore, Sheldon (2004) argues for the importance to focus on interactions between different dimensions of oppression, implying a focus on differences. Hence, it seems as if Sheldon has changed her point of view in the debate. Another issue is that the removal of *discriminatory structural barriers* represents a utopia in a short-time perspective. Hence, it is important to identify and acknowledge that PWDs experience various and different discriminatory barriers in their everyday lives. It is also important to identify and acknowledge that PWDs have different strategies for *overcoming* the barriers they encounter. As Cole (2008) argues, a focus on differences may uncover less obvious similarities in the lived experience of PWDs. Hence, such a focus may provide new approaches to overcoming the disability experience of *impairment*, and consequently new references for understanding impairment and disability.

1.3 Research Objectives

According to the human rights, everyone is entitled to equal rights and human dignity. Based on this, the social model of disability (Oliver 1996a) assumes that in order to reach human rights for all, there exist a need to remove discriminatory structural barriers in the society. As such, one of the main research objectives of this study is to identify what barriers, and also *opportunities*, that exist for PWDs to participate in the mainstream society of Kampala.

According to Giddens' (1984) structuration theory, structures are the outcome of social interaction. Hence, they are *negotiable*. Based on this, the UN Standard Rules (1993) opt for various agents from state; *macro level*, to interest organizations; *meso level*, to individuals; *micro level*, to negotiate access to participation. Another main research objective is thus to assess how the various agents negotiate access to *participation*, both through *social action* and *social practice*.

The UN Standard Rules (1993) focuses on the equalization of opportunities for PWDs to participate in the society. The social model of disability (Oliver 1996a) claims that removal of structural barriers equals the removal of the disabling experience of PWDs. Hence, PWDs should thus gain access to participation. However, total removal of barriers represents a utopia in a short-time perspective in the everyday lives of the PWDs in Kampala. The last research objective is thus to assess how the barriers are overcome, meaning acceptance of impairment while restoring a positive self-identity, in the everyday lives of the PWDs at the

micro level in Kampala, and moreover, assess the lived experience of the embodied selves of the PWDs.

1.3.1 Research Questions

- 1) What barriers and opportunities to participation exist in the mainstream society for the people being categorized as persons with disabilities?
- 2) How are the barriers being negotiated and overcome with regard to persons with disabilities access to participation in the mainstream society?

1.4 Significance of the Study

This study is a contribution to the debate on commonalities versus differences and diversification within the topic of disability. It does not reject a focus and emphasis on commonalities. The first objective of this study focuses on the identification of structural barriers and opportunities to participation for PWDs in Kampala. Hence, the study focuses on commonalities. This is because the various barriers and opportunities represent disabling or enabling *places of participation* in the lived experience of PWDs in Kampala. Another significance of such identification of barriers and opportunities is that the removal of structural discrimination toward PWDs may be more easily implemented in planning and policy processes at the macro and meso level. The second objective of the study is to assess how and by whom discriminatory structural barriers to participation are negotiated, hence, a focus on commonalities in means of negotiation and strategies. This might enable an assessment of necessities to change strategies of the various agents as to more readily reach the goal of equalization of opportunities. However, it also provides an assessment of various negotiating strategies of PWDs at the micro level to uncover different levels of *power from within*. The third, and last, objective is to assess how PWDs overcome the structural barriers and also to assess the lived experience of their embodied selves. The significance of this objective is, through a focus on difference and diversification, to provide new references for understanding the lived experience of disability through the realization that disability is more than a label.

1.5 Limitations of the Study

Research implies having to make choices. However, in a process of making choices, relevant topics and/or dimensions are left out of the study, indicating limitations (Berg and Mansvelt 2000). As such, this section provides a short list of some of the choices, or limitations, that

have been conducted throughout this study. For a complete list of limitations, see Chapter 8 section 8.5. First of all, and a major limitation to this study set in a poor African country, is that most of the literature used throughout is produced within a Western context. Hence, this may give a Eurocentric approach and understanding of disability in Kampala. A second limitation is that it is limited to Kampala, an urban context. Rural areas, which contain most of Uganda's population, may represent other structural barriers and opportunities to participation for PWDs in Uganda. A third limitation is the biased focus on public space. A more balanced focus between public and private space could have increased the understanding of the lived experience of PWDs. However, this bias is due to limited access to the informants. Throughout this study I have applied several criteria in the selection of my informants, and also included various variables to be able to give a thorough understanding of the lived experience of PWDs in Kampala. There are, however, several relevant criteria that have been left out, such as age and socio-economic status. Throughout my fieldwork, I identified these two categories, and in particular socio-economic status, as of major importance to access places of participation. They have, however, been left out of this study due to limited access to my informants, and as such, lack of relevant information. Sexuality is another variable that could have been applied to gain an insight into the lived experience of PWDs in Kampala. However, it was left out due to the possible sensitivity of the topic.

1.6 Organization of the Thesis

This thesis comprises eight chapters. Chapter two provides the theoretical, conceptual, and analytical framework of this study. Chapter three provides the methodological framework of this study. Chapter four provides background information on Kampala as the study area of disability. The empirical information and analysis is presented in Chapter five, six and seven. Chapter five focuses on the identification of barriers and opportunities to participation for PWDs in Kampala. Chapter six focuses on the negotiation of various places of participation and power-relations. Chapter seven focuses on the embodied experience of self in Kampala, and how PWDs overcome various barriers to participation in their everyday lives. Chapter eight provides summaries and conclusions related to the three research objectives and questions of this study. The chapter also provides recommendations in order to enhance the opportunities to participation of PWDs in Kampala, limitations of the study, as well as recommendations for further research based on experience gathered during this study.

Chapter 2

Theoretical, Conceptual and Analytical Framework

This study has set out to grasp the lived experience of persons with disabilities (PWDs) in Kampala, Uganda. There are several commonalities in the lived experience of PWDs in a given context, such as political and physical barriers, and to be able to negotiate these, they have to be identified. However, in order to grasp the lived experience of PWDs, there is a need to acknowledge not only the commonalities but also the diversities among PWDs. The category of disability has traditionally been understood as a taken-for-granted identity-label. The trajectory of *postmodern epistemology* has thus been to fragment the concept of identity and rather emphasize its fluidity through continuously changeable circumstances (Price and Shildrick 2002). Accordingly, the arguments of this study build mostly upon notions of postmodern epistemology.

The endeavor of this chapter is to operationalize the theoretical, conceptual, and analytical framework that has guided the work of this thesis. The chapter is divided into three sections. The first section provides the theoretical and ontological framework which in this study is represented by the *theory of structuration* and a complementary approach to *place*. The second section provides the conceptual framework of this study. The elaborated concepts are of relevance in order to grasp the lived experience of PWDs in Kampala, such as *capability*, participation, power and *empowerment*, *identity*, *categorization* and *intersectionality*, and *body* and *embodiment*. The third, and last, section of this chapter provides the analytical framework that will be used throughout this study which is the social model of disability, although with modifications. Definitions on *disability* and *impairment*, and the separation between the two concepts, will be provided in the last part of this chapter. This is because the two concepts build upon a general understanding and positioning of the concepts provided in section two of this chapter.

2.1 Structuration Theory

During the past decades there has been an ongoing debate on the *agency-structure* dualism. The Marxist perspective present individuals as passive recipients of the structures in society, while the Humanist perspective see individuals as knowledgeable agents producing social life through voluntary action (Hardcastle et al. 2005). The *structuration theory* was introduced by Anthony Giddens (1984) and emerged as a complement or alternative to structuralist

approaches, and was considered a less deterministic approach to the conception of structure and agency (Chouinard 1996). Giddens views society as neither existing independently of human activity nor being a product of it. This duality of social structures, the mutual dependency between structures and agents, is key in understanding this theory (Dyck and Kearns 2006). This notion of *duality of structure and agency* challenge the linear, temporal account of social phenomena by insisting that spatiality, or the way in which agency and structure combine in particular spaces, is central to the course of social change (Chouinard 1996). The research questions of this thesis focus on the barriers and opportunities that exist in the mainstream society in order to gain access to participation as well as how these barriers are negotiated and overcome. By understanding how agents produce and reproduce structures, then there is a potential for changing them (Hardcastle et al. 2005). The structuration theory thus provides a useful ontological framework for this research.

The relationship between agents and structures can be identified based on three theoretical levels upon which the society is built; *micro*, *meso* and *macro* (Schiefloe 2004). The micro level consists of individuals, and groups of individuals, the meso level consists of community and organizations, while the macro level consists of the society in general, including national institutions. The usage of scale and division of society into three theoretical levels is a social construction (Moore 2008). Hence, it is important to acknowledge that their separation is not as clear cut in reality. Nonetheless, such a division is useful as a category of analysis because it provides a means to identify agents at various layers in the society, and also a means to identify the linkages between them (Schiefloe 2004; Moore 2008).

2.1.1 Human Agency

The notion of duality implies that social structures are represented through the choices that agents make during social interaction, while at the same time, agents shape and reshape social structures in routinized day-to-day encounters (Teather 1999; Dyck and Kearns 2006). *Human agency* is thus not the intention people have to act, but rather their capacity for acting in the first place (Hardcastle et al. 2005). Agents are, according to Giddens (1984), knowledgeable about social actions in their everyday life. Giddens distinguishes between discursive consciousness, i.e. what people can put into words about their actions, and practical consciousness, i.e. the everyday actions that become routine although not put into words (Dyck and Kearns 2006). However, Giddens acknowledges that change occurs both as the

conscious negotiation with the structures as well as the result of unintentional and unacknowledged consequences of actions (Hardcastle et al. 2005).

2.1.2 Social Structures

Traditionally structures were considered an external force that determined human action. Giddens (1984), however, sees *structures* as social structures. Structure is thus regarded as rules and resources that exist only in the moment of social practice as established patterns of behavior produced and reproduced over time and space. They persist partly because they are viewed as chronically reproduced rules and resources and also because people operating within them consent to do so (Hardcastle et al. 2005; Dyck and Kearns 2006). The rules and resources are made available to the agent by structures of signification, domination and legitimation although defined by the hegemonic cultural powers within each space. The *structures of signification*, or interpretative rules, imply general language rules necessary for communication that constitutes meaning of what people think. These rules give meaning to the interaction albeit not necessarily understood or shared. The *structures of legitimation*, or norms, are rules relating to social conduct. These norms are interpreted and verbalized by people as rights and obligations accompanied by sanctions and rewards. Such rules are endorsed via sanctions that provide moral guidance and codes of social conduct for what people do (Hardcastle et al. 2005). While the structures of signification and legitimation are regarded as rules, the *structures of domination* are regarded as resources. Resources may be regarded as allocative resources, i.e. the economy, and authoritative resources, i.e. control of people in order to make them act in some way (ibid.). Following this, the structural components of society are both enabling and constraining as they are nothing more than the products of social interaction (Dyck and Kearns 2006).

2.1.3 Contextuality, Position and Power

Contextuality is an important concept in Giddens' theory. Contextuality implies that human interaction is situated in time and space, and concerns how social systems change over time and space. This involves the physical setting of interaction, the agents present, and the communication between them (Dyck and Kearns 2006). The position of the agent is of importance to the concept of contextuality, and different positions create different access to power and control. Power is understood as a productive resource and related to each context. However, people are never regarded as powerless (Hardcastle et al. 2005).

2.1.4 Social Action versus Social Practice

Action is an important concept in the structuration theory, and is understood to be a result of people using their agency within the structural contexts of their social setting via rules and resources (Panelli 2004). It is, however, of importance to separate the concepts of social action and social practice. *Social action* is part of the discursive consciousness of the agent, i.e. an intentional action in order to either produce or reproduce social structures. *Social practice* is, on the other hand, part of the practical consciousness of the agent which represents the routinized everyday activities (Dyck and Kearns 2006). Although agents are knowledgeable, their knowledge is limited. As a result, whether action is intentional or routinized, the consequences may be unintended. Such unintended consequences become conditions bounding further action. The binding of social systems through their extension over time and space suggests that the structural properties of social systems may be beyond the control of individual agents (ibid.).

2.1.5 Persons with Disabilities – Competent Social Agents?

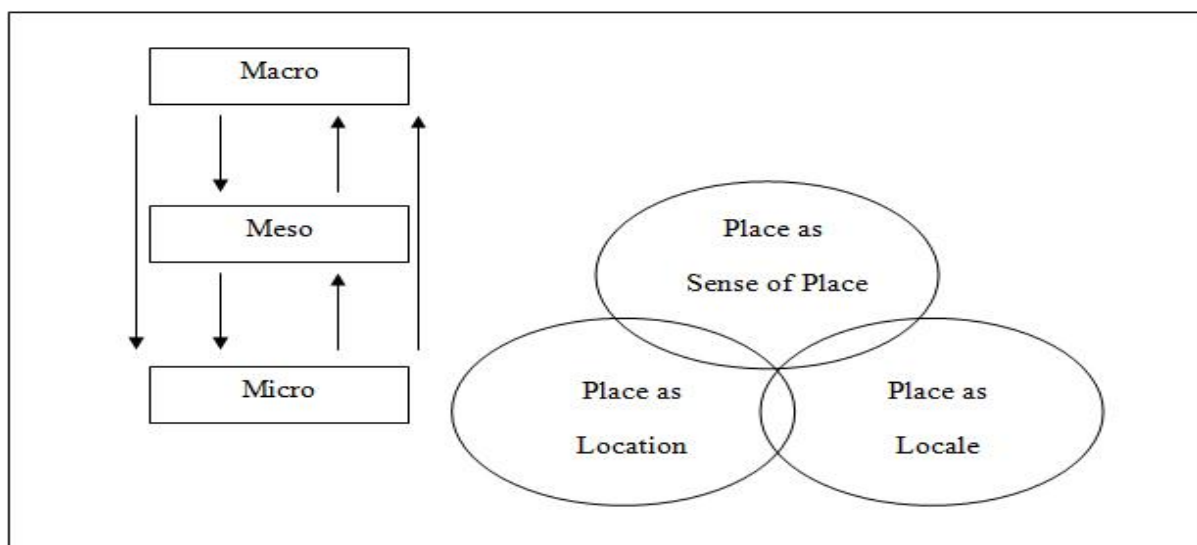
According to Giddens (1984), every person has the capacity or agency to act differently and to change and transform social practice through agency. Consequently, any individual including PWDs are to be regarded as competent social agents. However, it is of importance to acknowledge that every person has its own *set of capabilities* (Sen 1993; Burchardt 2004). See section 2.3.1 for further elaboration of the concept of capability. Hence, different agents have various access to assets and resources of which they can choose from in order to change and transform social practice. It is also important to acknowledge that every person has its own motives and strategies to act. To be able to conduct social action, an individual is in need of information and the ability to formulate an intentional action. However, as many PWDs have had limited access to education, it might be relevant to include a cognitive aspect which may represent a limited ability to acknowledge ones situation. Nonetheless, the disability experience should not be generalized. This implies that every PWD is an individual with the capacity to act as an agent. As such, although some persons have limited capability sets, they are all capable agents of change as change might be the consequence of unintentional social practice (Dyck and Kearns 2006).

2.2 Linking Structuration Theory with Space and Place

The shift from structuralism to constructivism was influenced by phenomenology. It represents a shift from a social reality determined by macro-structures to a social reality as

socially constructed. The consequence of such a focus on agency, is that development thinking has become spatialized (Nederveen Pieterse 2001). The notions of spatiality and contextuality are important features of the structuration theory as the course of social change depends on how agency and structures combine in particular *places* (Chouinard 1996). Place is, according to Sack (1997), that which is combining physical *space* with the localized cultural aspects; social rules and meanings. Human agency would be impossible without place. The debate on the meaning and content of space is important in understanding place. Up to now, I have been using both the concepts of space and place, and I will come to terms with this confusion before defining the places that will be used in this thesis. The relationship between space and place is, however, an ongoing debate. In this thesis I will use space as something general and place as something in particular. It is thus when space becomes an integrated part of social interaction and individuals relate to it, that space becomes place. Space embedded with meaning is place (Agnew 2005). Agnew (1987) identifies three main approaches to place; *location*, *locale* and *sense of place*. The three approaches are normally presented separately rather than complementary. However, Agnew (ibid.) argues for their complementarity because individuals and social interaction cannot be studied separate from the structures they are a part of (see figure 2.1 below). Figure 2.1 is a heuristic model of the link between the structuration theory and Agnew's approaches to place. The different structural levels influence each other. However, the lived experience of their effects can be located to the micro and meso level. I will now give a short explanation of each of these places and operationalize them into my theoretical framework.

Figure 2.1 Linking Structuration Theory and Place



Source: Author's own construct

2.2.1 Place as Location

The fact that space becomes place when embedded with meaning implies that the physical space that represents the setting, the restrictions and the resources of human practice, becomes *place as location* when the individuals within a particular context relate to them (Antonsen 2001). *Place as location* has been associated with economic geography and the theories of localization (Berg and Dale 2004), and it has by many been criticized for being reduced to nothing more than a passive background for social interaction (Simonsen 2001). However, Forbes (2000) argues that everything embedded with meaning can be read as a text. Hence, the physical environment of a city represents more than a passive background. The degree to which landscapes, such as a city, are made and represented indicates that landscapes are in some sense authored (Mitchell 2000). The form of the landscape actively incorporates the struggle over it although all members of a society are not equal in the process of authoring it. Following this, landscapes should be understood as the spatial surfaces of regulatory regimes (Peet 1996). As such, the *place as location*, such as the physical environment of a city, may be read as a symbol of government values and prioritizing toward PWDs (Pacione 2001). Löfgren (2006) accounts of how the built up environment creates a disabling barrier to a disabled body in his article ‘Your little doorstep is my wall’. According to himself, Löfgren did not realize the implications of the physical structure of the built environment until he became physically impaired himself. Even though Löfgren’s experience is related to a Norwegian context, his arguments make sense across national boundaries. He blames the disabling physical structures of the society to be a result of unconscious abilism due to ignorance and lack of understanding of the implications on the lived experience of PWDs.

2.2.2 Place as Locale

Place as locale is based on Anthony Giddens’ structuration theory, and implies that place is the setting, or meeting place, for individual’s everyday activities in time and space (Berg and Dale 2004). *Place as locale* is shaped through social practice and is related to the structures within a particular society. The social structures set the conditions for human interaction, but are also the result of this interaction (ibid.). Hence, potentially stigmatizing and disabling attitudes are both socially constructed through interaction and a result of the structures within a particular context (Freund and McGuire 1995). Place is, however, not a homogenous entity (Cornwall 2004). Places are dynamic, and power structures within them change over time (Lefebvre 1991). People move between domains of association, i.e. different meeting places of everyday activities, which implies that a person’s position and embodiment may change

due to context. This change has implications for the extent of opportunities of individuals or groups of individuals to negotiate attitudinal structures within a society (Cornwall 2004). In the article 'Theorizing and researching intersectionality: A challenge for feminist geography', Gill Valentine (2007) accounts of Jeanette, a hearing impaired woman, and her interaction with various *places of locale*. The article focuses on the lived experience of Jeanette. However, it also provides an example of how an individual's position and embodiment changes due to the various *places of locale* in which Jeanette takes part, such as work and interest organization. At work, Jeanette experienced to be excluded and differentiated from a hearing society due to her impairment. In the interest organization, on the other hand, her membership was related to her impairment and by being impaired she was regarded as 'in place'. As such, depending on context, Jeanette's story shows that place is no homogenous entity, and also that power-relations change due to context.

2.2.3 Place as Sense of Place

Place as sense of place is based on the subjective experience of place. This perspective stems from the humanist geography in the 1970s which focused to uncover how individuals and groups of people interpreted and attached themselves to the places where they lived their lives. However, this approach to the concept of *sense of place* has been criticized of seeing the individual without any relation to the social structures they are a part of. Although, to see an individual's *sense of place* as a sole result of the structures and context that surround them would be deterministic. However, this dualism between agents and structures has been overcome by the duality approach of the structuration theory (Berg and Dale 2004). Accordingly, people and the places where they live are mutually reinforcing each other, and the experiences of the *places of location* and *locale* may influence their *sense of place* (Freund and McGuire 1995). Identity and the notion of self are of importance to *place as sense of place* (Berg and Dale 2004). Connecting the production of identity to spatial processes involves drawing boundaries between oneself and the 'others' (Panelli 2004). In the article 'Negotiating psycho-emotional dimensions of disability and their influence on identity constructions', Donna Reeve (2002) focuses on the *sense of place* and *sense of self* of PWDs. Reeve links the production of *sense of self* to social exclusion and physical barriers within a given context. The argument of the article is that while some PWDs internalize the oppression from external structures, others resist and challenge them. As such, barriers within the physical environment, the socio-cultural environment as well as within the *sense of self* may be overcome in the everyday life of each individual.

2.2.4 'In Place'/'Out of Place'

Places are made through power-relations. The ability to define what constitutes appropriate behavior, or the hegemonic truth, in a particular place is an important form of power. The *hegemonic cultural power* constructs the normative landscape, or ideology, and defines the boundaries of proper behavior (Cresswell 1996). These boundaries are both social and spatial as they define who belongs to a place and who may be excluded (McDowell 1999). *Transgression*; the crossing of boundaries, and the reaction to it, underlines the values that are considered correct and appropriate (Cresswell 1996). A person, or a group of persons, who transgress a normative boundary may be considered 'out of place' as opposed to being 'in place'. Being 'out of place', or an outsider, is often used to describe people new to a place or people who do not know the normative landscape of a place. *Deviance* is often regarded as synonymous with being 'abnormal' as opposed to the 'normal' (ibid.). The deviant or impaired body is an obvious and omnipresent *subject position* regarded as 'abnormal' in various contexts (Chouinard 1999). As with transgression, deviance is created through reactions. It is not so much the quality of the act that a person or a group of persons commit as it is the label that the hegemonic cultural power applies to them. The process of differentiation through which 'others' are created is, according to Cresswell (1996), a basic ideological mechanism. People are being differentiated through place as *us* versus *them*, and 'in place' and 'out of place'.

2.2.5 A City – A Place in the World?

Considering that so far in this thesis I have used Agnew's (1987) complementary approach to place, I may be in danger of giving the impression that a city is an isolated and static unit in the world. Owing to this, I will argue for my use of the concept of place in a globalized world as well as introduce Doreen Massey's (1995) *progressive* understanding of place. A city is located within the borders of a nation-state, but nonetheless, as a place it has its own boundaries. Traditionally one sought the notion of place identity as a pre-given phenomenon. This is a *reactionary* approach to place, romanticizing the notion of something unique and static. This approach is thus challenged by Cresswell (1996) who argues that the meanings of places are historically constituted and vary through time. In a globalized world the concept of place has been questioned and thought to have lost its significance (Castells 1996). Nevertheless, as Massey (1995) argues, people still live in local places, and globalization and interaction between places have always existed, thus lately more intensely. Instead of being pre-defined entities, places are, according to Massey, meeting points for social interaction,

and through each encounter, new effects will emerge. Hence, each place will develop its own unique blend of processes. However, power-relations may be unequal in such encounters indicating different interdependence between places (ibid.). Accordingly, a city has its uniqueness and the lived experience of impairment and disability in a particular city may be experienced as different from the lived experience in another city, or place.

2.3 Poverty and Disability

PWDs frequently live in deplorable conditions. This may be the result of the presence of physical and social barriers which prevent their integration and participation in the communities where they live their lives. As a result, PWDs throughout the world are, to a large extent, segregated and deprived of their rights, and may lead marginal lives (Campbell and Oliver 1996). According to Ruggeri Laderchi et al. (2003), poverty eradication is a key concern for those interested in the development of poor countries, and provides the main justification for promoting economic growth and development. Despite the fact that everyone works toward poverty reduction, there is, however, little agreement on the definition of poverty. *Poverty* has traditionally been measured by a poverty line which equates well-being with income and purchasing power (Kabeer 2003). The Capability Approach as introduced by Amartya Sen (1980), on the other hand, rejects such utilitarian understanding of well-being, and endeavors to replace utility and income with *capabilities* as the *object of value* (Burchardt 2004). According to Baylies (2002) and Burchardt (2004), the capability approach and the social model of disability are complementary. See section 2.7.1 for elaboration of the social model of disability. This is because they both provide a way to conceptualize the disadvantage experienced by individuals in society, which emphasizes the social, economic and environmental barriers to equality. I will, however, only use the concept of capability in the assessment of available opportunities and the lived experience of PWDs, and not the capability approach as an analytical framework.

2.3.1 Poverty as Capability Failure – A Concept of the Capability Approach

A set of capabilities represents opportunities and the freedom to lead different types of life, and include various forms of *participation* in society. Hence, an individual that has limited opportunities to participation can be identified as *capability poor*. As such, to measure poverty and well-being by income is misleading, and therefore has to include an assessment of both personal characteristics, such as *impairment*, and the social, physical and economic environment, such as *disability* (Burchardt 2004). In order to grasp the notion of the capability

approach, it is important to understand its most basic, yet fundamental, concepts. Firstly, there are *functionings* which represent what an individual manages to do or be in leading a life (ibid.). Some functionings are very elementary, such as being adequately nourished and being in good health, while others are more complex, such as achieving self-respect or being socially integrated (Sen 1993). *Functioning achievement* refers to what an individual is or does at any given time. However, there are other functionings, or combination of functionings, that an individual could be or do at any given time, but chooses not to. A *capability set* is thus the whole set of combinations of functionings which an individual could achieve as well as those the individual is actually achieving (Burchardt 2004). Accordingly, the capability of a person reflects the alternative combinations of functionings the person can achieve, and from which the individual can choose one collection (Sen 1993). As PWDs in many cases are identified as capability poor, liberation from disability, as stated in the social model of disability, is about having the opportunity and freedom to formulate and pursue a *plan of life*, not about conforming to a pre-defined notion of normality (Sen 1999; Burchardt 2004). Sen has been criticized for not providing a specific set of minimally essential capabilities (Ruggeri Laderchi et al. 2003). However, Alkire (2002) argued that it was a deliberate move in order to ensure the relevance of the approach across societies and to allow the freedom to define what constitutes as objects of value to different persons and cultures.

2.4 Participation

As mentioned in section 2.3.1, an individual that has limited opportunities and access to participation, can be regarded as poor. *Participation* as a concept has a long history in development work and practice, although its meaning has varied throughout depending on schools of thought, institutional agendas and changing political circumstances (Hickey and Mohan 2004). Since the mid-1980s, though, participation has become mainstreamed in development work. The concept became a main focus for NGO-based development interventions whose work was focused to incorporate the knowledge and opinions of rural people in the planning and management of their own lives (Mikkelsen 2005). However, by the end of the 1990s, this mainstream approach of participation has to a large extent been criticized for its tendency to overlook the relevancy of underlying forces of socio-economic and political change (Hickey and Mohan 2004). Following this critique, the concept of participation has increasingly been linked to rights of citizenship and to democratic governance (Gaventa 2004). Given an opportunity to influence the institutions and processes which may affect ones everyday life, a person becomes an agent making and shaping its own

development (Cornwall and Gaventa 2001). According to Cornwall (2004), participation is a spatial practice, and in order to be able to participate, one needs access to these spaces. Access to participation can thus be related to the creation of spaces where there were previously none as well as changing spaces that were previously limited. Such an approach to spatio-political and socio-cultural practice is either being initiated on the one hand by those claiming rights to participation, such as some PWDs, or their interest organizations. On the other hand, access to participation is being initiated by the powerful, such as the government and the ministries. However, each party has its own implications for participatory politics, and the difference lies in the power and motivations for creating and/or entering spaces (Hickey and Mohan 2004). Accordingly, the opening of places of participation does not necessarily imply that individuals are empowered to occupy them (FRIDE 2006). Spaces of participation are thus never neutral (Cornwall 2004). See section 2.2 for the debate on space versus place.

2.4.1 Power, Empowerment and Place

The concept of *empowerment* is complex and it lacks a clear universal definition (FRIDE 2006). The notion of the concept varies depending on socio-cultural and political context, and definitions vary according to the disciplines that use the term. Accordingly, the concept of empowerment can either be understood as a process, a product, an approach or as an aim. However, in order to be of any real value, the concept requires a precise definition and use (Rowlands 1995). To be able to grasp the concept of empowerment, there is a need to understand its root concept, namely that of *power*. Traditionally, the notion of power holds negative implications. Power has been understood in the terms of *power over* thus an instrument of domination. For an individual or a group who systematically has been denied access to power and influence, such as many PWDs, the result may be what Rowlands terms *internalized oppression* hence obedience. However, the notion of power does not necessarily have to be negative. A positive notion of power implies that the increase of an individual's power not necessarily diminish that of another. This notion of power is that of *power to*, namely the ability to stimulate an individual or group to achieve what they are capable of (ibid.). Based on this understanding of power, the conventional definition of empowerment is about including people in decision-making processes, in particular those who used to be excluded. Hence enable these people to maximize the opportunities available to them. However, according to Rowlands, feminist perspectives identify that there is not only a need for access to decision-making processes but also a further process that make the people believe themselves capable of, and entitled to, occupy the spaces of decision-making. Hence,

beside the need for the *power to* is the need for the *power from within*. This understanding of power provides the basis for Jo Rowlands' understanding of the concept of empowerment, which I will follow throughout my analysis. Rowlands' approach to the concept of empowerment is three dimensional. The first dimension is based on the *power from within* where empowerment is about developing a *sense of self* and self-confidence. The second dimension is relational where empowerment is about the ability to negotiate and influence the nature of relationships and the decisions made within them. The third and last dimension is collective where empowerment is about working together in order to achieve a greater impact than what an individual could have managed alone (Rowlands 1995; FRIDE 2006). Following Rowlands' approach, empowerment is a process through which poor and marginalized people, such as many PWDs, can partake in order to achieve greater participation in the mainstream society. However, access to participation does not necessarily give empowerment. Access to decision-making processes implies a need for access to a space of political participation. However, spaces are produced and defined by the dominant group, or hegemonic culture, within them (Valentine 2007). Hence spaces have unequal power-relations. Spaces that are opened, changed or created in order to give access to poor and marginalized people might result in change of the *de facto* power-relations, and consequently empowerment. However, new relations of power and knowledge are continuously inscribed in new systems of organization (McCall 2005).

2.5 Identity

The notion of *identity* has throughout the history been heavily contested (Panelli 2004). Traditionally, orthodox and structuralist thinkers saw identity as a notion of the self as a stable and autonomous entity. This approach has been challenged for being too essentialist as it limits the opportunity of the individual to change and develop him or herself. During the 1990s, post-structuralists like Foucault elaborated on the concept. Instead of looking upon identity as something we have, it became regarded as a process in which individuals and groups of individuals position themselves from, and identify themselves through, a discourse. The notion of the self is no longer regarded as something stable but rather as something fluid that is expressed through different *subject positions* (ibid.). Identity is thus considered to be something that is formed and performed through discourses and social encounters. Identity may be performed through an individual's body, dress, actions, or space, hence through that individual's different subject positions. According to Hetherington (2000), identity is about establishing recognition and difference with others associated with processes of self-

recognition, belonging and identification with others. However, identity is not necessarily free or voluntary, as some identities or labels, such as disability, may be constrained or excluded in certain settings (Panelli 2004). Nonetheless, to use an identity or label to categorize an individual, or a group of individuals, as a homogenous entity, is essentialist.

2.5.1 Processes of Categorization and the Destabilization of the Categories

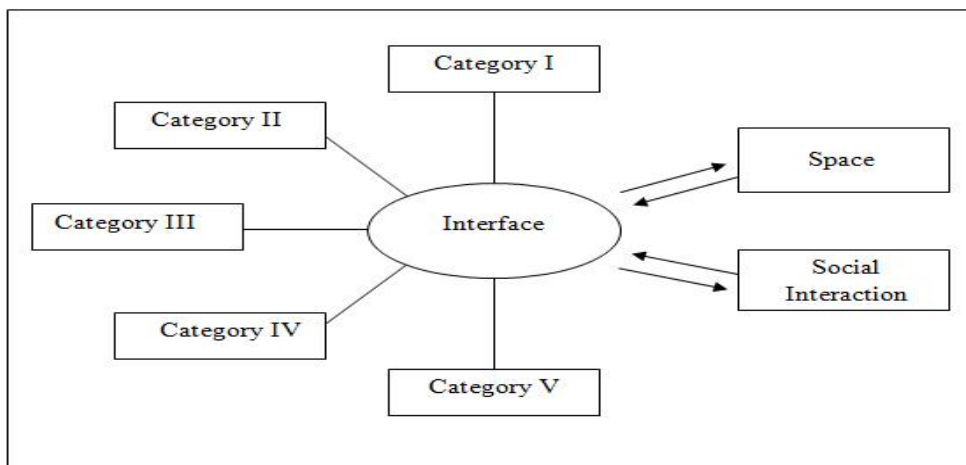
For an individual, the world is complex. We *categorize* its parts in order to make sense of the complexity of the world. We simplify the world to be able to define who we are. In relation to such categories, we form our identities. We identify ourselves with some categories as opposed to others. Although not all categories are dichotomous, such opposing categories are called *binary categories* (Cloke and Johnston 2005). Binary thinking often includes a position of *us* versus *them*, and the *us* is often regarded as superior to *them*, hence, representing asymmetrical power-relations (Gibson-Graham 2000). Examples of such binary categorization are *structure/agency*, *mind/body*, *impairment/disability*, *normal/abnormal*, and *sex/gender*. Binary thinking is treated as natural and given despite the fact that the binaries are contested as socially constructed categories (Thomas 2004). According to Jenkins (2000), there is, however, no necessary equation of categorization with stigmatization and oppression. Following this, Gibson-Graham (2000) argues that there is a need to blur the boundaries of the categories on each side of the divide in order to undermine their solidity as to show how the negatively ‘other’ is embedded with the supposedly superior identity. Accordingly, the *destabilization* of the binary serves to familiarize a certain identity of a negatively ‘other’, hence, deconstruct the meaningfulness of a given identity (Doel 1999 a, b).

A relevant example is the separation of *impairment* and *disability* as I will come back to in section 2.7.2. According to Thomas (2004), when defining impairment and disability, the body is treated as obvious and objective. Hence, this dualism is based on the Cartesian separation of the mind and body (see section 2.6 for further elaboration). Accordingly, the binary categorization of impairment and disability fails to acknowledge that they are both socially constructed and that one cannot separate the two in order to understand the lived experience of the individuals at stake (ibid.). The concept of intersectionality and its related concept of situated accomplishment are means of negotiating the binary thinking of categories as to be able to grasp the lived experience of PWDs.

2.5.2 Intersectionality

The concept of *intersectionality* is a contribution to the postmodern and feminist debate concerning commonality versus difference and diversification. The interest for intersectionality stems from the development and critique of research within the fields of gender and race. Feminist researchers, focusing on women, were criticized of treating women as a universal and homogenous category (Yuval-Davis 2006). As such, they failed to give a fair account for the *lived experience* of the individuals defined by the interfaces between different categories (McCall 2005). Critical race theorists, however, rejected the tendency of isolating the experience of race as opposed to the interrelatedness between several categories, such as including gender, class, or disability (Valentine 2007). Despite the fact that identity is understood as a process, to regard an individual as the result of a collection of separate categories would thus be an essentialist approach to understanding someone's identity. The concept of intersectionality describes the interconnections and the interdependence of different categories (ibid.). This implies that each individual has its own unique interface of different categories. The concept of intersectionality does not, however, add anything new to the post-structural approach to the concept of identity until it is related to space and social interaction. While interacting with and negotiating different power-relations in the spaces of everyday life, an individual is forming its own life and identity. This is referred to as *situated accomplishments*, and focus in particular on how individuals perform their identity (West and Fenstermaker 1995). A heuristic model of intersectionality is provided in figure 2.2 below. However, the number of categories in the figure is just an example. Depending on each context, some parts of an individual's identity become emphasized while others are suppressed or made irrelevant (Valentine 2007).

Figure 2.2 Intersectionality



Source: Author's own construct

Even though the concept of intersectionality provides an opportunity to gain insight into the lived experience of individuals, it is still of importance to be aware of its critiques. Following Valentine (2007), who finds the concept useful in her work, states that the concept of intersectionality overemphasizes the abilities of individuals to actively produce their own lives. This is due to the fact that in all spaces of participation where individuals live their lives and perform their identities, there are unequal power-relations. Hence, some identities are more difficult to enact rather than others.

As mentioned above, the concept of intersectionality is a contribution to the debate about *commonality* versus *difference*. In relation to disability, the disability movement and the social model of disability reject the emphasis on difference and lived experience, which the concept of intersectionality offers (Sheldon 1999). See section 2.7.1 for further discussion. Oliver (1996a) and Sheldon (1999) argue that the introduction of feminist concepts such as intersectionality that focuses on lived experience may result in a fragmentation of their collective action, hence, challenge the unified voice of the movement. Cole (2008), on the other hand, suggests that the concept of intersectionality is not only a means for understanding difference, but rather a way to detect less obvious similarities.

2.6 The Body and its Embodiment

What is the *body*? This question has fascinated philosophers throughout history. Nonetheless, there is no universal agreement to the question (Valentine 2001a). Some argue that the body is a concrete material of flesh and bones while others find it clear that it is more than that (Teather 1999). The matter of the body, however, cannot be taken for granted and treated as obvious (Longhurst 2001). Anyhow, there are some debates about the meaning and nature of the body that have received primacy in the literature, such as that of the *mind* and *body* dualism (Valentine 2001a). As mentioned in section 2.5.1, the world is categorized in order to comprehend its complexity. Until the 1960s, geography was dominated by the Cartesian dualism of mind and body which has by many philosophers and social theorists been treated as natural and given (Thomas 2004). The mind represented male domain for reason and knowledge and the body had female associations, and was secondary, and as such, undermining women's capacity to be rational (Teather 1999). Reason was thought to enable the mind and soul to reach the divine while as the senses confine the soul to the changeable corporeality (Alcoff 1996). Although this dualism has been recognized for its influence on geographical knowledge production, the debate has been evolving since the 1960s,

particularly through the work of Merleau-Ponty (Gabe et al. 2004). The contemporary understanding, as argued by Probyn (1991), implies that the body and self are enfolded within each other; an *embodied self*. According to Nast and Pile (1998:1), '*We all have a body, or at least, we all are one. Although these things appear to be universal, our embodied experiences are unique*'. This implies that bodies and their meanings can only be understood by the individuals themselves as well as by the surrounding society in specific spatial, temporal and cultural contexts (Longhurst 2001). In this respect, the notion of embodiment concerns the lived experience of our bodies in the world. Hence, the mind is put back into the body, the body is back in the society, and the society is back in the body (Gabe et al. 2004).

2.6.1 Body and Space

Based on Nast and Pile's (1998) argumentation, we must have bodies since we are alive. Bodies are coherently something material and because we have bodies, we must be located somewhere. Hence, our bodies occupy space as well as they are spaces themselves (Teather 1999). There are three ways in which the body can be thought of as a space. The first is as a material surface marked and changed by the culture. Secondly, the body may be thought of as the material basis for our connection with the world, and finally, as the distinction between the surroundings and our psychological experience (Valentine 2001a). It is thus through the body that space is perceived, lived and produced (Lefebvre 1991). The body is both an object and a target of power, and as the bodies are both space in itself as well as occupying space, access to and use of space varies according to bodies and their embodiments (Teather 1999). Bodies are thus omnipresent subject positions through which we negotiate our access to spaces either involuntary or through deliberate choice.

2.6.2 The 'Normal' versus the 'Abnormal' Body

The variation in appearance, practices and mobility of bodies in different cultures is used by social scientists as an argument for bodies to be socially constructed (Davis 1997). This implies that bodies and their meanings can only be understood in their specific spatial, temporal and cultural contexts. What is to be regarded as a 'normal' versus an 'abnormal' body in a specific context is thus a socially constructed binary category. Accordingly, what is regarded as culturally 'normal', and proper, is based on the shared beliefs within a group of people in a particular place (Helman 2007). As place is produced and defined by the most powerful group, the hegemonic culture defines which body that is regarded as being 'normal',

or 'in place'. Hence, it is through the dominant notion of the 'normal' body that the distinction of the disabled body as a negatively 'other' is constructed (Chouinard 1999).

2.7 Disability and the Disabled Body

Disability is a term which has many different understandings both historically and contextually. In the Western context, the notion of the disabled body is linked to the industrial revolution and the introduction of capitalism at the turn of the 18th century. Owing to the inability to partake in the new organization of labor, the disabled body was regarded as the negatively 'other' (Gleeson 1999). This view of the causes of disability has, however, been criticized for being flawed due to its association with Marxism (Shakespeare and Watson 2001). Post-structuralists suggested that disability is rather a linguistic and discursive matter in which the being or becoming of disability is a social construction of those who can exercise power through forms of knowledge (Thomas 2004). In the non-Western context, on the other hand, physical abnormality is often seen as the result and expression of some abnormality in that person's relationships with their social or supernatural environment (Helman 2007). However, many *traditional belief systems*, such as the pre-industrial Western context and also the non-Western context, often externalize the cause of disability. This implies that events occurring outside the disabled body, such as *witchcraft* and divine punishment are the original causes of the disability (Barnes et al. 1999; Helman 2007). See Chapter 7 section 7.2.1 for further elaboration of disability and witchcraft.

2.7.1 Approaches to Disability – Two Models

At the beginning of the 20th century, the personal tragedy view of disability and impairment, currently referred to as the *medical, or individual, model of disability*, was securely entrenched (Barnes et al. 1999). However, the discourse on health and illness did not consider a disability a defining state (Donoghue 2003). Parsons' theory on the sick role (1951) was considered an authority within the field of disability. Illness was considered a social role in which an individual was not expected to be able to fulfill obligations and responsibilities. Disability studies, however, did not come into the academy until the 1950s, although still influenced among many by Parsons (Barnes 2004). The focus was on bodily abnormality in which this was thought to cause some degree of disability or functional limitation (Barnes et al. 1999). It was assumed that PWDs wanted to be what was regarded to be 'normal'. Hence, any kind of impairment should be avoided, eradicated or normalized by any possible means (French and Swain 2004). Disability was thus a condition which could be overcome by

medical knowledge and rehabilitation (Oliver 1996a). However, during the 1960s and 70s, this approach to disability began to change with the emergence of a disability movement (Barnes 2004). Building a joint identity broadened the personal to the political, and the PWDs started to create a more positive image of themselves (French and Swain 2004). Accordingly, during the 1980s, several researches of which were mostly disabled, began to focus on how society disabled people with various forms of impairment (Barnes 2004). The *social model of disability* was introduced and first published by Mike Oliver (1983). Disability was no longer regarded as an individual limitation but as society's failure to meet the needs of the disabled. Such societal failure may systematically lead to discrimination throughout society through prejudicial social attitudes, values and practices (Oliver 1990). Accordingly, the focus of the model was to remove the existing physical and societal barriers for an individual to be able to participate in the society (Shakespeare and Watson 2001). Throughout the 1990s, a focus on rights and independent living was coupled with the social model. Although popular in use, the social model has been heavily criticized. Many disability researchers have been concerned for its focus on the collective experience of disablement and consequently lack of sufficient space for exploring the personal effects that impairment might have for an individual (Robertson 2004). According to Oliver (1996a), this focus has not been to deny the lived experience of impairment, but rather been a pragmatic attempt to address issues that can be changed through collective action rather than medical treatment. The model has also been criticized for being born out of the experiences of the Western minority world (Swain 2004).

The social model of disability provides the analytical framework for this study, although with modifications, and I will justify this for two reasons. The first reason is that although my research has been conducted in the poor majority world, Stone (1999) argues that there is evidence that the model makes sense across cultures and countries for many PWDs because it does not have a pre-defined set of discriminatory structural barriers. The second reason is that the social model identifies disability in a type of causal relationship with society, and not with impairment. Accordingly, there exists a need for social action in order to overcome the discriminatory societal barriers. As mentioned above, the social model will be applied to this study with modifications. While Oliver (1996a) argues for excluding the lived experience of impairment, it will be used in this study as to complement a focus on the physical and societal barriers for two reasons. Firstly, a focus on individuals and their lived experience with impairment and disability through encounters with structural barriers may detect differences. Hence, destabilize the so-called homogenous category of disability. Secondly, and following

an argumentation by Cole (2008), a focus on lived experience and differences may actually detect less obvious similarities between the individuals. As argued in Chapter 1 section 1.2, this may provide new approaches to overcome the disability experience as well as new references for understanding impairment and disability.

2.7.2 Defining Impairment and Disability – The Terminology

When writing about disability and the lived experience of the impaired body, it is of importance to clarify the terminology. This is because the terminology itself can be disabling and discriminatory. Traditionally, the terminology of impairment corresponded with the medical model of disability (Bolt 2005). Disability was perceived and classified in terms of a meta-narrative of deviance, lack and tragedy separated from the notion of normality (Corker and Shakespeare 2002). This notion became evident with the set of definitions provided by the International Classification of Impairments, Disabilities and Handicap (ICIDH-1 1980) of the World Health Organization (WHO),

Impairment: In the context of health experience, impairment is any loss or abnormality of psychological, physiological or anatomical function.

Disability: In the context of health experience, a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for human being.

Handicap: In the context of health experience, a handicap is a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfillment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual.

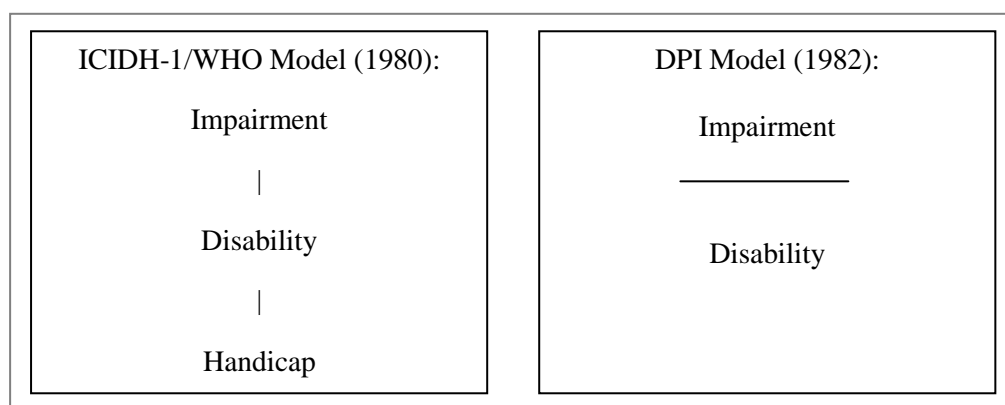
By including the concept of handicap in this definition, i.e. the social disadvantage of being disabled in a hostile environment, it was perceived that one took one step away from the medical model of disability (Bury 1996). However, it was still based on the assumption that the disabled body was not ‘normal’, and rehabilitation programs were set up in order to enhance the functioning of the disabled bodies. This set of definitions was criticized by the Disabled People’s International (DPI) (Bolt 2005). Accordingly, the concepts of impairment and disability were redefined by the DPI (1982) as,

Impairment: The functional limitation within the individual caused by physical, mental or sensory impairment.

Disability: The loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers.

This set of definitions put disability in a causal relationship with society rather than impairment, and the concept of handicap was rejected by the DPI because of its pejorative connotations (Bolt 2005; Winance 2007). See figure 2.3 below for the causality in the two sets of definitions. As such, I will use the concept of impairment when I refer to a physical limitation within the individual, and the concept of disability when I refer to a limitation of opportunities. However, my informants use only the concept of disability. Consequently, when quoting my informants, the concept of disability will be used for both experiences.

Figure 2.3 Causality in the Two Sets of Disability Definitions



Source: Oliver (1996a)

Accordingly, the social model of disability can be regarded as a shift from the notion of impairment as the cause of disability to the way in which physical, cultural, and social environments exclude or disadvantage those being labeled as disabled (Barnes 2001). This shift in terminology has been acknowledged by the ICIDH-2, now called International Classification on Functioning, Disability and Health (WHO 2008a), as the emphasis is on body functions and structures, activities and participation, as well as environmental factors. Along with the development of the social model of disability, there became an increasing focus on disability as exclusively social, and according to Oliver (1996a), had nothing to do with the body. As such, impairment is found among people in all societies. A disability, however, is not just the result of the individuals capabilities, or lack of such, but rather depends on the environment, the expected daily activities, and the attitudes of others (Gleeson 1999).

There is, however, a further clarification of terminology to be made, namely that of *people* with disabilities versus *persons* with disabilities. The debate concerns *us* and *we* versus the first-person *I*. Those arguing for using the terminology of *people* and *us* are emphasizing the

oppression of disabled people as a group (Bolt 2005). I acknowledge the relevance of the general oppressive societal structures toward PWDs, and I will use it myself in the assessment of commonalities. However, I choose to use the term *persons* with impairment and disabilities rather than *people* in order to further acknowledge the personal experience of their lived embodiment but also to avoid presenting them as a homogenous group.

Chapter 3

Methodological Approaches and the Research Process

According to Kitchin and Tate (2000:1), '*research is the process of enquiry and discovery*'. How you choose to solve the research process depends on your research questions and the theoretical framework. The research questions and what topic the researcher decides to focus on reflect in many cases the researcher's position within the philosophy of science. The main methodological dualism depends on epistemological differences between conducting quantitative or qualitative research (Grbich 1999). *Quantitative methodology* focuses on breadth and numbers, and the goal is to obtain generalizations. Quantitative methods are perceived to be objective, which implies that the data are believed to exist in the world, and it is the researcher's job to collect them without being able to influence the results (ibid.). The *qualitative research tradition*, on the other hand, focuses on contextualized understanding and meaning of processes and individuals (Thagaard 2003). The information collection is subjective and produced in the meeting between the researcher and the informant.

The research objectives determine the methodology. I chose a qualitative approach to my research as the purpose of my research is to identify the barriers and opportunities that exist for persons with disabilities (PWDs) with regard to participation in the mainstream society. I also assess how the barriers are negotiated and overcome through everyday practice. The nature of my research is *exploratory* as I work to identify important variables instead of starting the research with a pre-defined set of ideas on the topic (Kitchin and Tate 2000). Focusing on interpreting individuals' thoughts and actions to a higher level of abstraction than that which is immediately perceived is a hermeneutical approach to the *ethnographic methodology* (Thagaard 2003). Ethnography is a holistic approach in the study of people and cultures, and stresses the inter-dependency among the component parts (Mikkelsen 2005). The ethnographic methodology is *inductive* which means that one seeks new perspectives and questions to approach topics that one does not have thorough pre-knowledge of. It is a flexible methodology that focuses on process and meaning, and in order to do this, one works with a few cases to go in-depth of the topics and the informants (Kitchin and Tate 2000). The *hermeneutical approach* does not seek to find an absolute truth, but is based on the idea that phenomena can be interpreted at different levels. Meaning can only be understood and interpreted in the context of the phenomena. The classical approach to hermeneutics saw solely the written text as the medium for interpretation, but more contemporary approaches

argue that everything that is embedded with meaning can be read as a text (Forbes 2000). Following this, interviews and observations of landscapes and social interaction that all are embedded with meaning can also be read and interpreted as text. My approach to the hermeneutics is, on the one hand, to relate to the lived experience of my informants and their interpretations of it. On the other hand, I conduct my own interpretations based on a reconstruction of the social agents' interpretation through the use of theoretical concepts. This approach is called a *double hermeneutics* (Thagaard 2003).

3.1 Methods and Choice of Informants

My information collection consists of primary and secondary information. The advantage of conducting *primary information* collection is that you always know how the information has been produced. However, with time as a limitation, you have to consider the necessity of generating all the information yourself. Using *secondary information* on the same topic of other researchers may as well be used in order to argue for the trustworthiness of your work (Kitchin and Tate 2000). See section 3.6 for limitations of secondary information.

3.1.1 Primary Information Collection

In my primary information collection I have used a *triangulation of methods* to be able to answer my research questions. In my theoretical framework I use the structuration theory (Giddens 1984). This theoretical approach structures the society into different levels; micro, meso and macro. I also use Agnew's (1987) complementary approach to place in my theoretical framework. The usage of these theories requires different methods. I have used *informal conversations, in-depth interviews, key informant interviews, and observations*. In the following section, I will give a thorough explanation of the application of the methods. Under each method I will argue for the choice of informants.

3.1.1.1 Informal Conversations

Prior to the in-depth interviews, I conducted some *informal conversations* as a small *pilot-study*. I did not know how sensitive the topic of disability was, nor did I know how sensitive it would be to make notes during the interview. I also decided upon doing the informal conversations prior to the interviews as this might give me valuable information to add to my *interview guide* (Valentine 2001b). My assistant and I approached a group of PWDs, who were most willing to talk. See section 3.2 for elaboration of the role of my assistant. These people were all men with walking impairments. Beforehand, my assistant and I had rehearsed

the interview guide, and I had explained explicitly to my assistant what the intentions were. The informants questioned why we did not make notes during the conversations as we would lose information. It appeared to be more important for them that their stories were recorded rather than me caring about the sensitivity of the topic. Despite the fact that these preliminary conversations gave me valuable information on how to conduct interviews on a sensitive topic, there were some *limitations*. Firstly, I only spoke with men with walking impairments. Women with walking impairments and persons with visual impairments might have responded differently. Secondly, these men might represent a particularly confident selection of PWDs, while others might have been more intimidated by my presence and questions.

Choice of Informants

My assistant led me to an area of the city where she from previous observations had identified as a place where many PWDs were located. I had also been directed to this area by other residents of Kampala. We started out by walking around in the area to observe potential informants. We approached several people, and spent the day chatting with them. As mentioned above, they were all men and had walking impairments as we could not locate any women or any persons with visual impairments. We were, however, directed to women with walking impairments, of which one became one of my 'basic' informants, but nobody we spoke to knew where we could find anyone with visual impairments in the streets.

3.1.1.2 In-Depth Interviews

Interview as a method is a way of gaining access to information about events, opinions and experiences (Dunn 2000). One of the major strengths of interviewing is that it allows the researcher to learn what is relevant to its informants. The qualitative interview can be organized in different ways (Thagaard 2003). The topic for my research is disability, and to some of my informants a sensitive topic. My informants at the micro level, is in my study represented by the PWDs themselves. To approach the topic at this level, I chose the *in-depth interview* based on a *semi-structured interview guide* (Kitchin and Tate 2000). I formulated and sequenced my topics in advance as to not risk asking insensitive or leading questions. However, as my goal was not to compare the answers of my informants, I was allowed better possibilities to follow topics that I had no knowledge of in advance, such as gaining insight into the lived experience of the embodied selves of my informants. Another strength of the semi-structured interview guide approach was the flexibility of conducting a more conversational interview, albeit depending on each interview-situation (Kitchin and Tate

2000; Thagaard 2003). The main topics of my interview guide (see appendix 1A) was my informants' background, their experience with their surrounding physical environment, social attitudes of the society in general, and their own lived experience with their impairments. I wanted them to tell me about their life in retrospect as well as their present life situation. I started by asking them about their background as I thought that this could give the interview a general start for what I believed to be the more sensitive topics. I also thought that to cover their life while growing up would give a better understanding for their responses to the rest of my questions. My intention was to *funnel the interview* from general issues to more personal and sensitive topics (Dunn 2000). It became apparent that stories of their lives while growing up were of the most sensitive topics because this gave them a chance to reflect on previous experiences with their impairments. Consequently, I changed my approach from starting with questions about their background to questions that naturally followed the conversation we were having prior to the formal interview situation.

As research, at least within the qualitative tradition, is based on social interaction, and thereby a *social production*, it is not objective but subjective. Knowledge is then *situated* (Haraway 1988). The knowledge produced in an interview situation depends on the relationship between the researcher and the informant (Dunn 2000). I was in control of the three interviews conducted in English while the six interviews in Luganda were more influenced by my assistant. It is important to have time to build *trust* and *rappport* with the informants to create a good atmosphere for the interview, as well as *framing the interview* situation (ibid.). However, my time with and access to my informants was limited. On the other hand, as some of my informants expressed gratitude of me taking interest in their life situations, I realized that despite the above mentioned limitations I did get access to some rich information.

I started each interview with a short introduction of myself and my study. I emphasized that partaking in my study was voluntary and that all information given to me would be *confidential*, meaning that everything they told me would stay with me and that they would not be recognized in my study. As my position as a white, academic researcher seemed to rise expectations, I explicitly told them that I was only a student with no funding. I also told them that if they did not want to spend their time on me, I would understand. Before we started the interview, I implied that the interview would take approximately 45 minutes, and I asked for permission to use my tape-recorder. However, in some settings I chose not to use my tape-recorder. The two main arenas for my interviews with my 'basic' informants were in the

streets and in two vocational schools. Most of my informants in the vocational schools spoke English, and the interviews were set in classrooms away from any noise. In these situations I used my *tape-recorder* which may have enhanced the trustworthiness of the study. However, as English was not the native language of my informants, I might have lost valuable information as they might have had trouble finding words to express themselves properly. In the streets, however, the setting of the interviews was in most cases in street market areas, with lots of traffic and people around us. Most of my informants did not feel comfortable speaking English, and the interviews were carried out by my assistant in their local language Luganda. Instead of using a tape-recorder, my assistant made *notes*. After each of the interviews that took place in Luganda, my assistant and I went through all the questions and responses to fill in the gaps in the notes she made. Every day after fieldwork I wrote my *diary* with the day's immediate reflections and observations as well.

Choice of Informants

I applied four criteria to select my informants. The first one was impairment. There are many types of impairment, but I chose two, those of persons with visual impairments and persons with walking impairments. There are gradations of visual and physical impairments as well as my informants are much more than their impairments. See Chapter 2 section 2.5.1 for discussion on such categorizations. I have, however, chosen to use the two categories of type of impairment for three reasons. Firstly, these two groups comprise the highest prevalence of impairment in Uganda (MGLSD 2006). Secondly, the two groups have different needs with regard to mobility and how to access the society. Thirdly, the two categories of impairment are visible, hence, easily identifiable. The second criterion was informants who had become impaired throughout their life, something they all had. This was applied as it could possibly result in informants who could reflect on the differences of being part of the mainstream society prior to their impairment. My third criterion was gender. I wanted to assess whether there were any differences between men and women with impairments and their access to participation in the mainstream society. Lastly, I chose to focus on the age-bracket of 20-30 years. I wanted them to be adults as to be able to reflect in a broader and deeper way on their impairments and their experiences of disablement. However, to focus on this age-bracket alone made me lose the opportunity to compare generational differences between PWDs. Initially, I thought that people of older age would feel that disability was a topic too sensitive to discuss. Still, I realized during my fieldwork that I could, however, get access to some elderly impaired persons. Despite its relevance, I chose

not to use them as informants because they were people of positions, and there would be a *bias* toward people in the streets who, by my experience, were more interested in my money.

My original intention was to use the interest organizations as *gate-keepers* to get access to the PWDs. However, the organizations I had identified were administrations with hardly any focus on the grassroots-groups in Kampala. I realized this at the same time as I observed that socio-economic status appeared to be of great importance for PWDs to gain access to the society. Hence, socio-economic status was added as a last criterion for selecting informants. To achieve this, the *bias* of using the organizations for recruiting informants would be too obvious. Consequently, I also went to the streets and identified informants myself. I chose to identify their differences by how they earned an income or were related to income-generating activities. My informants were one beggar, three participants in informal activities, such as street vendors, four students at vocational training schools, and one teacher with university education. See table 3.1 below for number of ‘basic’ informants by type of impairment and gender. However, due to the small selection of ‘basic’ informants in this study, with only one person in the formal employment sector, socio-economic status has been cut from the analysis. Considering the small number of informants at the micro level, I will refer to them by names throughout the analysis. However, in order to ensure their *confidentiality*, I will use *pseudonyms* (see appendix 2 for list of informants).

Table 3.1 Number of ‘Basic’ Informants Aged 20-30 Years by Type of Impairment and Gender in Kampala 2007.

	Females	Males	Total
Persons with visual impairments	2	1	3
Persons with walking impairments	2	4	6
Total	4	5	9

Source: Own fieldwork

In the streets, I used a *snowball-method* to find my informants (Thagaard 2003). My assistant and I started by walking in the streets where we identified relevant informants. By approaching these, some had friends or knew someone who also were impaired, and introduced us. Through the interest organizations and the officials, I managed to identify the few relevant vocational schools where I could find informants, and approached them by just showing up. I had to get access through the school administrations, although they seemed to be worried of what I was asking the students as if they thought my focus was the quality of their schools. In

one of the schools I was asked for a research certificate, which I did not have. However, as I could refer to a person of position who had identified the school for me, I got access anyway. In the other school, the school administration apparently tried to control my understanding of the school by entertaining me with a show. Instead of giving me time to observe their daily routines and talking with the students, the students sang for me and the director asked questions to the students with impairments in front of the whole school. This provides an example of attitudes toward, and understandings of, PWDs.

It was very difficult to find persons with visual impairments. I asked people in all the organizations and offices, and everybody directed me to the specific interest organization. However, they either could not or would not give me access to any informants. At the same time I surprisingly realized that most schools, organizations and programs for this particular group were not located in Kampala but rather in rural areas. Consequently, I got better access to persons with walking impairments which creates a *bias* within the category of type of impairment. This also represents a bias of visibility. I only got access to PWDs that I could identify myself. As such, this represents a major bias toward the PWDs who are not easily identified or do not have access to the streets. Another bias in my selection of informants is gender. There were more men with impairments located in the streets than women, which made them easier to access.

3.1.1.3 Key Informant Interviews

Key informant interviews aim to obtain special knowledge (Mikkelsen 2005). I used such key informant interviews at the *meso* and *macro* level. The meso level, or the community level, is represented in my study by three interest organizations and a sub-county city council. The macro level is represented by officials; the Minister of Disability and Elderly Affairs, the Executive Secretary of the National Council for Disability, and a Member of Parliament. The main topics of my interview guides (see appendix 1B and 1C) were the identification of barriers and opportunities, how the barriers are being negotiated, and also whether or not there were any underlying stakeholders influencing their priorities. To conduct the key informant interviews, I used the *semi-structured interview guide approach*, as I was *content focused* but open for information that I did not know about in advance (Kitchin and Tate 2000). This gave me an opportunity to compare the answers I received from the different organizations and officials, and to confront my informants with the information I had gathered. I started the interviews by introducing myself and my study, and I implied that it would take

approximately 30-45 minutes. I asked for permission to use my tape-recorder, and in most cases I brought my assistant to make notes. Most of my key informants seemed to have their own agendas for the interview which I solved this by starting with a general question about their organization or position, giving them an opportunity to define themselves what they wanted to tell me. After this I was more content specific in my questions. I conducted only one interview with each key informant, albeit I had the opportunity with most of my key informants to return in case of more questions. Despite the fact that this represented an opportunity to possibly enhance the *trustworthiness* of my findings, time was a limitation.

Choice of Key Informants

Prior to my fieldwork in Uganda, I spent time to identify the field and the relevant key informants at the meso and the macro level. I e-mailed those I could retrieve an address to before my arrival. However, I received one reply only. In retrospect, this might be understood due to lack of technology, and also because of suspicions about my sincerity. Accordingly, I had to get most of the contacts as I arrived in Uganda. I started my fieldwork by focusing on getting contacts with representatives at the meso and macro levels, as I thought this would be most time-consuming. I used two different approaches. The first, and most important one, was contacts and the *snowball-method* (Thagaard 2003). Initially I had one friend. This someone knew someone who could direct me to another one. This was how it all started. My contacts snowballed from the meso level to the macro level and back. I did not realize the importance of *networking* and relevant contacts until I experienced that a member of one organization admitted to having cross-checked my identity as he was not sure of my sincerity. Afterward, I always introduced myself by giving them a copy of the introductory letter from my university, and my business card. Another approach to gaining access to the field and my informants was to just show up at someone's office or organization. In all cases I either got an interview straight away or left with an appointment of one. Doing research on disability in Uganda was an appreciative task, especially being a Norwegian academic. This might be granted the fact that various Norwegian agents actively work on disability issues in Uganda. As such, in all organizations and offices where I introduced myself and my study, they all seemed to know people within the corresponding Norwegian disability organizations. This worked as a *gate-opener* for me. My key informants consist of three different institutions at the macro level and four at the meso level (see table 3.2 below). I chose my key informants by *position* and *workplace*, and not by any personal characteristics.

Table 3.2 Number of Key Informants at Macro and Meso Level by Position

Macro Level		Meso Level	
Minister of Disability and Elderly Affairs	1	City Council Nakawa Sub-Division	1
National Council for Disability (NCD)	1	NUDIPU	1
Member of Parliament (MP)	1	NUWODU	1
		UNAB	1
Total:	3	Total:	4

Source: Own fieldwork

3.2 Assistant

As a Norwegian girl conducting research in Uganda I was to be reckoned as an *outsider*. Accordingly, I was in need of an assistant to be able to negotiate my status, but also to be able to gain a more comprehensive understanding of the local context (Bartunek and Louis 1996). I got in touch with my assistant through contacts at the Makerere University. She was a 27 year old Ugandan woman who spoke Luganda, the local language of the region. She was a teacher by profession with a bachelor in Geography and History with previous experience as a research assistant. However, she had no prior knowledge of conducting qualitative studies. I made her read my project proposal, but it seemed to be more culturally polite to imply that she understood rather than asking questions. Being an inexperienced researcher myself in a cultural context of no prior knowledge, I realized this only through actions in the field. My assistant's role was to write notes during interviews and to *interpret* in the situations where the informants did not speak English. While interpreting, I wanted her in particular to focus on the informant's choice of words and phrasings regarding disability. After a week of fieldwork, it became apparent that she lacked a general understanding of my work, such as telling my informants that my work would give them *sympathy* and that it would result in *interventions*. I explained some important topics, such as *positionality*, *power*, and *ethical considerations*, something I should have done from the start, and she made an effort to learn. Being a woman with university education in Uganda did not give her an immediate *insider* status, however, it was negotiable. In the beginning it seemed important for her to introduce herself as a teacher by profession. By explaining how this created a socio-economic gap between herself and the informants, we negotiated this by introducing her as a student. She also started by dressing up or down depending on who we were interviewing. The cultural differences in how to conduct research were, however, many, and she did not realize how she influenced the field, even though she controlled most work conducted in Luganda. She did not tell me immediately that my informants did not understand my questions, which lead to

leading questions from her. Nor did she explain different local concepts, such as '*talo*'¹, because she thought I would not understand. On our last day of fieldwork, we were having a discussion of understandings of my work and findings. She had a completely different understanding than I as she had not translated all the information to me, even though we went through every interview straight away.

3.3 Focus-Group Discussions

Focus-group discussion as a method is good for understanding the discourses which shape practices of everyday life, and as such, to understand attitudes related to issues of disability (Cameron 2001). Accordingly, focus-group discussion as method could have been fruitful in my research. However, due to limited access to my 'basic' informants, and also to the fact that I got a reasonable good understanding of social attitudes through in-depth interviews and observations, I chose not to conduct focus-group discussions.

3.4 Observation

According to Thagaard (2003), *observation* is a particularly good method to study interaction between people in their natural context. In my fieldwork, I used observation as method for two reasons. The first was to identify barriers in the physical environment in the city with regard to mobility, such as staircases and pavements. Secondly, I used observation to see the able-bodied people's reactions and behaviour toward PWDs. However, as an *outsider* conducting research in a culture different from my own, I have no knowledge of people's underlying attitudes. However, I may be able to detect some relevant conditions through observation of their behaviour. Throughout my fieldwork, conducted between June 11 and August 6 2007, I used observation continuously. My informants were in the streets and so was I. This form of observation is categorized as *non-participant hidden observation* (Kearns 2000; Thagaard 2003). For example, one Friday night I went to a club where there were stage performances. The response from the audience was to applaud the entertainers. However, when a person with a physical impairment performed, which happened only once, the response was not only to applaud but also to give money. In this situation, I used hidden observation in a public arena and I did not reveal my role as a researcher. Using hidden observation creates an *ethical dilemma*. See section 3.9 for discussion and justification. While conducting my interviews, I also used observation as method. This form of method is

¹ '*Talo*' is related to witchcraft in central Uganda. It is not a concrete object but rather an abstract concept. They believe that '*talo*' is something you can step on, and may result in someone becoming sick and even disabled. This is done by a person with evil intentions and is often related to jealousy.

categorized as *semi-participant observation*. I choose to refer to it as semi-participant as my informants are impaired and I am not, and I will therefore not completely understand their experience of their situation. In some cases, when one of my informants, my assistant and I moved from the location where we approached him or her, to the place where we conducted the interview, I observed the mobility of that person within the physical and built-up environment. As we walked together, I also tried to notice the reactions of the able-bodied people that we passed. Such observation may be good to gain an understanding of the physical and social environment. However, it does not give an understanding of the lived experience of the PWDs, which is a reason why observation as method has been combined with in-depth interviews. A relevant *dilemma* to the quality of the observations is related to my presence (Wadel 1991) because observation involves participating both socially and spatially (Kearns 2000). While conducting interviews in the streets, I got more attention than my informants as I was the outsider. People stopped to see what was going on, and asked who I was and what I was doing there. I used observation as a tool for using *critical reflexivity* on myself and how I influenced the information gained. This has been important in order to overcome some of the bias and to be able to argue for the *replicability* of my study, albeit I may never be able to completely overcome this dilemma (Wadel 1991).

3.5 Researcher`s Position and Reflexivity

My fieldwork was set in Kampala, the capital of Uganda. Conducting research in a culture different from my own and anything I had of prior experience implied a great challenge but also some advantages. Meeting a new culture represented many things that were both different and unfamiliar. The advantages of doing research in a culture different from mine were that I was able to question the *taken-for-granted knowledge* in the society, and I was in most cases allowed to ask questions as I was not expected to have prior knowledge of it. However, doing research in Kampala had its challenges for me. The society is complex, hence, difficult to understand and overview. As such, I lacked the local knowledge to understand actions and body-language from my observations, as well as my informants' choice of words and expressions (Thagaard 2003).

In such a context, I had to be aware of my *position* as an *outsider* (Dowling 2000). In a research situation, I, as a researcher, will always bring with me my own *cultural competence*, or *cultural filters* (Neumann 2001). This implies that I am a carrier of my own culture and experiences; in the hermeneutical tradition called my prejudices or pre-understanding. I am a

young, white Norwegian woman grown up in the 1980s and 90s Norwegian welfare society based on egalitarian philosophies (Berg 2007). I have a fundamental belief in human dignity, one of the articles of the Human Rights (UDHR 1948). I am also an academic doing my master degree which to many of my informants may imply knowledge and power (Thagaard 2003).

Critical reflexivity of my prejudices and position as a researcher became an important focus itself in order to understand how I influenced the research process and the information I gathered (Østbye et al. 2002). It was also important to be reflexive on myself in understanding my position as a researcher and how this influenced the access I had to the field and relevant information (Dowling 2000). Throughout the whole fieldwork I kept a field *diary*, and it helped me to continuously scrutinize my own reflections and actions.

3.5.1 Field Relations and Negotiation of Power

Using the methods that I have used in my fieldwork; interviews and observation, implies that I, as a researcher, established direct contact with my informants. The relations that developed between my informants and myself are of great importance for the information material gathered (Thagaard 2003). The issue of *trust* is important in building a good relationship, and related to trust is the concept of *rappport* which implies a situation of mutual trust and *confidentiality* (Dunn 2000). My chance to build relations with my informants was limited because of the access I got. Spending more time than necessary on an interview with my informants in the streets, did not feel right as I kept them from conducting their business. In the schools, my access was limited to a few hours for conducting all of my interviews. However, people seemed to appreciate that I chose to focus on them. Despite the apparent socio-economic and socio-cultural gap between my informants and myself, it appeared to me that people were still willing to talk and to tell me their stories.

With regard to my limited access to the field as well as my position as an outsider, I had to negotiate a role that could help build the necessary trust in the interview-situations. Accordingly, the role you take or you are designated to by your informants, is important for the *field-relations* and the quality of the information collection (Thagaard 2003). I chose to introduce myself as a student conducting research. To acknowledge that I was a researcher could possibly have created a larger socio-economic distance between me and my informants. However, being a white Norwegian girl did imply that I was an outsider. Nonetheless, my

position as a student implied a role they could relate to as well as indicate my independence from government or any other institution of power (ibid.).

Built into the relationship between a researcher and the informant is the issue of *power*. My position as an academic and a researcher may have induced power and knowledge, which could imply a *potentially exploitative power*, especially to the people in the streets (Dowling 2000). In my situation, where my focus was a marginalized group, I may have been, according to Thagaard (2003), experienced as a representative of the powers that are oppressing them. Another position of power was my *embodiment* (Kearns 2000). Being white in Uganda creates attention and expectations. Being white, I experienced, represented the power of money, connections and opportunities. For example, while interviewing an official, I experienced that despite my emphasis on being just a student with no funding, the official turned to my assistant and asked her in Luganda about what he really could get out of me. I chose not to use this particular official in my study. In other situations I was expected to start fund-raising. I could not change the colour of my skin, but I could, however, *negotiate* my situation of power through various *subject positions*, such as clothing, language, how I introduced myself, and using a local assistant. As my assistant learned how to negotiate her differences to the field, her role as an insider in the local culture helped me gain better access to and understanding of the field. An example of her *insider status* was revealed when we were doing informal conversations with people in the streets. Both of us spoke with the informants, but not at the same time. As one of the informants told me that he was disabled because someone had hit him, she was told that it was the result of witchcraft. Apparently the informant did not think that I would understand the local beliefs, but as my assistant was part of the local culture, she got access to this version of the story. Another example of negotiating power is that of clothing. I chose to dress up for officials in order to be taken serious, and to dress down for people in the streets as to narrow the socio-economic gap between us. However, in retrospect, this strategy might have failed me as dressing smart appeared to be an indicator of showing people respect.

3.6 Collection of Secondary Information

Secondary information, or sources of data, consists of already existing literature (Ringdal 2001). There are several reasons and justifications for using secondary information (Kitchin and Tate 2000). In my fieldwork, issues of *time*, *access* and *trustworthiness* were the most important. Conducting all research yourself is time-consuming and a costly process. Getting

access to the field can be a challenge, and would possibly limit my opportunity to important information. However, the *limitations* of secondary information are many. Such sources of data are *cultural products*, which imply that they are often written with another purpose, and may not be suitable for my work. Other limitations are *inaccuracy* and *poor documentation* (ibid.). In my thesis, I have used secondary information as background material. I have also used such information to compare my findings with other literature produced within the same context in order to possibly enhance their trustworthiness. During my fieldwork, I collected various government documents and statistical information, such as legislations on disability issues and housing and population censuses. I experienced that in some cases it was very difficult to even get access to public documents and was in need of contacts to do so. A friend of mine had a contact within a public office, and through this person I got the documents I wanted, albeit I had to pay for what was originally free.

3.7 The Process of Information Analysis

The intention of research is to gain a deeper understanding of a given topic. To be able to gain a comprehensive view and understanding of a topic, the information gathered has to be divided into parts and elements (Thagaard 2003). The qualitative information material in this research is gathered using methods such as in-depth interviews, key informant interviews and observations. The nature of this study is *exploratory*, which implies that the intention of the research is to identify relevant variables and to seek new perspectives on the given topic (Kitchin and Tate 2000). However, in order to gain a deeper understanding of the information gathered, and to be able to divide the information into parts and elements, the information had to be *categorized* and *coded* (ibid.). It is the research objectives and questions that determine the methodology of a research, and it is the theoretical, conceptual and analytical framework that determines the research objectives and questions. Accordingly, the categories and codes used in order to divide the interviews and observations into parts and elements are based on the theoretical, conceptual and analytical framework of this study. However, as both the theoretical and analytical framework does not provide any pre-given sets of variables, the exploratory nature of this study has been sustained.

After a process of *transcribing* all the interviews, they were categorized and coded. The three empirical chapters of this study were organized following the three research objectives and questions, and the interviews were categorized and coded accordingly. Chapter 5, for example, focuses on identifying various barriers and opportunities to participation for PWDs

in the mainstream society of Kampala, Uganda. The theoretical framework of the chapter is the structuration theory (Giddens 1984) which seeks to identify various active structures at macro, meso and micro level in the society. It also consists of a complementary approach to place (Agnew 1987) which organizes the structures into having a political, socio-economic, socio-cultural, and physical character. The analytical framework, meaning the social model of disability (Oliver 1996a), focuses on the identification of barriers and opportunities. Hence, the goal of the categorization and coding is to identify the relevant structures in Kampala, Uganda, that either creates barriers or opportunities to participation for PWDs, and also to identify connections between the various topics (Kitchin and Tate 2000). The research process and analysis of this study has been conducted following a *double hermeneutical approach* to the *ethnographic methodology* (Thagaard 2003). A process of categorization and coding implies an interpretation of the individuals' thoughts and actions to a higher level of abstraction than that which is immediately perceived. However, by using quotations of my informants, the goal has been to highlight my arguments, but most importantly to relate to the lived experience of my informants and their interpretations of it (ibid.).

3.8 Limitations

There are several *limitations* to my fieldwork. As I did my fieldwork in a context I had no prior knowledge of, I had a limited overview of the society. It took me time to adjust and to organize practical issues, such as to find an assistant and to access relevant informants, organizations and institutions. I did my fieldwork in an urban setting while I realized after some time that most of the programs organized for PWDs were surprisingly located in rural areas. If I had had more time and financial resources, I might have been able to access such rural programs as well.

The Ugandan society consists naturally of more and other impairments than persons with visual and physical impairments. However, to be able to gain a better understanding of these two categories, and due to limited time, I have chosen a restricted selection of type of impairment in my study. This selection was also chosen because these types of impairment were visible, hence easily identifiable. Another limitation with regard to my choice of informants is the restricted age group. A larger age bracket or various age groups might have given greater insights to the lived experience of the embodied selves of the PWDs.

In Kampala, most people with education speak English. However, the local language is Luganda. Many of my informants in the streets have had limited access to education, and therefore they speak only Luganda. Three interviews were conducted in English and six in Luganda. I had to use my assistant as interpreter, and I lost valuable information in the translation. Language also limited my access to relevant informants.

I did not take any *photos* of my informants in an attempt to ensure their *confidentiality* and *anonymity*. However, this may be experienced as a limitation due to lack of visualization of the contexts which I discuss throughout this study.

I also had some personal limitations. I had no prior experience in conducting research, nor had I ever been to the African continent. According to Thagaard (2003), the greatest challenge while conducting research in a foreign culture is to be able to understand the local cultural codes. To conduct research in a context of no prior knowledge was interesting, albeit I may have misunderstood many of the social situations. Doing research took a lot of effort and energy. I started out with three very intense weeks, but I reached a limit and had to take some *time-off*. Taking time-off was for me an energy boost, as I got *distance to the field* and had time to reflect, both of what I had already done and how to understand this, and what new approaches I should take. I finished off with two very intense weeks of fieldwork.

3.9 Ethical Considerations

Conducting qualitative research implies some *ethical considerations* and there exists some *general guidelines* (Dowling 2000; Thagaard 2003). The most important guidelines are considered to be the issues of *informed consent*, *confidentiality*, and *do no harm*. I ensured informed consent through introducing myself and my study to my informants by asking them for *voluntary participation*. After each interview, I asked again if they still accepted me using the information given to me. Confidentiality was more difficult. In my introduction to each interview I thoroughly explained what confidentiality implied, namely *privacy*. I also explained that this was to be ensured as all information given to me would stay with me and that they would not be recognized in my thesis. Conducting interviews in the streets made it difficult to ensure that other people were not listening to the interviews. In some cases it appeared to me that some people did not understand the reasons for such caution. In the before mentioned example of the school, in section 3.1.1.2., the impaired students were asked questions in front of their class by the director. I chose not to ask any question and came back

later for private interviews. Do no harm is one of the major guidelines for conducting research. I may unintentionally have caused my informants harm as some of the topics I raised might have been upsetting (Dowling 2000). However, I tried to balance the sensitivity of my questions in each of my interviews. Anyhow, in two of my interviews I experienced that my informants started to cry or became silent. I immediately gave them the opportunity to continue with the next question as to ensure that it was my informants who decided to what degree they wanted to 'reveal' traumatic aspects of their lives.

Considerations of informed consent, confidentiality and harm were, however, not the most relevant in my fieldwork but rather the issues of *promises* and *funding*. Do not make promises you cannot keep is an important guideline in order to make sure that the informants do not lose faith in researchers and other field workers (Thagaard 2003). I did not make any promises to my informants as I introduced myself as a student without funding. Despite of my introduction, some of my informants seemed to expect that I could start fundraising, make contacts for them in Norway, or help out with medical bills. I was consistent and referred to my introduction and explained how my funding would create an ethical dilemma for my work. To give someone money for information would not create voluntary participation in my research. However, as mentioned in section 3.2, my assistant did make promises, such as that my work would result in interventions. Fortunately I found out and could disclaim her statements.

As mentioned in section 3.4, I used *hidden observation* as a method which creates an ethical dilemma. However, my usage of hidden observation can be justified through the fact that I did not focus on one person in particular, and it did not harm people or influence their integrity or values (Thagaard 2003).

Another dilemma is related to the fact that I am a Western academic going abroad to conduct a fieldwork on a marginalized group, using my informants to gain information, and then returning home to get a university degree. Many informants may experience that they have been used. However, as Eria, one of my informants exclaimed, '*A major change that has occurred with regard to disability in Uganda is that someone has come from abroad and shown interest in my disability*'. Accordingly, rather than feeling used, he felt appreciative of being listened to and feeling that he mattered.

3.10 Criteria for Good Research Practice

According to Kitchin and Tate (2000), all good studies aim to be *valid* and *reliable*. During the past two decades there has been an ongoing debate about the truth and validity of knowledge of qualitative research. Some of its advocates argue that conduct of research is linked to what it is possible to know and how you can know it (Harrison and Livingstone 1980). In my fieldwork, I conducted in-depth interviews which are a subject-subject production of information, and the richness of the material depends on this *intersubjective encounter* (Dunn 2000). As mentioned in section 3.1.1.2, such information is situated and constructed knowledge (Haraway 1988). Qualitative research is about choices. The challenge to ensure good research practice is to attempt *transparency* through the researchers' acknowledgement of perspective and position, as well as reflexively making explicit the choices that have influenced the whole research process (Berg and Mansvelt 2000). The concepts of validity and reliability are based in the quantitative research tradition which focuses on objectivity and generalizations. I, however, choose to use the concepts *trustworthiness* about validity and *replication* about reliability following a discussion on the concepts by Grbich (1999).

3.10.1 Trustworthiness

Trustworthiness relates to the accuracy and truthfulness of the findings (Berg and Mansvelt 2000). To ensure accuracy in my information collection I used a tape-recorder, had my assistant make notes during the interviews, as well as my assistant and I discussed our understandings of the field throughout the fieldwork. However, as some of the interviews were conducted in Luganda, I did not control the whole information collection. As mentioned in section 3.2, it appeared that my assistant had a different understanding of the field than myself as she had not given me all the information from the interviews. Nevertheless, due to time as a limitation I did not have an opportunity to go back to my informants to discuss my findings while still in Uganda. This could possibly have increased the trustworthiness of my findings as well as helped fill in some of the missing information. On the other hand, one of my key informants referred to the Norwegian Association of Disabled (NAD) and their participation in a local project. I contacted NAD in order to ensure the trustworthiness of the information given to me. However, it appeared that NAD had never been involved in this project. Although I cannot cross-check all information given to me, I have acknowledged the processes, biases and limitations that have influenced my fieldwork. As such, I have stayed true to the information given to me through the transcription, analysis and interpretation.

3.10.2 Replication

Replication considers the stability of methods and findings and refers to their repeatability (Berg and Mansvelt 2000; Kitchin and Tate 2000). In a qualitative study one may be able to ensure replication through thorough scrutiny of the choices made during the fieldwork in the methodology chapter. *Triangulation of methods* and use of several informants as well as thorough scrutiny of the biases that occurred in this study, have been conducted to possibly enhance their replication. However, there are some factors to elaborate. My fieldwork was set in Kampala, Uganda, consisting of first three weeks followed by two weeks in the period between June 11 and August 6 2007. Based on my theoretical work, Chapter 2 section 2.2.5, I do not believe that time and place are static categories. If I, or someone else, had conducted my work at another time within the same location, the findings might have been different. My own embodiment influences the replication of my work. I am a young academic Norwegian woman at the same age as my informants. The fact that I am a Norwegian might have given me access to some informants that a local person may have been denied. Being a woman with a female assistant may have increased the sense of trust and level of in-depth information from my female informants. However, a local man of higher age might have had easier access to some of my informants and also to retrieve other in-depth information than what I did.

3.12.3 Transferability

The goal of quantitative methodology is to obtain *generalizations*. The qualitative methodology, on the other hand, seeks to contextualize understanding and meaning of processes and individuals rather than to generalize any findings (Thagaard 2003). However, the concept of *transferability*, which is related to the notion of replicability, makes sense within the qualitative methodology rather than generalizations (Ringdal 2001). This is because one can assess whether or not a qualitative research project and/or its findings are transferable to similar contexts. Due to the limited number of ‘basic’ informants of this study, and the fact that qualitative research is the result of social interaction, the findings of this study may not be transferable to other contexts. However, as the study is set in an urban context in East Africa, it might make sense to transfer the research project to other urban areas of East Africa as the cultural and political aspects are somewhat similar.

Chapter 4

Study Area – Uganda, Kampala and Disability

This chapter will provide a brief contextualization of disability and Kampala. The main emphasis of this chapter is to be able to understand the topic of disability within a system of structures. The structures that I have identified as relevant in Kampala and Uganda, and which provide the basis for further discussion, are of *political, socio-economic, socio-cultural, and physical character*.

Kampala is the capital of Uganda, and to be able to understand the structures within Kampala, I will give a short introduction of Uganda and the topic of disability. The political structures are part of the macro structure of the country, and as such, these will follow the presentation of Uganda. I will also clarify definitional issues related to disability in Uganda before I continue with an introduction of Kampala, the study area of this thesis. Living in a large city as opposed to a small rural village creates special opportunities and barriers for persons with disabilities (PWDs). The description of Kampala as my study area will include a presentation of some relevant socio-economic, socio-cultural and physical structures.

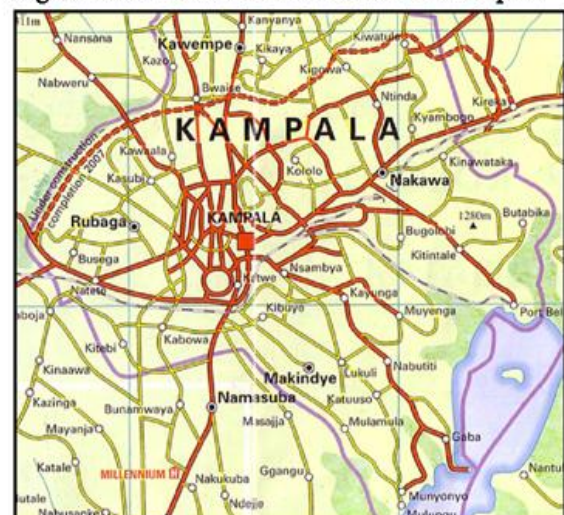
4.1 Uganda

Figure 4.1 Map of Uganda



Source: CIA World Factbook (2008)

Figure 4.2 Administrative Divisions in Kampala



Source: MacMillan (2006)

Uganda is a relatively small, landlocked country in the eastern part of Africa, as can be seen from figure 4.1 above. Based on census figures from the 2002 Population and Housing Census, the Ugandan population consists of approximately 24 million people (UBOS 2006).

The national *disability prevalence rate* was in the 2002 Census measured to be 3.5 per cent, which gives an approximate in absolute figures of 838.000 PWDs in Uganda.

In the Human Development Report (2007/2008), Uganda was given a human development index (HDI) rank of 154 out of 177 countries with data. The HDI is a measure of well-being beyond income, and includes life expectancy, illiteracy, and GDP per capita. The life expectancy in Uganda is 49.7 years, the illiteracy rate is 66.8 per cent in the population above 15 years, and Uganda's GDP per capita is 1,454 PPP US\$. However, it is of importance to acknowledge that these measures do not consider gender, income, or any specific health inequalities among the population.

Uganda is a *rural country* as 87.6 per cent of the total population lives in rural areas, which consequently give a 12.4 per cent urban population (UBOS 2006). More than 85 per cent of the population has agriculture as the main income-generating activity (IFAD 2008). However, agriculture only contributes for approximately 40 per cent of Uganda's GDP (Ministry of Agriculture 2008). Land as an asset is of major importance as to be able to partake in agriculture as income-generating activity. The Land Act of 1998 granted PWDs the right to land ownership. However, women are still excluded (see Chapter 5 section 5.2.6) (Manji 2006).

The *leading causes of disability* in Uganda are communicable illnesses and diseases, such as poliomyelitis (polio) and malaria (MGLSD 2006). Other major causes include congenital or peri-natal disturbances, accidents, and war. Approximately 55.9 per cent of the impaired population experienced to become impaired in the age bracket of 0-9. The leading types of impairment in Uganda are difficulty with legs with approximately 29 per cent and those having sight problem with approximately 25.4 per cent of the impaired population.

4.2.1 Political Structures – System of Governance

Uganda has a turbulent political history. Since independence in 1962, the country has been under one-party, multi-party, and military rule (Tanzaran 2003). In 1986, the National Resistance Movement (NRM) took power with Yoweri Museveni in leadership. The NRM and Museveni still hold power today, in 2008. The political system they represent used to be described as a non-party democracy (Francis and James 2002). However, this changed with the election in 2006, due to, among other explanations, external pressure from aid donors, and Uganda has currently a multi-party democracy (Makara et al. 2007).

During the 1980s, Uganda was a poor commodity-dependent country, which had to secure more loans, and those willing to give these were the multinational agencies such as the World Bank (WB) and the International Monetary Fund (IMF) (Roberts and Hite 1999). In exchange, Uganda had to submit to the conditionalities of the Structural Adjustment Programmes (SAPs), which the government did in 1987. One of the main aspects of the SAPs was *decentralization* of government. As the government through the SAPs had to emphasize macro-economic stability, they had to cut back on government spending on social programs. Hence, the intention of decentralization was to bring political and administrative control over services to the point where they were actually delivered, and to improve accountability, effectiveness, and also increase people's ownership of programs (Tanzaran 2003). The legislative framework of decentralization is provided by the Local Government Statute of 1993, the 1995 Ugandan Constitution, and the Local Government Act of 1997. These acts resulted in a system of governance comprising of Local Councils (LC) at village, parish, sub-county, county, and district levels (Francis and James 2002). The Local Government Act provided for the representation for PWDs at all local government levels. See Chapter 5 section 5.1 for more details on PWDs inclusion in the political system in Uganda.

4.2.2 Defining Disability in Uganda

According to Nabukhonzo (2003), Population and Housing Censuses remain the major source of disability statistics because there have been very few disability specific surveys carried out, and none in Uganda. There has been conducted Population and Housing Census since 1911 in Uganda. However, disability issues have only been included in the last two censuses, in 1991 and 2002. In the 1991 Population and Housing Census, disability was defined as,

'Any condition, which prevents a person from living a normal social and working life'
(Nabukhonzo 2003).

The 1991 definition has been criticized for not providing a good instrument for identification of disability in the field. Hence, the census has been criticized for giving an inaccurate prevalence rate of disability (DisabilityAfrica 2008). In the 2002 Population and Housing Census, on the other hand, disability was defined as,

'One who is limited in the kind of or amount of activities that he or she can do, because of ongoing difficulty (ies) due to a long-term physical condition or health problem that has lasted six months or more. This includes all those difficulties that are expected to last more than six months' (Nabukhonzo 2003).

According to UBOS (2006), this definition is based on the World Health Organization's (WHO) Classification of Functioning, Disability and Health (ICIDH-2) after recommendations from the United Nations Statistics Division. This definition emphasizes the interplay between impairment of body organ level and the environment in which PWDs live. However, according to Lwanga-Ntale (2003), the prevalence rates identified in the 2002 Census still does not mount up to the WHO's recommended estimate of a general 10 per cent of the population (see Chapter 1 section 1.1). As such, one might assume a *flawed prevalence rate*, which may risk undermining of issues of disability in the policy and implementation process.

4.2.3 The Disability Movement in Uganda

Before the National Union of Disabled Persons of Uganda (NUDIPU) was formed in 1987, PWDs were not involved in the planning and implementation of programs meant to benefit them (Ndeezi 2004). NUDIPU is the umbrella organization for all PWDs in Uganda. Some interest organizations had been formed prior to this event, such as the Uganda National Association of the Blind (UNAB) in 1970. However, the establishing of NUDIPU aimed at creating a unified voice to challenge the structural exclusion of PWDs in the mainstream society. According to Ndeezi (ibid.), the formation of an umbrella organization for all PWDs in the country was the first of its kind in Africa. The Disability Movement in Uganda has gained political influence considering that their work has been accepted by the NRM. However, with the onset of the WB and the IMF strategy for Poverty Reduction Strategy Plan (PRSP), or Poverty Eradication Action Plan (PEAP) as it is called in Uganda, the Disability Movement was somehow excluded (Dube 2005). In order to mainstream disability issues in poverty reduction, PWDs had to be included in Uganda's PEAP. According to Albert and Hurst (2005), Uganda was a country most likely to achieve this as the Disability Movement was strong. Although the Disability Movement was included in the consultation process, their inclusion in the final report was constricted. It has been argued that their participation had been used by the government only as a means of legitimizing the PEAP process.

4.3 Kampala – A Capital City

Kampala is the capital city of the Republic of Uganda (see figure 1 and 2 above), and is located in the central region of the country. The origins of Kampala date back to 1891 when the Kabaka of Buganda, i.e. the king of the Baganda Kingdom, had his court on Rubaga and Mengo hills, two of the seven hills that now make up Kampala. The city has served as a

political and administrative capital since 1893. However, when the British declared Uganda their protectorate they transferred the capital to Entebbe. Kampala was once more turned into a capital city in 1962 when Uganda became independent (UBOS 2007).

Based on census figures from the Kampala District 2002 Population and Housing Census, the population of Kampala consists of approximately 1.2 million people (UBOS 2007). The disability prevalence rate in Kampala is 1.7 per cent of the total city population, which gives an approximate in real figures of 19,000 PWDs in Kampala. As acknowledged by UBOS (ibid.), this figure is the population that slept in Kampala on the night of the census. Hence, the disability prevalence rate may be higher during daytime.

By 2002, approximately 40 per cent of Uganda's urban population was located in Kampala. However, more than half of the population of Kampala was not born in the city. Consequently, the *rural-urban migration* is excessive, even though the trend of in-migration into Kampala is decreasing due to opening and growth of other urban areas. However, the annual population growth rate is still 5.6 per cent (UBOS 2007). A large city, such as Kampala, represents great opportunities, in particular for PWDs, such as escaping negative societal attitudes that prevail in rural areas (Lwanga-Ntale 2003). The city, on the other hand, represents barriers within the physical structures. The following section will assess the socio-economic, socio-cultural and physical structures within the city of Kampala, and how these represent opportunities and barriers for PWDs in a large capital city.

4.3.1 Socio-Economic and Socio-Cultural Structures

A city, such as Kampala, is a large, dense and permanent settlement of heterogeneous individuals (Pacione 2001). The large concentration of people results in individual variability and a relative absence of personal relationships, while the density and heterogeneity involve diversification and disintegration of rigid social structures. Consequently, a city, such as Kampala, might have a higher tolerance for deviance than rural areas, and thus represent an opportunity for PWDs to become more *anonymous* (ibid.).

Uganda's population comprises different ethnic and cultural groups. The cultural groupings, such as Baganda and Basoga, are headed by traditional kings who are not politically elected but have an indirect role in community governance. Kampala belongs to the Baganda Kingdom of which the local language is Luganda (UBOS 2006). The population in Kampala has by the 2002 Census been divided into six main religious beliefs. However, more than half

of the population belongs to the Christian belief; Catholics and Anglicans, and the other major religion is Islam (UBOS 2007). See Chapter 7 section 7.2.1 for information about *traditional belief systems* in Kampala.

Kampala is a business hub. Compared to rural areas where most people partake in agriculture as their main income-generating activity, Kampala represents a large variety of opportunities, such as industry, services, and higher education (UBOS 2007).

Access to education is an important socio-economic structure, as education can build capacity of the population in various skills, raise awareness on various issues, and improve general standard of living (UBOS 2007). The Universal Primary Education policy of 1997 (UPE) works to ensure that in a family, at least four children have access to primary education. In a family with an impaired child, that child has to be prioritized before the others. The literacy level in Kampala, by 2002, was 95.1 per cent for men and 92.2 per cent for women, indicating a gender disparity. The national literacy rate is recorded to be 70 per cent, indicating a great urban-rural divide. For PWDs, on the other hand, the literacy level in Kampala was 83.4 per cent. Out of these, only 38.4 per cent had completed their primary education and 17 per cent of the PWDs in the city had no education at all (ibid.).

One of the key objectives of the PEAP is the promotion of employment creation as economic activity is important in order to enhance an individual's welfare (UBOS 2007). Approximately 50 per cent of the total population of Kampala has paid employment in the formal sector and 32.5 per cent are self-employed in the informal sector. In comparison, 21.4 per cent of the PWDs are employed in the formal sector while 17.1 per cent are economically active in the informal sector. According to the 2002 Census, more than half of the PWDs in Kampala are women. However, they constitute only 7.1 per cent of the paid employee work force, indicating a major gender disparity of the PWDs in the employment sector. It has been acknowledged that there is a need for a labor force survey in order to give a conclusive unemployment rate in the city. Anyhow, the percentage of those looking for work in Kampala constitutes 12.8 per cent of the total population compared to 5.7 per cent of the impaired population (ibid.).

4.3.2 Physical and Built-Up Environment of Kampala

Kampala covers a total land area of 195 square kilometers (UBOS 2007). As mentioned in section 4.3, the annual population growth rate in Kampala is 5.6 per cent. Such rapid

population growth in a city represents increased demand for employment, land for housing, social services and infrastructure. However, Kampala city has been unable to accommodate the needs, and the urban dwellers have responded in what is described by Nyakaana et al. (2006) as a haphazard manner dominated by urban informality in most sectors. The physical expansion of Kampala has been planned through various planning schemes, with the National Environment Action Plan introduced in 1994 as the last (UN-Habitat 2003). However, there is limited access to information about these planning schemes, and according to Nyakaana et al. (2006), they have had little success due to lack of implementation and enforcement. Another reason for the shortcomings of these planning schemes is the individual ownership of land introduced with the Land Act of 1998. This has resulted in conflicting land use policies between the city management and the land owners (Mukwaya 2004).

The population density of Kampala was, in 2002, 7.259 persons per square kilometers as compared to the national population density which was 124 persons per square kilometers (UBOS 2007). However, the spatial distribution of the population in Kampala is not even among the five administrative divisions constituting the city; Central, Kawempe, Makindye, Nakawa and Rubaga (ibid.). See figure 4.2 above for the location of the five divisions. This is explained by variation of economic development, availability of residential space, distance to town center and distribution of social infrastructure (Nyakaana et al. 2006). The largest proportion of the city population is located in the divisions of Makindye, Rubaga and Kawempe, which are all located in the outskirts of Kampala. These divisions contain several slum areas, in which most of the 'basic' informants of this study reside. However, the Central Division of the city had the highest proportion of Kampala's homeless population, with a total of 43 per cent. Most of the PWDs reside in the outskirts of the city, which make them rely on public means of transportation in order to reach the Central Division where they conduct their business. The public transport system will, however, be discussed in Chapter 5 section 5.3.3.

Chapter 5

Barriers and Opportunities to Participation in the Mainstream Society of Kampala, Uganda

To be able to understand the *lived experience of persons with disabilities* (PWDs), in this case those who live in Kampala, it is of importance to identify the *barriers* and *opportunities* which exist within this particular context. This is because the barriers and opportunities represent different *places of participation* of which PWDs are either included or excluded. Based on Massey's (1995) arguments, barriers and opportunities within Kampala cannot be understood in isolation. Within the field of disability, Uganda is under the influence of *agents* at the global level, in particular the UN Standard Rules on Equalization of Opportunities for Persons with Disabilities (1993) and the Human Rights (UDHR 1948). Uganda is also part of the African Union which declared its Decade of Disabled Persons of 1999-2009. The African Decade constitutes a proclamation of the full participation, equality, and empowerment of PWDs in Africa (OAU 2000). Hence, Uganda, and Kampala being the capital of Uganda, is both under global and regional influence to focus on PWDs. However, Uganda is a sovereign state with its own constitution, and also a decentralized country (see Chapter 4 section 4.2.1). Each of the different levels of political organization has their own influence on how to focus on the barriers and opportunities of PWDs.

The endeavor of this chapter is to identify various barriers and opportunities to participation for PWDs in Kampala. Although all barriers to participation are not human made, the three main topics or places of participation that will be covered in this study are *political participation*, *socio-cultural* and *socio-economic participation*, and access to *the physical and built-up environment*. Under each of these headings follow more specific topics for discussion. However, the organization of each section is not as clear cut in reality, and some of the topics will be discussed several times although with differing focuses.

5.1 Political Participation

To participate in a society, an individual has to be able to influence the *decision-making bodies* and processes of that particular society. Without any influence, an individual will be unable to neither remove any existing barriers nor enhance any possible opportunities for participation. Hence, being unable to influence decisions may affect an individual's everyday

life (Cornwall and Gaventa 2001). During the past decades, PWDs and their interest organizations have reached increased levels of influence on the decision-making bodies in Uganda. However, there are still some challenges to be met. Global influences from the UN Standard Rules (1993) and the Universal Declaration of Human Rights (1948) as well as the regional influence from the African Union have had a positive impact on Uganda's focus on disability issues, creating a friendly political environment. Under the objectives and directive principles of the Constitution of Uganda (1995), PWDs are included as follows,

'The State shall ensure gender balance and fair representation of marginalized groups on all constitutional and other bodies' (Objective vi) and *'Society and the State shall recognize the right of persons with disabilities to respect and human dignity'*(Objective xvi).

In 1996, the Parliamentary Elections Statute provided for five representatives of PWDs in Parliament. In 1997, the Local Government Act provided for the representation of PWDs at all local government levels; a male and a female at each level, and in 1998, a Minister for Disability and Elderly Affairs was appointed. In 2003, the National Council for Disability Act was introduced. This Act mandates the National Council for Disability (NCD) to bring issues of disability to the attention of the government, non-governmental organizations (NGOs), the private sector, and individuals, in order to improve the lives of the PWDs. Accordingly, PWDs are now represented at all levels of decision-making. The Disability Movement has also both increased in size and influence during the past few decades (see Chapter 4 section 4.2.3).

5.1.1 Legal framework

Honorary Baba Diri, a visually impaired Member of Parliament (MP), stated that, *'We as politicians and representatives of the people, our primary role is to ensure that the laws are there and the policies are there'*. Uganda has demonstrated its commitment to the promotion and protection of the rights of PWDs through the adoption and implementation of national and international policies and legal instruments that concern PWDs (MGLSD 2006). There have been several changes with regard to PWDs access to participation in the political field. In 2006, the Persons with Disabilities Act was introduced, and it was clearly influenced by international policies through its focus on the elimination of all forms of discrimination and the promotion of dignity and equal opportunities. Although the legal framework may imply political will as well as opportunities for the PWDs, it has been acknowledged by all of my informants at the macro and meso level; from the Minister to the interest organizations that the implementation has yet to come.

According to the Minister of Disability and Elderly Affairs (the Minister), the implementation of the legal framework favoring PWDs has been a challenge. He explained that during the SAPs of the 1980s, Uganda adopted a decentralized system of governance (see Chapter 4 section 4.2.1). The Minister continued,

'Due to the decentralized system of governance, you put policies at the centre, they are supposed to be implemented at local government, but it costs a lot to assure that local governments do understand these policies and laws, and to put them into place. Uganda being a developing country has limited funds'.

Following this argumentation, the Minister also informed that the government gives money to councils of vulnerable groups in every district, including youth, women and disability. However, disability councils receive the least because the ratio is considered under the population of the 2002 Census. Hence, PWDs are under-prioritized due to definitional issues as identified in Chapter 4 section 4.2.2. The National Union of Disabled Persons in Uganda (NUDIPU) acknowledged that the operationalization and implementation of laws and policies are lacking behind owing to the fact that the government does not have the necessary resources. Hence, there are limited funds in all sectors. However, the MP stressed that issues of disability are continuously put last in the competition for resources. She explained that, *'The attitude is due to the fact that malaria and AIDS are killing so many people, but disability they say you can live with'*. Anyhow, despite the fact that the implementation of the legal framework favoring the opportunities of PWDs is lacking behind, there are still some positive effects to be observed. As will be discussed in section 5.2.1, PWDs have traditionally been treated as lower level human beings due to societal attitudes. Nevertheless, because of the legal framework in place, Jack, a walking impaired street vendor, stated in an informal conversation that, *'I now feel like I am being considered like other people'*. By being included in the legal framework, Jack's *sense of self* and confidence had increased. Accordingly, the legal framework may represent an attitudinal shift as to how PWDs consider their own value.

5.1.2 Information of Political Opportunities

Despite the fact that the implementation of the legal framework is lacking behind, it can be used by the people to demand for their rights as acknowledged by the MP. However, as NUDIPU discovered in 2002, the organization had had a lot of impact at the national level providing for issues of PWDs, but people at the micro level still had limited knowledge about it. For people to be able to take advantage of the legal framework in place, they need information about their opportunities. As a result of the Persons with Disabilities Act of 2006,

PWDs can take legal action toward anybody discriminating against them. NUDIPU gave an example of a walking impaired student who went with his friends to dance, but was denied access to the discotheque. The student reported the incident to the Uganda Human Rights Commission, and he was compensated by the discotheque. Another example given to me by the Minister was of a law student who was denied access to a bus due to his disability. As the student took the matter to the police, he was able to demand for his rights. However, to be able to demand for their rights, people are, as mentioned above, in need of information. Several of my informants, as I will come back to in section 5.3.3, experience discrimination with regard to access to public means of transportation. In the words of Eria, a walking impaired street vendor, *'Movement is not easy because we have to spend more money than normal fares to reach our destination of choice because some 'taxi' operators do not want to support us, especially those of us who use wheelchairs'*. Accordingly, my informants experience discrimination almost every day, but as they are unaware of their rights and opportunities, they are unable to do anything about it.

5.2 Socio-economic and Socio-cultural Participation

'Disability creates and exacerbates poverty by increasing isolation and economic strain, not just for the individual but for the family: there is little doubt that disabled people are among the poorest in the poor countries' (Coleridge 1993: 64).

Poverty and disability are closely interlinked. Disability may be both a cause of poverty as well as a consequence (MGLSD 2006). Disability is most likely the reason for poverty due to lack of livelihood opportunities and more general participation in the society. However, poverty may as well be causing disability. Impairment is to a large extent caused by curable diseases like polio and malaria (see section 5.2.4). Hence, as many poor people cannot afford accessing the necessary health care, the result may be impairment (Ghai 2001). The socio-economic status of parents is often linked with opportunities accessible for the children. Disability exposes people to limited livelihood opportunities which consequently may lead them into a state of poverty and vulnerability (MGLSD 2006). Accordingly, access to assets and resources is of major importance for PWDs in order to increase their opportunities to participate in the mainstream society.

The next part of this chapter will touch upon the topics of both *socio-economic* and *socio-cultural* aspects with regard to barriers and opportunities to participation in the mainstream

society of Uganda, and in particular Kampala. I will start by discussing the socio-cultural and attitudinal barriers and opportunities as attitudes influence all areas of the society.

5.2.1 Attitudes

Disability is to a large extent a stigmatized label due to the notion of the ‘normal’ body (Chouinard 1999; Gabe et al. 2004). According to the Executive Secretary of the NCD, many people in Uganda have a tendency to see PWDs as useless. In Luganda, there is a word called ‘*kaseru*’ which means ‘stupid’ and is given to the PWDs. In relation to the *structuration theory* this is an example of the *structures of signification* meaning the dominant discourse on disability in Uganda. The NCD has worked to identify the origin and meaning of such stereotypical words and in particular their roots. The causes are to a large extent connected to *witchcraft*. Despite the fact that Uganda is a very religious country, traditional belief systems are still of great importance to its inhabitants. As long as disability is thought to be connected with witchcraft, disability is regarded as something dangerous and negative. The topic of witchcraft will, however be discussed in more detail in Chapter 7 section 7.2.1.

The labeling of PWDs as negatively ‘others’ is an example of the *structures of legitimation* of the structuration theory, representing the norms of social conduct. Uganda is to a large extent a repressive society due to scarcity of resources and other assets, and for this reason, PWDs fall down in a hierarchal pecking order. Accordingly, PWDs have become vulnerable and marginalized members of their societies due to ignorance, superstitions, and lack of awareness (MGLSD 2006). In many cases, PWDs have received low priority in the society with regard to access to participation, such as access to education, health care, employment, and land. As a result, PWDs have in most cases inadequate access to services and information, as well as limited participation in the socio-economic development process.

One of the objects of the Persons with Disabilities Act of 2006 is, ‘*To eliminate all forms of discrimination of persons with disabilities on the ground of their disabilities*’ (Act 3: d). The Act also states that all sectors of government and community are to be encouraged to promote and include disability issues into all economic, political and social development policies and programs. However, it is acknowledged that there is a pressing need to promote positive attitudes and images of PWDs as capable and contributing members of the society in order to achieve the goals of the Act.

According to the MP, the government started a community based rehabilitation program to sensitize communities and to create awareness. The emphasis is to sensitize parents of disabled children to make them realize their child's *capabilities* and create opportunities for the child to participate in the society. However, the MP acknowledged that the government program of awareness-raising has been entirely funded by NGOs. Hence, revealing the lack of priority that the government is giving to the issue of disability. Despite the lack of financial resources, the work that has been conducted on sensitization and awareness-raising on PWDs has had some positive results. The MP said that parents used to hide their disabled children. However, many parents are now aware of programs that might give their children opportunities. Hence, most parents no longer hide their children. Another important attitudinal change is that PWDs might even get married to able-bodied people as disability is no longer experienced as the bad omen that it used to be. The opportunities of marriage are thus to a large extent related to the issue of men and financial assets.

5.2.2 Gender

Uganda is a *patriarchy* with regard to discriminatory cultural practices such as women's lack of access to education, property inheritance, and to make decisions affecting their own lives (MGLSD 2006). According to the National Union of Women with Disabilities in Uganda (NUWODU), parents prefer to educate a boy rather than a girl because the girl is going to get married. Hence, the family may not gain from the resources of her education. Owing to the fact that the girl is going to get married, she will not inherit land from her parents. Although women in general are being discriminated against because of their gender, when it comes to an impaired woman, she will also, according to NUDIPU, be discriminated against by fellow women. Through discrimination of women with impairments, able-bodied women may increase their own opportunities in the society. Consequently, women with impairments find themselves low on the hierarchical pecking order.

In Uganda, disabilities affect men and women in different ways, and the impact is more severe for women than men due to social and cultural roles as mentioned above. Such discriminatory cultural practices affect the livelihoods of women with impairments more than men with impairments. The topic of marriage exemplifies this difference between men and women. Marriage is also an important example of societal attitudes as marriage may be able to give women greater access to participation. As mentioned in section 5.2.1, there has been some attitudinal change with regard to PWDs marrying able-bodied people. According to the

Executive Secretary at the NCD, a person who was disabled because of polio would have to pay dowry for the polio separate from the dowry for the woman. Consequently, there was a financial barrier in order to access marriage as well as an attitudinal barrier. This change is, however, related to the opportunities of men. Several of my male 'basic' informants were married. Some of them were married to able-bodied women and some had more than one wife. However, none of my female 'basic' informants were married although they all wished for it. Two of the women, Asha and Elizabeth, were, on the other hand, single mothers. According to NUWODU, many women with impairments in Uganda are either single mothers or they co-habit with men. A man might be willing to love an impaired woman, but because of attitudes of their families and the surrounding society, they shy away. In many cases the men come at night and disappear in the morning to make sure that the society is unaware that they are befriending an impaired woman. As the MP put it, *'It is like going to the market place. You do not choose a woman who may not be able to take care of you and your children'*. As an impaired woman is not regarded as able to conduct the expected daily activities of a married woman, the societal attitudes do not regard her as eligible for a man.

5.2.3 Education

'The easiest and most systematic way of keeping a people marginalized and denied all opportunities is by denying them education (...) So the first step in breaking out of marginalization and denial of opportunities is to acquire relevant education and then be in a position to compete in the world of scarce opportunities' (Ndeezi 2004:32).

Most of my 'basic' informants had relatively little education. Only one of them, Lincoln, had a university degree, while most of the others have had to drop out of school due to their families' lack of resources. One of my informants, Abraham, had no education at all. However, it is of importance to acknowledge that all of my informants but Michael grew up in rural areas where there is less access to education than in urban areas. The Universal Primary Education policy (UPE) was introduced in 1997, and is Uganda's strategy of free education for all, focusing on integrating children with disabilities into the general educational system. According to the Minister, the main achievement of the UPE with regard to PWDs is its emphasis on that a family with a disabled child, has to consider that child before others. The UPE gives children with disabilities the right to go to school and as such represents a major opportunity with regard to participation. According to statistics from the Ministry of Education, more PWDs are now accessing schools albeit there is still a challenge of retention (Ministry of Education and Sports 2004).

With regard to accessing education there are, however, still some barriers to overcome. The UPE states that children are supposed to go to a school near their homes. However, distance may still be a barrier. For a child who has to crawl due to walking impairments, any distance may be experienced as too far, and a child with a visual impairment may be in need of a guide which may not be achievable every day. The UPE emphasizes that at least every new classroom built should be accessible for children with disabilities, and the schools should have ramps and special toilets. However, according to NUWODU, there are still some headmasters that defy such requirements. Despite many physical barriers, school enrollment has increased and the children need attending to (Ministry of Education and Sports 2004). Through the UNISE Act of 1998, the government has provided for the training of teachers for children with special needs. Anyhow, according to Ndeezi (2004), the teacher/pupil ratio may in some classrooms be 1/150, which represents a challenge for the teacher to attend to both the class and to give preference to the child with special needs. Yet another barrier for children with disabilities to access education is the issue of scholastic materials. A visually impaired child cannot read print. Text in Braille is expensive, and due to limited availability, the child will be in need of someone who can read for him or her. Consequently, the UPE may represent a place where a disabled child can go to socialize but not obtain any quality education. An opportunity is, however, attending special schools. However, these schools are relatively few as well as they, in most cases, are far from the homes of the children with disabilities. In addition, children from poor families and their parents might not even afford the boarding fees.

Despite the fact that there exist some major challenges, the UPE represents a great opportunity for children with disabilities in order to access education, in particular due to the emphasis on the prioritization of an impaired child before others. However, some families still neglect the education of their impaired child despite the fact that the laws create an opportunity for sanctions. As stated by the MP, *'The laws are there, the policies are there, but there is still a lack of implementation'*. Consequently, many people feel that educating an impaired child is useless because they will not be able get a job afterward. Hence, many children with disabilities rarely access education. Poor access to education in childhood implies that a high proportion of PWDs remain illiterate and unskilled (MGLSD 2006).

Despite the existence of many barriers for children with disabilities in accessing education, it is not impossible. Lincoln, a visually impaired man, came from a poor rural family with no

education. Despite his family's socio-economic status he managed to complete his A' level exams with excellent results and was further granted a government scholarship to continue at university. He now holds a bachelor degree from the Makerere University in Kampala.

5.2.4 Health Care Services

Through the Persons with Disabilities Act (2006) '*Persons with disabilities shall enjoy the same rights with other members of the public in all health institutions including general medical care*' (Act 7: 1). Accordingly, this law ensures PWDs the right to health care. The government of Uganda has put in place the Uganda National Minimum Health Care Package to ensure that the people of Uganda receive essential services (MGLSD 2006). However, despite the laws and policies in place, PWDs to a large extent face various barriers in order to access health care services in Uganda (ibid.). NUDIPU acknowledged that more hospitals are now being built with the component of accessibility being incorporated as a result of advocacy from the interest organizations. Even though PWDs may be able to enter the health care services, they still may face negative attitudes from the health care workers. An impaired woman may be as sexually active as any other person, and when pregnant is in need of going to a hospital for the delivery. Elizabeth, a visually impaired woman, told me her story of giving birth. Owing to stress related to her being both visually impaired and pregnant, she developed hypertension and had to go to Mulago, a public hospital in Kampala. In the hospital, the nurses insulted her by asking why she had to become pregnant when she was blind. According to NUWODU, such experiences discourage a person from accessing health care services preferring to deliver at home albeit lacking professional help. Accordingly, this may result as a barrier for the well-being of impaired women.

With regard to health and disability, the issue of *prevention* is of major importance. See Chapter 4 section 4.1 for leading causes of disability and distribution among the population by age and type of impairment. The leading causes of impairment in Uganda are curable diseases like poliomyelitis (polio) and malaria. Polio is a communicable disease, and in communities with high population density, high-birth rate and poor hygiene, the transmission may be very intensive with infections occurring frequently in the very young. The consequence may be paralysis (Hovi and John 1994). Improvement in hygiene may, however, result in decreasing contamination of the environment thus reduce the number of infected children. Malaria, on the other hand, is a water vector habitat disease. It is caused by the biting of mosquitoes, in particular by the Plasmodium Falciparum, which breed in pools or

open water bodies at night (Silfverberg 1994). The consequences of malaria may be weakness in one or both limbs on one side of the body, speech disorders, behavioral disorders, blindness, hearing impairment, epilepsy, and cerebral palsy (Holding and Snow 2001). Improvements in water supply, sanitation and waste disposal, as well as health education could reduce the number of infections. However, with regard to both polio and malaria, people are in need of *information* about how to avoid the various diseases as well as how to detect symptoms in order to get the necessary treatment. Despite the fact that preventive measures could result in decreasing numbers of people experiencing impairment and disability, the interest organizations, according to NUDIPU, prefer to influence service providers to provide appropriate services to those already impaired, such as the distribution of assistive devices (see section 5.3.1 and Chapter 6 section 6.2.4.1).

5.2.5 Employment

The Persons with Disabilities Act (2006) states that,

'A person shall not discriminate against a qualified person on ground of that person's disability in regard to any job application procedures, hiring, promotion, employee compensation, job training, and other terms, conditions, and privileges of employment' (Act 12:1).

The MP recognized this act as an opportunity for participation based on the good will of the government. Through this act, PWDs are identified as capable individuals. However, as the National Policy on Disability (MGLSD 2006) acknowledges, access to employment is a major challenge as PWDs to a large extent have limited skills due to lack of education. Consequently, government established a vocational training program to equip PWDs with employable skills.

I identified two such vocational establishments in the Kampala area. The students are admitted for two years and may learn for example tailoring, mechanics or computer science. At one of the vocational schools, the Uganda National Association of the Blind (UNAB) has established a special program for persons with visual impairments. A person may be qualified as for example a social worker but do not get a job. The intention of the program is thus to add value to that person through access to this high-tech program to learn computer skills. However, the Executive Secretary of the NCD identified different economic events as a barrier to success of these programs. Apparently a large percentage of the textile industry in Uganda is covered by second hand clothes from Europe (New Internationalist 2004).

Consequently, the skilled personnel from the vocational schools become more expensive than the second hand clothing.

An opportunity for a PWD with vocational training is that this person may not be in need of a formal employer due to possession of self-sustaining skills. However, to start a business one is in need of financial resources. Micro-finance projects could have been a solution to this problem, but according to the NCD, the micro-finance companies in Uganda have rejected to extend to the PWDs. In addition, in cases where PWDs have been included, they have had to pay more interest than the able-bodied. This may reflect the hard reality that the micro-finance projects do not do charity work and that the PWDs might represent a risk with regard to repayment of the loans.

Nonetheless, there are PWDs who do hold the necessary qualifications, but still experience that they are being discriminated against in the competition for employment. With regard to this, the MP identified the lack of facilities as a major barrier. Being a visually impaired person herself, she was a good example that a visually impaired person can work well if the necessary facilities are in place, such as a guide and a Braille typewriter. However, for an employer, a visually impaired person may be regarded as a burden as he would have to employ two people; the PWD and a guide, and in addition pay the salary of the two. The Persons with Disabilities Act (2006) states that an employer can claim tax exemption as an incentive on any costs incurred as a result of appropriate modifications of work premises to facilitate the employment of PWDs. There are, however, hardly any changes to be observed. NUDIPU identified the high unemployment rate as a barrier for this incentive to work (see Chapter 4 section 4.3.1). Consequently, a lot of people are willing to work for less payment than they normally would have. Hence, PWDs who require special facilities stand no chance in the competition.

Only one of my 'basic' informants, Lincoln, was formally employed based on his education, and this was through his respective interest organization. Four of my 'basic' informants, however, I found at the two vocational training schools mentioned above. One of them, Elizabeth, a visually impaired woman, spoke of the experience of blind people being economically isolated. She experienced the competition with sighted people as very difficult because the employers in her opinion thought of the blind as not being able to do perfect work. She called for the government to create job opportunities for the visually impaired. The rest of my 'basic' informants I met with in the city center. Some of them had vocational

training but due to the abovementioned structural impediments they had to work as self-employed streets vendors. The rest of my informants had no formal training, and one of them was a beggar. All of them, however, looked upon Kampala as an opportunity for conducting income-generating activities; for doing business, or at least gaining some money.

5.2.6 Access to Land

All of my 'basic' informants but Michael come from rural areas all over Uganda. Despite the fact that none of them spoke of access to land, they all mentioned rural activities in which they were either expected to partake or thought of as incapable of. The move to Kampala was by most of them related to the fact that the city offered other income-generating activities than agriculture. More than 85 per cent of the Ugandan population lives in rural areas and an equal percentage has agriculture as the main income-generating activity. Hence, land is an important asset in Uganda (IFAD 2008). As identified in Chapter 4 section 4.1, Uganda can be referred to as a poor country. According to the Executive Secretary of the NCD, the NCD was started in order to fulfill the National Planning Framework. This is a policy which is consistent with the Uganda Vision 2025 which is a long-term development framework in Uganda promoting the inclusion and participation of PWDs in order to achieve equitable human progress (MGLSD 2006). It is a poverty eradication program, and to eradicate poverty in a rural country like Uganda, it must be done through agriculture. The National Agriculture Services (NAG) is a government service provider at sub-county level which provides services required by farmers. However, in order to achieve and access such an opportunity, people are in need of access to land. The Land Act of 1998 states that *'it provides for the rights of PWDs in respect to Customary Land – It provides for access to ownership, occupation or use of Land'* (Section 28). However, according to NUWODU, all children are supposed to inherit land from their parents, but to a large extent, children with disabilities are not considered worth inheriting land. Hence, the lack of operationalization of the Land Act of 1998 represents a major barrier to participation for PWDs.

According to NUWODU, the issue of gender is of major importance as access to land for women with impairments is even more difficult than for men. Women in general do not inherit land from their parents as they are supposed to get access to land through their husbands. Prior to the draft of the land bill which became the Land Act of 1998, Ugandan women's groups advocated for the inclusion of statutory spousal co-ownership of family land. The clause was drafted and the amendment tabled in the Parliament, but when the Land Act

was published it was not included. The President had to admit that he had personally interfered to delete the amendment (Manji 2006). Hence, women's access to land was denied. However, an impaired woman may experience an even greater barrier to land as her opportunity of getting married is very small (see section 5.2.2).

5.2.7 Information

Informational barriers can be just as disempowering as societal or environmental barriers (Bonnie 2004). The issue of HIV/AIDS might have been covered under the topic of health. However, it is more a matter of *access to information* when identifying barriers to participation of PWDs in Uganda. Uganda was one of the first countries of Sub-Saharan Africa to experience the impact of HIV/AIDS. However, according to the WHO, Uganda has also been one of the few countries which through a broad-based national effort have managed to reduce the urban prevalence rate excessively (WHO 2008b). Despite this effort, HIV/AIDS is still by NUWODU identified as a major problem for PWDs, and in particular for women. Owing to negative attitudes in the society, women with impairments have difficulties in getting married although they may be in relationships. As a result, many women with impairments have various sexual partners. Even though HIV/AIDS organizations have been successful in Uganda, the issues of women and PWDs are lacking behind. Apparently the information is there, but the PWDs do not access it. A major barrier is the illiteracy due to lack of access to education. Another barrier is that PWDs may not be able to access information meetings due to either distance or an unfriendly physical environment. Accordingly, one can identify a *gap of information* from the *macro* and *meso* level to the *micro* level. It might be possible that information spreads from individual to individual at the micro level, but none of my 'basic' informants mentioned any of that kind.

5.3 The Physical and the Built-up Environment

The *physical and built-up environment* of Kampala may represent disabling barriers or an enabling environment for the PWDs that reside there. This section focuses on the *barriers* and *opportunities* within the areas of *mobility* and assistive devices, access to buildings, to means of transportation, managing the traffic and road side pavements, as well as *safety* and *security*. The topics will be highlighted by examples from my informants on their particular experiences from Kampala. Lastly I will use an example from the New Taxi Park. This example relates of conflicting interests between the local government and the PWDs in the

streets of Kampala, and may give some insights into the situation of what it is like to be impaired in Kampala.

5.3.1 Mobility and Assistive Devices

Most of the topics that will be discussed in this section are related to the issue of *mobility*. According to Gleeson (1999), the issue of mobility and *accessibility* are very important in order to understand the *lived experience* of disability. Being able to negotiate the physical environment may increase a person's mobility and accordingly enhance that person's opportunities to participation. Assistive devices represent an opportunity in order to increase a person's mobility. However, such assistive devices are expensive and most people have to pay for them themselves. Of my informants with walking impairments, only Charles owned a wheelchair, and Rashid and Abraham used a stick for walking. Several of the others used their hands to help them move about. Of my visually impaired informants, Elizabeth and Lincoln had a white cane to help them walk and orientate themselves in the environment. The white canes had been provided for them by their interest organization.

5.3.2 Buildings

According to the Persons with Disabilities Act of 2006, *'It shall be the responsibility of all organs in a public or private institution to provide suitable exits for persons with disabilities'* (Act 19: a), such as easy-to-find building entrances, safe and well-dimensioned staircases, and ramps, and *'universal standards or designs of public toilets'* (Act 19: b). The focus on disability issues has been increasing during the past decades in Uganda, and of major importance has been accessibility to the physical infrastructure and the built-up environment. PWDs are to a large extent excluded from accessing for example a building due to its architecture. Despite the fact that accessing a building does represent a barrier, lack of access to the services provided within that building, such as education, health care, or employment, may be of greater importance to PWDs. Accordingly, access to the physical and built-up environment may have great implications with regard to participation in the socio-economic development process. In an informal conversation, Charles, a walking impaired man, provided an example of how the built-up environment represents more than just a physical barrier to him. Being a street vendor he is in need of stock supplies for his business. However, as he cannot access the necessary building in order to buy the supplies, he needs someone to help him although at an extra expense. NUWODU points out that despite the fact that there is an increasing focus on accessibility to the built-up environment, most buildings were put up

before disability was even an issue. By my knowledge, there are only two ramps in Kampala, namely at the Parliament and at an interest organization for PWDs.

5.3.3 Transport

According to the Persons with Disabilities Act of 2006 shall, *'Any person providing public transport services provide access to transport-disadvantaged persons, such as persons using mobility devices'* (Act 22: 1). Access to public means of transportation increases a persons' mobility and consequently that person's access to participation. The public means of transportation in Kampala consists of 'taxis', which are Toyota Hiaces functioning as buses, 'boda bodas', which are mopeds, and special hires. Buses are only for long distance routes and do not operate within the city. According to the MP, there are provisions for the public 'taxis' to have racks where they can put wheelchairs, but due to lack of money, it has still not been implemented.

Most of my informants live in the outskirts of Kampala. Hence, they rely on public transportation to access their everyday activities. According to the Persons with Disabilities Act (2006), public transportation is supposed to be accessible for all people. However, several of my informants had been denied access to the 'taxis', and as such relied on the 'boda bodas' for transport. Owing to their impairments, some of them had to be lifted onto the moped. Consequently, the expenses increased although the fares are supposed to be relatively standardized. As mentioned in section 5.3.1, only Charles owned a wheelchair. He was a street vendor and used his chair to move about to sell his stock. Despite the fact that a wheelchair is an expensive assistive device, he had to leave it behind every day when he was going home due to lack of accessibility to the public means of transportation. From the experience of my walking impaired informants, there is a financial barrier included in the aspect of access to transportation. With regard to persons with visual impairments, there is an aspect of danger while traveling alone, at least while using the 'taxis' (see section 5.3.4).

Despite the fact that there are many barriers with regard to accessing public means of transportation for PWDs in Kampala, there are as well some opportunities, at least with regard to the legal framework. The Persons with Disabilities Act (2006) has made it illegal to deny PWDs access to transportation. Accordingly, if a person experiences any discrimination, he or she may take that person to the courts of law (see section 5.1.2).

5.3.3.1 Traffic and Pedestrians

According to the Persons with Disabilities Act of 2006,

'It shall be the duty of the Government to make public roads and highways accessible to persons with disabilities including equipping pedestrians crossings with traffic control signals controlled by a pedestrian push-button system, providing pedestrian traffic lights with clearly audible signals, and use of alarms or bells to signal approaching traffic' (Act 23: a, b, c).

To enhance the mobility of PWDs, the issues mentioned in the Persons with Disabilities Act should be in place albeit to a large extent they are not. The traffic picture in Kampala is somewhat chaotic. The streets are very busy filled with cars, 'taxis', 'boda bodas' and special hires. There are only a few zebra-crossings and traffic lights, and they are hardly respected by the vehicles. In Kampala Road, the main road of the city, there is a zebra-crossing with a traffic light that is often protected by police officers. However, it is still difficult to cross the road. For persons with walking impairments it is difficult to cross the roads as they are not able to move about fast enough. Vincent, one of my 'basic' informants who walked by the aid of his arms, worried that he might be knocked down by one of the vehicles. Persons with visual impairments are unable to orientate themselves in the landscape. Hence, they are unable to observe approaching vehicles. As such, they are in need of a guide although that is more a question of affordability. Mobility is also related to the issue of pavements. Even within the city center and by the main road, the pavements are full of potholes and the curbs are high. Therefore, the streets and pavements are both difficult and dangerous to maneuver.

5.3.4 Safety and Security

The aspect of safety and security is important in order to develop a *sense of place* and belonging to a city or any other place (Freund and McGuire 1995). However, there was a great divide between my walking impaired and visually impaired informants. An understanding of safety and security for persons with walking impairments was related to issues of financial security (see section 5.3.5). For persons with visual impairments, such as my 'basic' informants Lincoln and Elizabeth, it was more a matter of safety for their lives. Elizabeth related of two dimensions on the matter. The first dimension was the city center versus the outskirts of Kampala. Although she was not referring to the physical environment, she explained Kampala city center as friendly where people are helpful and sympathetic. In the outskirts of Kampala, on the other hand, she was afraid to meet thugs who might rape her. The second dimension was the aspect of moving by day versus at night. Being a visually impaired woman she was in a situation where she had to trust people, be it for directions or

help in some other way. By daytime, most people were nice to her. She related, however, of an experience where she had to move at night by public means of transportation. She heard someone nearby and she asked for directions. As she had to trust them, she followed them to what she believed to be a 'taxi'. They brought her to a remote area and they tried to rape her. Not all PWDs experience such dramatic incidents but most of my informants live in the outskirts of Kampala. While many visually impaired persons have to trust their surroundings, many persons with walking impairments might not have been able to outrun someone, if they had experienced a similar situation like Elizabeth.

5.3.5 Financial Security: The New Taxi Park and the Kampala City Council

Three of my 'basic' informants, Rashid, Eria, and Asha, as well as the four people with whom I had informal conversations, Abraham, Jack, Charles, and Yusuf were street vendors in the area around the New Taxi Park in the city center of Kampala. The area around the Old and the New Taxi Park are full of people going to and from their destinations, as well as the area is full of street vendors (see figures 5.1 and 5.2 below). All of my informants depended on access to this area in order to conduct their business and to generate an income. In 1995, the Kampala City Council (KCC) designated a certain plot at the Old Taxi Park to the PWDs. However, there is a conflict between the KCC and the PWDs which affect the financial security of my informants. Apparently, the plot had been sold off to investors by the KCC without any regard for the PWDs relying on that same area for business. During interviews, all of my informants expressed worries about their future due to this conflict. When confronted with the matter, the Councilor for PWDs at the City Council Nakawa Sub-Division could verify the sale of the plot. He could, however, also inform that due to advocating, the President had responded by assigning the PWDs a new plot near the New Taxi Park, and that they were in the pursuit of receiving a land title to secure the plot. Apparently, this particular conflict between the KCC and the PWDs at the New Taxi Park is a matter of an informational barrier.

Despite the fact that the conflict between the KCC and the PWDs represent an informational barrier, the relationship between the two parties is not all that simple. Asha, a female street vendor at the New Taxi Park, lived in constant fear about the KCC. She had experienced that the KCC arrived at the plot, took her things, and dumped them somewhere outside Kampala. Although the street vendors paid a daily fee in order to conduct their business in designated areas, this happened regularly. The City Council official acknowledged that the PWDs at the

New Taxi Park sometimes were removed from the area, in particular during large events. He could inform that when the former president of the United States, Bill Clinton, was visiting the country, the PWDs were removed from the streets and dumped somewhere. He expected that the same thing would happen during the forthcoming Commonwealth Heads of Government Meeting (CHOGM) hosted by Uganda in November 2007.

Figure 5.1 Old Taxi Park, Kampala 2007



Source: Author's own photo

Figure 5.2 Market Street, New Taxi Park, Kampala 2007



Source: Author's own photo

5.4 Summary

The endeavor of this chapter has been to identify barriers and opportunities for PWDs to participate in the mainstream society of Kampala, Uganda. The barriers and opportunities identified were of political, socio-cultural and socio-economic, and physical character. The political structures and the legal framework represent opportunities for PWDs to gain access to the society. However, lack of implementation of various policies and also lack of information of the opportunities available to the PWDs, create further barriers to the inclusion of PWDs. Disability is to a large extent a stigmatized label, both as a consequence of that PWDs are often regarded as the negatively 'other' compared to the notion of the 'normal' body, and because disability has often been linked to witchcraft. There is a gendered bias due to Uganda being a patriarchy, putting women with impairments lower on the hierarchical pecking order than men with impairments. Negative attitudes toward PWDs influence all areas of the society, implying barriers to participation of socio-cultural character. There exist an interrelation between poverty and disability. Access to education, health care, employment, land, and information represent barriers to participation. Lack of access to land in rural areas is a major incentive for PWDs to move to urban areas to gain access to income-generating

activities. However, lack of access to education and also need of special facilities make PWDs appear as a burden rather than a resource to employers in the formal sector. Despite a focus on the removal of discriminatory practices with regard to PWDs mobility, such as access to buildings and transport, there is lack of implementation and enforcement. The physical and built-up environment of Kampala thus represents mobility barriers for PWDs.

Chapter 6

Negotiation of Places and Power

The barriers and opportunities to participation, as identified in Chapter 5, represent structural components of the Ugandan society. The barriers identified were of political, socio-cultural and socio-economic, and physical character. Such barriers represent different *places of participation* to which persons with disabilities (PWDs) have been denied access. Despite the fact that, according to Giddens (1984), structures are social structures resulting from social interaction, constraining structures continue to exist. As such, PWDs continue to be excluded from various places of participation. Disability is a socially constructed identity label, and someone has the power to define PWDs as the negatively ‘other’ compared to the able-bodied. This suggests *unequal power-relations* in places of participation. Place is defined and produced by the hegemonic culture. The *hegemonic culture* is thus in power to define the boundaries of proper behavior; those being ‘in place’ or ‘out of place’ in a particular context, or place (Cresswell 1996). With regard to the barriers and opportunities as identified for access to participation of the PWDs in Kampala, they are in most of the places identified as ‘out of place’ hence excluded. For PWDs to be able to access participation there is a need for either changing existing places or creating new ones. Giddens’ (1984) notion of *duality of structure and agency* is of importance to understand changing power-relations within different places of participation. Based on the notion of a hegemonic culture, places are never neutral, and within each place, or contextuality, agents hold different access to power and control (Cornwall 2004). Accordingly, as structures are the result of social interaction in *place as locale*, they are *negotiable*.

This chapter will focus on how the access of PWDs is negotiated within the particular context of Kampala, Uganda. I will start by identifying the different *agents of negotiation* at the different levels of society; macro, meso and micro, as well as introduce the different agents’ means of negotiation. Secondly, I will assess the negotiation of each of the different places of participation; political, socio-cultural and socio-economic, and the physical and built-up environment. Each of these places represents places that are either opened or closed for PWDs. Hence, for PWDs to gain access to the society there is a need to either open, change or create places of participation.

6.1 Agents of Negotiation

Agency is not the intention people have to act, but rather their capacity to do so (Hardcastle et al. 2005). Although the different agents in my study have both different *means of negotiation* as well as different access to power, they are all equally agents for change. Based on the theory of structuration, I have separated the agents in my study into three levels; the *macro*, or national, the *meso*, or community, and the *micro*, the PWDs.

6.1.1 Macro Level

The agents at the macro level in my study are represented by Honorary Kyebakoze Madada, the Minister of Disability and Elderly Affairs (the Minister), Honorary Baba Diri, a visually impaired Member of Parliament (MP), and Mr. Mirembe, the Executive Secretary of the National Council for Disability (NCD). The three agents at the national level are all in positions with the power to define. However, they are all representatives working for PWDs albeit within different positions. Hence, through means of negotiation such as *advocacy* and *awareness-raising*, the three agents may be able to negotiate access of PWDs into different places of participation at different levels of the society.

6.1.2 Meso Level

The City Council Nakawa Sub-Division, here represented by a Councilor for PWDs, Mr. Ssalongo, is a government body at the sub-county level. Hence, the City Council is in a position which has the power to define. However, through the Local Government Act of 1997, two PWDs are represented with the responsibility to ensure and to negotiate that the focus put on the PWDs in the national policies and laws, are being implemented in the policies of the local government. The City Council Nakawa Sub-Division is also responsible for *awareness-raising* and *sensitization* of people within the parishes belonging to the Nakawa Sub-Division. Hence, they are negotiating societal attitudes.

The National Union of Disabled Persons in Uganda (NUDIPU), the National Union of Women with Disabilities in Uganda (NUWODU), and the Uganda National Association of the Blind (UNAB) are the three interest organizations in my study. NUDIPU, represented by Mr. Ssenoga, is the umbrella organization for all PWDs in Uganda, NUWODU, represented by Ms. Guzu, is the national organization for all women with disabilities, while UNAB, represented by Mr. Luyima, is the national organization for persons with visual impairments. The organizations were all founded in order to voice the interests of their particular members,

and they are based on the equalization of opportunities of the UN Standard Rules (1993). The negotiating means of the three organizations in my study are *advocacy*, *capacity-building*, and *awareness-raising*. They all have branches at district level, and through capacity-building of branch leaders they enable them to continue advocacy work at their specific levels of representation. This is the strategy of the organizations to reach the micro level.

6.1.3 Micro

The agents at the micro level of my study are represented by nine PWDs with whom I conducted in-depth interviews; my ‘basic’ informants, as well as four PWDs with whom I conducted informal conversations. My ‘basic’ informants were of both gender and either visually impaired or walking impaired. The persons with whom I conducted informal conversations were all male with walking impairments. As discussed in Chapter 2 section 2.1.5, all PWDs are competent social agents. It is, however, of importance to acknowledge that each individual possess different assets, motives and strategies. Hence, the PWDs at the micro level may negotiate constraining barriers through either intentional *social action* or unintentional *social practice*.

6.2 Places of Negotiation

Chapter 5 identified different barriers and opportunities for PWDs to access participation in the mainstream society of Kampala, Uganda. The barriers and opportunities represent the structural components of the Ugandan society, or places of participation, to which PWDs are either included or excluded. According to the identification process conducted in Chapter 5, the places that have already been changed or created are the representation of the PWDs within the political structures; from the national to parish level, and the inclusion of the PWDs into the legal framework. Through the legal framework, several places have been opened for participation, such as access to education and land. However, although some places of participation have been created or changed, there is still a need for further negotiation with regard to access to equal opportunities to participation within the mainstream society.

In this section I will focus on the *negotiation of barriers* within the different places of participation; the political, the socio-cultural and socio-economic, and the physical and built-up environment.

6.2.1 Negotiation of Political Participation

During the past two decades, PWDs have been granted more and more access to the political system. PWDs have also been included in the legal framework. Accordingly, the *place of political participation* is a place that has been opened. The opening of the place of political participation may be partly explained due to the increased focus on disability issues at the global and regional level. The various agents at global and regional level represent power to negotiate toward the Ugandan government and its prioritization of, for instance, the equalization of opportunities for PWDs. Hence, the result of the negotiation and influence from global and regional agents has been the opening of political participation for PWDs. In Chapter 5, the Local Government Act of 1997 was identified as an opportunity as it ensures that PWDs are represented at all levels of decision-making. However, as the Executive Secretary of the NCD acknowledged, the existence of PWDs in Parliament was a major struggle as there was a need for incessant advocating toward various Members of Parliament to achieve the opening of the place of political participation.

Even though the place of political participation has been opened for PWDs, there is still a need for further negotiation to ensure equal participation for all parties, in particular with regard to the political will to implement the various laws and policies that have been amended. However, despite the lack of implementation, the laws and policies in place represent means of negotiation for further advocacy work by the various interest organizations, such as negotiation of access to employment. According to the Persons with Disabilities Act (2006), given that a PWD is qualified, an employer is not allowed to discriminate against that person because of his or her impairment. Although formal employment represents a fairly closed place of participation for PWDs, this Act can be used for further negotiation of access. This was the case in June 2007 when agents at the macro level as well as the interest organizations at the meso level, organized a workshop to sensitize employers of various factories and industries. The overarching goal was to negotiate access to employment for PWDs through the creation of awareness of the abilities of PWDs. With arguments rooted in an already existing legal framework, the agents had more legitimacy. Hence, they had more power to negotiate.

Despite the fact that the place of political participation has been opened, and that the legal framework provides the advocating agents an opportunity and legitimacy for further influential means of negotiation, there still exists a need for change. UNAB, for example,

advocate toward the government, the Parliament, the executives and the justice, as these agents are the ones who scrutinize and approve policies and laws. The idea is that when agents who hold the power to define, start to understand issues related to disability, the laws and policies that are made, will favor them. Hence, the agents at the meso level continuously work to change the place of political participation as to create better opportunities for PWDs to equal participation in the society.

6.2.1.1 Negotiation of Access to Information of Political Opportunities

Despite the interest organizations intentions to reach the micro level with information and services, there still exists a gap, in particular in Kampala. As acknowledged by NUDIPU, they have had an impact at the national level, but people at the micro level have limited knowledge about it. According to Rashid and Charles, two of my informants, people know of NUDIPU, and this knowledge of the existence of an interest organization just for them, has created great expectations. However, many of the people in the streets do not know what NUDIPU is all about. Rashid and Charles told me in separate interviews that, *'I hear that NUDIPU has got financial support but unfortunately the funds do not reach us. I expect money from NUDIPU to take care of my children and my wife'*. As a means of negotiating the lack of support from their interest organization, Eria, another of my informants, chose to start his own association. Although NUDIPU is not a service-provider, this case provides an example of a *gap of information* to the people in the streets. It might also highlight the lack of focus that the interest organizations have on urban areas. This case does not involve only NUDIPU but provides an example of how the interest organizations negotiate upward in the hierarchy of power rather than down toward the micro level. However, supposing the gap between NUDIPU, or any other interest organization, and the PWDs in the streets of Kampala was non-existent, the information provided by NUDIPU could represent an opportunity for the PWDs to be able to negotiate access to various places of participation. Through information and knowledge, an individual can more easily interpret the context in which he or she lives, hence make use of available opportunities (FRIDE 2006). My informants in the streets experience everyday discrimination through, for example, being denied access to public means of transportation. Information provided by, for example, NUDIPU, could enable the PWDs to demand for their rights.

6.2.2 Negotiation of Socio-Cultural and Attitudinal Barriers

Impairment is found among people in all societies. It is, however, through the notion of the ‘normal’ body that the hegemonic culture in a particular place has the power to define what is to be regarded as ‘abnormal’ and ‘out of place’. In Uganda, *disability* is to a large extent a *stigmatized label* due to ignorance and superstitions. Owing to their impairments, many PWDs experience discrimination and exclusion from various places of participation, such as identified in Chapter 5. PWDs do not get access to employment because they are regarded as a burden and thought to be useless. By their parents, PWDs are not considered worth inheriting land. When giving birth at the hospital, women are harassed because an impaired person is not supposed to have children. Accordingly, there exist a need for negotiation of attitudes toward the notion of the disabled body as the negatively ‘other’.

6.2.2.1 Negotiation of the Disabled Body as the Negatively ‘Other’ – Macro and Meso Level

The Minister of Disability and Elderly Affairs stated that,

‘As political supervisor, I am trying to sensitize my colleagues in politics, those who allocate resources to ensure that in their work they care about persons with disabilities. Disability is something that can happen at any time to anybody’.

Accordingly, through *social action*, the Minister campaigns that disability affects everyone and not just ‘the others’. Anyone can become the victim of a car accident or fall ill. Another campaign at the macro level is NCD’s work to prevent NGOs to give handouts to PWDs. Such charitable based work toward PWDs is based on the *medical model of disability* which explains disability as functional deficits in the individual. From this perspective, the disabled body is dependent because the body is defective (Goble 2004). However, through a rights-based approach, the NCD works to remove such negative attitudes toward the disabled body to enhance their opportunities to leading independent lives. These two cases represent how different agents at the macro level work to actively negotiate and change societal and attitudinal barriers toward PWDs. The two agents, the Minister and the NCD, work to influence those with the power to define within the macro and meso level. At the meso level, on the other hand, UNAB takes another approach. Regularly, UNAB organizes sports events together with the Uganda Blind Sports Association. Although these events have several motives, one is the awareness-raising and sensitization of local communities with regard to the negotiation of negative attitudes toward the visually impaired. With the local communities as their spectators, the visually impaired can show their potential and their abilities through sports.

6.2.2.2 Negotiation of the Disabled Body as the Negatively 'Other' – Micro Level

All of my informants but Michael come originally from rural areas. A story of the negative attitudes toward the disabled body in the rural areas was provided by Elizabeth, a visually impaired woman. Elizabeth lost her sight in her late teens and, as a result, she had to drop out of school and was brought to the village of her relatives. She said, *'You could not even touch someone because you would be blamed if that person fell sick'*. Although not in relation to the same story, Asha, a walking impaired woman, informed me that through an interest organization, she had been taught how to behave in the society. As a result of negative attitudes and superstitions toward PWDs, she learned how to behave differently and more careful than other people. As people apparently are more willing to blame PWDs when something goes wrong, like in the case of Elizabeth, through behavioral training, Asha learned how to be able to avoid such attitudinal barriers. From the part of the interest organization, this is a social action in order to enable PWDs to negotiate their social relations in their everyday lives.

As mentioned above, all but one of my informants have a rural background albeit at some point they have chosen to go to the city. My selection of informants might not enable me to separate the norm from the exception with regard to PWDs general choice of living within a rural or urban setting, but Lincoln gave me one of his reasons. Lincoln, a visually impaired man, explained that,

'People in the city are more understanding than in the village because in the city, you can get help. In the village, somebody could look at you and start imagining that "let me see if this person falls into a ditch" or "let me see if this person can avoid the mud"'.

Accordingly, one of the reasons, although not necessarily the most important, that PWDs come to Kampala or another city, is to escape from the negative societal attitudes of rural areas, such as experienced by Elizabeth. The example provided by Lincoln does not represent a social action of conscious negotiation of attitudinal barriers to deliberately change them. It is, however, an example of a conscious choice where individuals choose to live in a place where their physical presence may be more *anonymous* (see Chapter 4 section 4.3.1). Hence, avoidance of negative societal attitudes in rural areas may be experienced as a negotiation as well. Although the choice of location may be both free and voluntary for some, it is still of importance to recognize that structural impediments, such as access to income-generating activities or lack of access to land, may influence or limit their so-called choice of location.

Yusuf, a walking impaired man, is one of my informants who left his rural village. When he came to Kampala, he started to work as a street vendor at the New Taxi Park area. Having a disabled body working in a public arena, he was exposed for reactions. In an informal conversation he told me that,

'In Kampala, I felt that people looked upon the disabled body as dirty. When I arrived in the city, I wanted to fit in. I observed that people in Kampala dressed smart. I started to dress smart as well, and I did not feel dirty anymore'.

When arriving in Kampala, Yusuf experienced that the society looked upon him as a negatively 'other' due to his disabled body, and consequently, he felt 'out of place'. He negotiated his outsider status, however, by a different *subject position* than his body, namely through his clothes. As a response to feeling dirty, Yusuf was able to identify a means of negotiation. Hence, he conducted an intentional social action to gain access to an already existing place of participation.

6.2.2.3 Negotiation of Expected Daily Activities

Although the body in itself, with its material signification in a particular context, functions as an agent for change, the negotiation of the disabled body as the negatively 'other' implies more than just being present on the public arena. According to its definition, a disability is *'The loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers'* (DPI 1982). Hence, the hegemonic culture within a particular place has the power to define the expected daily activities, and those unable to fulfill these activities are the negatively 'other'.

As identified in Chapter 4 section 4.1, Uganda is a rural country with agriculture as the main income-generating activity. Accordingly, an important expected daily activity in Uganda is digging. To negotiate daily expected activities, an individual can either chose to partake in order to show that he or she is able, or find something else and be successful. In an informal conversation, Yusuf, a walking impaired man, told me about the time when he was still living with his relatives in the village, *'My relatives thought me incapable of the work necessary. I showed them by going to the garden and dig with them'*. Through this exercise, Yusuf negotiated his relatives' expectations of the disabled body.

Sports may not be qualified as an expected daily activity. It is, however, a daily activity for many young boys and girls. Based on this argumentation, I will use an example given by Michael, a walking impaired, football-loving male, as a negotiation of expected daily

activities. Based on the notion of disability as an individual problem, the body is regarded to be deficit or broken, and Michael told me about his broken body. Michael wanted to join a football-team, but the coach said, *'What can you do? Do you want to get broken?'* The other team-players were laughing and teasing him, but he answered, *'Mister, I have to play. Whether I die, whether I break, let me break'*. *'But what can you do? Can you really play?'* the coach replied. He brought a ball, and Michael controlled it. The coach said, *'This boy can play'*. Michael was accepted and joined the team. The expectations to someone like Michael having a walking impaired body, was that he could not play football. Hence, he should be excluded from participation, and he had to prove them otherwise. Michael's story is both an example of negotiation of the disabled body as the negatively 'other' as well as expected daily activities.

6.2.2.4 Negotiation of Patriarchal Structures

As identified in Chapter 5, impairment affect men and women in different ways, and as a result of discriminatory cultural practices, women with impairments have greater barriers to accessing various places of participation. Originally, issues of women with impairments had been covered for by a gender desk at NUDIPU at the meso level. However, during a women's forum in Uganda in 1999, it was acknowledged that women did not fully benefit from the NUDIPU programs. Hence, it was better to set up an independent women's organization. NUWODU was founded in 1999 during a women's forum with representatives of women from all districts in Uganda. Through this action, the interest organizations at the meso level work to increase their abilities to negotiate and advocate for women's issues. See section 6.2.3.3 for a case on how women at the micro level negotiate patriarchal structures in their everyday life.

6.2.3 Negotiation of Socio-Economic Barriers

Disability is most likely the reason for *poverty* due to limited livelihood opportunities. Chapter 5 identified several barriers within each of the different places of socio-economic participation; education, health services, employment, land, and information. Hence, the various places of socio-economic participation are to a large extent closed for PWDs. To increase livelihood opportunities that may enable PWDs to escape poverty, there is a need for negotiation of the places of socio-economic participation.

6.2.3.1 Negotiation of Access to Education

The Universal Primary Education policy (UPE) from 1997 represents a place of participation that has been changed in order to include PWDs. Although this place has been changed, there is still a need for further negotiation as to include PWDs on equal terms as able-bodied students. In Kampala, the City Council Nakawa Sub-Division has had cases where families have denied their children to go to school. According to the Councilor for PWDs at the City Council, they make household calls in order to sensitize the parents and to create awareness of the opportunities that exist for PWDs. However, my 'basic' informants were too old to benefit from the UPE.

Elizabeth, a visually impaired woman, was halfway through her college education in economics when an inherited disease caused her visual impairment. Consequently, she was taken out of school and brought back to her relatives in the village. *'I am not illiterate but I cannot read. What am I?'* she exclaimed, and neither herself nor her family thought it possible for a person with a visual impairment to continue any kind of education. However, through UNAB, the existing barriers for Elizabeth to continue her education were negotiated. A member of UNAB made both Elizabeth and her family, realize her opportunities and her potential despite Elizabeth's impairment. Hence, UNAB negotiated attitudinal barriers through awareness-raising. Elizabeth was brought to a Vocational Rehabilitation Center in Kampala where UNAB has an IT program for the visually impaired. Accordingly, Elizabeth got access to learn how to read and write Braille, and could once again communicate through the means of writing. Granted access to an interest organization, Elizabeth was enabled to make use of the existing opportunities in the society. However, not all PWDs have access to an interest organization which could have helped them negotiate access to participation. On the other hand, Lincoln, as mentioned in Chapter 5 section 5.2.3, was, despite his family's poor socio-economic status, his visual impairment, and lack of support from an interest organization, able to get himself a bachelor degree from the Makerere University. The story of Lincoln provides an example of how an individual is able to *transgress* socio-economic and socio-cultural structures that exists within a society. However, this case represents an exception rather than the norm.

6.2.3.2 Negotiation of Access to Health Care and Preventive Measures

Impairment is defined by DPI (1982) as *'The functional limitation within the individual caused by physical, mental or sensory impairment'*. The consequence of impairment may be a

disability which is defined as *'The loss or limitation of opportunities to take part in the normal life of community on an equal level with others due to physical and social barriers'* (DPI 1982). However, as identified in the Chapter 5 section 5.2.4, through *preventive measures* the number of incidents which may result in impairment can be reduced. According to NUWODU, the government, at macro level, runs immunization programs toward children which have led to a great reduction in polio infection. At the meso level, UNAB, for example, organize sensitization programs toward parents, not only of children with visual impairments. As children are most easily affected by various diseases, it is important that parents are aware of the causes of impairment as well as how to prevent them. In addition, in order to reach a larger number of people, UNAB cooperate with Sight Savers Uganda to engage in bigger campaigns on the prevention of blindness albeit such campaigns are only directed at *rural areas*.

6.2.3.3 Negotiation of Access to Employment

As a consequence of negative attitudes as well as high unemployment rates in Kampala as identified in Chapter 4 section 4.3.1, employment as a place of participation is in many regards closed for PWDs. As mentioned in section 6.2.1, agents at the macro and meso level negotiate access to employment for PWDs in the formal sector.

In Chapter 5 section 5.2.5, an opportunity for PWDs to engage in employment, in particular for those with vocational training, was to start a business on their own. However, PWDs' lack of access to micro-finance projects represented a barrier. As a result, the NCD, at macro level, formed home-based community banks where the PWDs each brought a certain amount of money to which they could apply for projects at a low interest rate. However, this has mostly taken place in rural areas as they are reluctant to start such programs in urban areas. Projects in urban areas are identified as difficult due to the cycle of migration. The NCD did start a micro-finance project in coordination with a community based rehabilitation program in Bwaise in the outskirts of Kampala. According to the Executive Secretary of the NCD, out of 40 participants, only 18 were still there when they returned to evaluate the project. Consequently, the project was cancelled. Although the NCD and other agents work to negotiate PWDs access to engage in employment, this particular place of participation stay rather closed for the PWDs residing in Kampala. At the micro level, several of my informants now working as street vendors in the New Taxi Park area, have a background with vocational training. Due to lack of employment opportunities in the formal sector as well as in self-

employment as mentioned above, they have negotiated the barriers through choosing the opportunities available to them. Hence, they are working in the informal sector in the streets.

Although the label of disability to a large extent is stigmatizing and negative, several of my informants in the streets have learned how to use it to their advantage while negotiating their access to employment. All of my informants but Abraham who worked as street vendors from the area around the New Taxi Park were part of trading associations. The members of these associations were all PWDs. These associations were used to secure a steady income for their members as well as negotiate access to the informal market through a unified voice. The women had, however, negotiated their access through starting their own association due to patriarchal structures within the mixed gender associations. Vincent, on the other hand, was not a street vendor but a beggar. He had located himself in the New Taxi Park area due to the high density of travelers and people passing by. He used the label of disability to create sympathy from the passers-by. Hence, he managed to gain an income.

6.2.3.4 Negotiation of Access to Land

As stated in Chapter 4 section 4.1, more than 85 per cent of the Ugandan population lives in rural areas with agriculture as the main income-generating activity. Hence, land is an important asset. According to the Land Act of 1998, PWDs have been provided the right to ownership, occupation and use of land. As such, this Act represents a place of participation that has been opened for the PWDs albeit not for women. As identified in Chapter 5, women can only access land through marriage. Together with several women's groups, NUWODU negotiated women's access to land through advocacy. However, through the Land Act of 1998, land continues to be a closed place of participation for women (Manji 2006).

Despite the good intentions of the Land Act toward PWDs, children with disabilities are to a large extent not considered worth inheriting land by their parents. The NCD work to change such an exclusion of PWDs. According to the Executive Secretary of the NCD, if the parents accept to give them two acres of land, the government opens the land, and after selling the first harvest, government pulls out. The PWD can thus use the money from the harvest to continue cultivating. However, with regard to the harvest, the Executive Secretary had a personal experience from assisting an impaired person to sell ground nuts. At the market, people were reluctant to buy the ground nuts as they believed them to be full of disability. As such, the NCD negotiates the negative attitudes of the parents which are constraining the

PWDs' access to land. However, the story also reveals a further need for awareness-raising and sensitization of the general societal attitudes in order for PWDs to access a market.

Given that you have access to land, as mentioned in Chapter 5 section 5.2.6, the National Agriculture Services (NAG) is a government service provider at sub-county level which provides services required by farmers albeit not focusing on PWDs. According to NUDIPU, the NAG program only target active people. Most PWDs are, however, somehow involved in farming. As such, through capacity-building as a means of negotiation, NUDIPU works to make PWDs more productive as to be identified as targets by the NAGs. Instead of advocating the service-providers to increase the participatory level of the PWDs, UNAB has their own empowerment programs. Through community rehabilitation programs, they make household calls to visually impaired persons. If a visually impaired person has a garden, UNAB design that garden in order for that person to orientate himself easily. They also train him on how to, for example, plant maize in a modern and adaptive way. By giving self-sustaining skills in agriculture to persons with visual impairments, they negotiate their abilities as well as their level of independence.

6.2.3.5 Negotiation of Access to Information

As identified in Chapter 5 section 5.2.7, information about HIV/AIDS is an important barrier for the well-being of PWDS, in particular the women. UNAB, for example, has two different strategies to negotiate this informational barrier. The first strategy is to target the leaders of the various HIV/AIDS programs in order to sensitize them on issues of disability and how to increase their *accessibility to information*. The information may, however, not exist in Braille as for persons with visual impairments to be able to read. Hence, the second strategy of UNAB is to provide cassettes with information in a language which is understood in the particular area of distribution. However, these cassettes may still not reach everyone who needs them. Accordingly, despite the negotiation of UNAB or any other agent, lack of access to information, be it about HIV/AIDS or any other topic, continue to represent a relatively closed place of participation for PWDs.

6.2.4 Negotiation of Access to the Physical and the Built-Up Environment

The place of physical and built-up environment represents a place that has to some degree been opened for PWDs. As a result of the increasing focus on disability issues in Uganda throughout the previous decades, the notion of accessibility has been mainstreamed. The physical accessibility to schools and hospitals has for instance been emphasized. However,

the physical and built-up environment still represents a major barrier for PWDs to perform their everyday activities. Most of my ‘basic’ informants still need assistance in order to access public means of transportation. Some of my informants still need help in order to access the stock supplies for their businesses. For pedestrians, it is still as dangerous to walk on the pavements as it is to cross the roads. Accordingly, there exists a need for negotiation of the place of physical and built-up environment.

6.2.4.1 Mobility and Assistive Devices

As identified in Chapter 5 section 5.3.1, the issue of *mobility* is of major importance for a PWD because increased mobility of an individual may enhance that person’s opportunities to participation. Despite the fact that assistive devices may increase an individual’s mobility, they are expensive, and as such, representing a financial barrier. However, some of the interest organizations at the meso level work to negotiate PWDs access to assistive devices. Anyhow, NUDIPU, used in this example, is not a service-provider, and their advocacy strategy is to hand out assistive devices to the leaders in their respective communities. The underlying idea is that they demonstrate to the communities as well as relevant service-providers that if a person is given, for example, a wheelchair, that person becomes as mobile as an able-bodied person. Consequently, they become more productive. However, this work is mainly located in *rural areas*, and may result in an increased gap between the PWDs with resources and those without, hence creating a further barrier. NUWODU, on the other hand, provides assistive devices to all the women with impairments who take part in their workshops. This is part of their capacity-building of rural women. Instead of primarily focusing on assistive devices, UNAB provides mobility skills for people who have become visually impaired at adult age in order to restore some of their mobility. However, this training is provided at a rehabilitation center in the eastern part of the country.

In *urban areas*, on the other hand, Elizabeth, a visually impaired woman, found that she was in need of a guide in order to move about as she wished. She said to herself, ‘*Now that I am blind who is going to give me a hand? I am young, and if I can really get a chance I will produce my own child who can be my guide in the future*’. Now Elizabeth has a child whom she expects will be a good guide for her mother. Elizabeth identified the lack of provision and support in order to increase her mobility, and accordingly, acted as an *agent* to enhance her own life.

6.2.4.2 Negotiation of Physical Barriers and the Built-Up Environment

Following the discussion above, although through different means of negotiation, the interest organizations as well as my ‘basic’ informants have learned how to negotiate and maneuver the physical and built-up environment of Kampala. The PWDs find ways of managing their everyday activities within a *limited place of participation*. However, according to NUWODU, despite the fact that some buildings, such as some schools and hospitals, have been upgraded to enhance their accessibility, there is current advocacy work toward Parliament to make a bill. However, NUWODU acknowledged that many people in Parliament still do not care about issues of disability and accessibility.

Access to public means of transportation is another way of negotiating mobility within the physical and built-up environment. It was identified in Chapter 5 section 5.3.3 that although there are provisions for the ‘taxis’ to have racks for wheelchairs, it has still not been implemented. Nonetheless, PWDs continue to use the public means of transportation in their everyday activities albeit at increased expenses. Through the PWDs everyday practice, they do not let this particular place of participation exclude them. Continuously social practice may result in an increased focus on the need to adjust and upgrade the public means of transportation in order to change this place of participation to increase the PWDs’ access.

6.2.4.3 Negotiating and Living in the Streets of Kampala

There are hardly any persons with visual impairments to be observed in the streets of Kampala, at least not of the people conducting business there. According to UNAB, there were many visually impaired persons in the streets in the 1990s. However, in 1999, together with the KCC, UNAB organized a massive campaign to bring them out of the streets. The motive was that they did not want persons with visual impairments to be associated with poor, dependent people. People were offered a package which included going to their center in the eastern part of the country to learn skills and self-dependence. The PWDs were expected to return to their families in the villages. Despite the fact that enhancement of PWDs’ skills may increase their opportunity to participate in the society, there still exists several structural impediments for them to partake in the daily activities in rural areas. To live an independent life in rural Uganda, most people are in need of access to land. They also have to be capable of conducting the work expected. Accordingly, UNAB acknowledged that some people had returned to the streets although most of them did not.

6.3 Summary

The UN Standard Rules (1993) emphasizes that the various agents in the field of disability, including interest organizations and the PWDs themselves, are opted for to play an active role in order to gain access to the mainstream society. The endeavor of this chapter has thus been to identify the negotiation of structural barriers and the power-relations within them. I have identified agents at the macro, meso and micro level in Kampala and Uganda. The negotiating means at the macro and meso level are advocacy, capacity-building, and awareness-raising. Despite good intentions from the various agents at these two levels to reach PWDs at the micro level, there still exists a gap. It appears that the various agents are more focused on advocacy work toward agents at a higher level in the structural hierarchy rather than capacity-building and awareness-raising at the micro level, in particular in urban areas.

At the micro level, the means of negotiation are either intentional social action or unintentional social practice. The impaired body is an omnipresent subject position challenging societal structures such as negative attitudes. By some of my informants, the body is used consciously as a means of negotiation to challenge the hegemonic cultural power. On the other hand, negotiation of the disabled body as the negatively 'other' implies more than just being present on a public arena, such as negotiation of expected daily activities. However, it seems to be the norm rather than the exception to avoid or adapt to the existing hegemonic cultural power rather than to challenge it.

Chapter 7

Overcoming the Barriers - The Embodied Experience of Self in Kampala

The UN Standard Rules (1993) emphasizes the importance of persons with disabilities (PWDs) access to *equal opportunities* to participation in the mainstream society. To a large extent, Uganda has therefore during the previous decades put a stronger focus on the inclusion of PWDs in the society. Following this, and based on the social model of disability (Oliver 1983), Chapter 5 in this thesis identified existing barriers and opportunities for PWDs to participate in the Ugandan society. These barriers and opportunities represent places of participation to which PWDs are either included or excluded. Chapter 6, on the other hand, focused on the negotiation of various agents in the *place as locale* in order to gain access to these places of participation. Until this point, the emphasis has thus been that in order for PWDs to be able to have equal opportunities to participation, the places of participation have to be opened, created or changed (Cornwall 2004). However, the opening of places of participation for the PWDs may not necessarily be enough for them to participate as PWDs also have to believe that they are capable of, and entitled, to occupy them (Rowlands 1995). From the analysis in Chapter 6, it seems to be the norm rather than the exception, in particular at the micro level, to avoid or adapt to the existing hegemonic cultural power rather than to challenge it, although not in all cases. Hence, this chapter will therefore focus on the *differences* of the *lived experience* of PWDs in Kampala rather than the commonalities as identified in Chapter 5. An emphasis on differences in the lived experience of disability may provide a means to destabilize the so-called homogenous group of disability. In addition, it may also detect less obvious similarities among the individuals (Cole 2008). Hence, it may provide new approaches to overcome the disability experience and also new references for understanding impairment and disability.

By using the theories of place; *location*, *locale* and *sense of place* as complementary, I may be in danger of giving the impression that the physical environment and the social attitudes together shape the *sense of place* and lived experience of my informants. However, such an approach would be deterministic. As identified in Chapter 2 section 2.2.3, people and places are mutually reinforcing each other, and the dualism is overcome by the duality approach of the structuration theory (Giddens 1984). Through the notion of *embodiment*, the body is the material basis for the lived experience in the world (Gabe et al. 2004). Accordingly, the body is the where, why and when of our daily activities and experiences (Hughes 2004). Hence, the

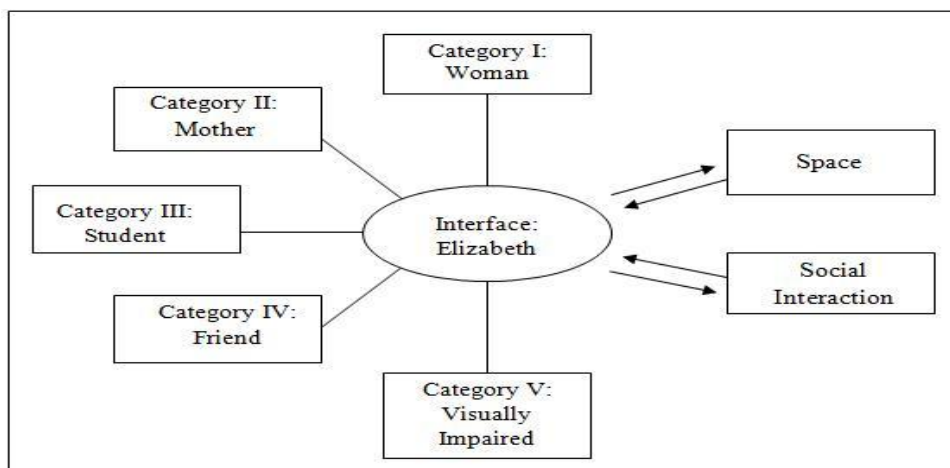
impaired body is an omnipresent *subject position* in the everyday life of my ‘basic’ informants, and thus provides a good starting point to understand an individual’s *sense of place* and *sense of self*. How my informants *overcome the barriers* in the different places of participation varies from individual to individual. According to the medical model of disability, it was assumed that the problem lied within the individual. Through technical intervention by skilled personnel the person would get help to overcome the barriers and return to an approximation of normality. The social model of disability, on the other hand, assumes that the removal of structural barriers will automatically lead to the overcoming of disability (Goble 2004). Although the removal of structural barriers, which according to the social model are the reasons for disability, would be ideal, it represents a utopia, at least in a short-time perspective. As such, although striving toward the total removal of barriers in order to overcome disability, the PWDs need to overcome the barriers that exist in their everyday lives today. As argued by McElroy and Townsend (2004), the goal is not recovery, but rather restoring relative well-being and positive self-identity in spite of impairment. Accordingly, overcoming in this study implies that the PWDs not necessarily accept the disability experience, but rather accept the impairment. In addition, overcoming further implies that the PWDs do not focus on the barriers, but rather focus on the opportunities available to them, and maximize them. However, the embodied experience of self in Kampala may affect the PWDs identity and *sense of self*, for example through internalization of external expectations. Accordingly, this study has a psychological perspective which include coping strategies as well as own expectations to life. However, the concept of embodiment, as argued above, provides a geographical means to understand an individual, its actions and experiences within a given system of structures. This chapter will therefore focus on the lived experience of the embodied selves of my informants at the micro level.

7.1 More than a Label? Identity Formation and Intersectionality

Throughout this thesis, I have presented PWDs as a rather uniform category only separated by type of impairment and gender. However, in Chapter 2 section 2.5.1, it was acknowledged that such *categorizations* are social constructions in order to make sense of a complex world. The consequence of such categorizations may be a continuation of the differentiation of PWDs as the negatively ‘others’, and as such, a given identity label. However, it is of importance to acknowledge that each individual has its own unique interface of different categories. As *identity* is a process (Panelli 2004), such categories may thus develop and change over time. Accordingly, each individual has its own lived experience regarding

interaction with space and social relations. Considering that individuals do not confine to a singular social grouping, it is, according to Sheldon (2004), important to focus on interactions between different dimensions of oppression, such as disability, gender, socio-economic and socio-cultural status. However, according to Oliver (1996a), such a focus may only serve to marginalize each individual's experiences, and consequently further divert attention from common concerns and issues, such as has been conducted in Chapter 5 and 6. I choose, however, to understand the lived experience of the PWDs through the concept of *intersectionality*. The relevance of this concept in my study is that it provides an opportunity to understand the lived experience of my informants in a new perspective. Hence, my informants are more than the label of disability. Furthermore, the lived experience of this label varies among my informants. According to McCall (2005), the concept of intersectionality helps to highlight the understanding of how an individual experience intersection of different categories in its everyday life. This is because the concept of intersectionality describes the *interconnections* and *interdependence* of different categories (Valentine 2007). For further elaboration of the concept, see Chapter 2 section 2.5.2. McCall (2005) argues that such intersection of categories is best understood through case studies. I will use the case of Elizabeth, a visually impaired woman. Although Elizabeth has frequently been used as an example throughout this thesis, I will continue to use her as she was rich on information and particularly open about her lived experience compared to most of my other 'basic' informants. By focusing on Elizabeth's *situated accomplishment*, meaning how she forms and performs her identity in various *social interactions* and *spaces*, I might be able to gain an insight into how Elizabeth negotiates her identity and lived experience of her embodied self.

Figure 7.1 Example of Elizabeth's Intersectionality



Source: Author's own construct

Woman, mother, friend, student, and visual impairment are some of the categories that constitute Elizabeth's lived experience of her embodied self (see figure 7.1 above). To the society, Elizabeth's visual impairment may be the most obvious category, and the impaired body represents expectations about her life and her person. However, Elizabeth's *sense of self* emerges and unfolds in the different spatial contexts and social relations in which she partakes in her everyday life. Depending on each situation, some categories, such as student or visually impaired, will be emphasized while others will be suppressed or made irrelevant (Valentine 2007). This is either the result of Elizabeth's identification with certain identities in a particular situation or context, or the result of asymmetrical power relations in certain places.

Elizabeth did not become visually impaired before she was in her late teens, and as I will come back to in section 7.4, it was by Elizabeth experienced as a *tragedy*. She had to leave her education and go back to her village. She had to stay indoors because she could not move easily on her own due to her lack of sight. Elizabeth and her family thought her life was over because the expectation was that a blind person can do nothing. Accordingly, from identifying herself with the categories of being a young, able-bodied student, she was now *'the blind'*. *'The blind'* was how Elizabeth perceived herself, and the noun combined with the definite article represent, according to Bolt (2005), an antithetical to *'the sighted'*, and as such, *deviant* in relation to the assumed normality. Through the process of losing her sight, Elizabeth also lost most of her friends. She experienced that to her old friends, she was no longer Elizabeth but rather *'the blind'*. Within the *place as locale*, the stigmatizing power-relations defined by the hegemonic culture have given Elizabeth the involuntary identity label of disability. The concept of intersectionality has by Valentine (2007) been criticized for overemphasizing the capabilities of individuals to live their lives and perform their identities. However, from the case provided above, it appears that Elizabeth, although she had not accepted the category of disability, she had complied. At this point of her life, Elizabeth's situated accomplishment was emphasized by her disability while any other category was made irrelevant. Despite evidence of the opposite, Elizabeth's life started to change. Through contact with the Uganda National Association of the Blind (UNAB), she was given an opportunity to study again. Although Elizabeth, at the point of the interview, did not fully accept her visual impairment, the contact with UNAB gave her an opportunity to emphasize her situated accomplishment as a student. It also helped her establish a sense of belonging and identification with others. Elizabeth had also become a mother after she became *'the blind'*. While she identified herself

with being ‘the blind’ and disabled, Elizabeth wanted to commit suicide. However, after becoming a mother she explained her *sense of self* as follows,

‘I used to think of poisoning myself. Right now, when I think of my child, I cannot think of poisoning myself because I know I have to live for her, and she is also there for me. So at least now, she is my consolation’.

As such, the category of being a mother was more important as a way of identifying herself than being ‘the blind’ and disabled. Consequently, the category of disability had been suppressed, although not made irrelevant, in the lived experience of the embodied self of Elizabeth.

As mentioned above, the relevance of the concept of intersectionality is that it might provide an understanding of my informants as more than the label of disability. According to Valentine (2007), all individuals have their own unique *interface of categories* which are formed and performed in various spaces and social interactions. However, as identified in Chapter 5 section 5.2, PWDs in Kampala experience limited access to various livelihood opportunities. Hence, many PWDs have limited resources, and also live in an environment that, in most cases, does not encourage human development. Accordingly, many of my ‘basic’ informants let their lived experience affect their *sense of self* and self-perception. However, whether intentional or not, in the topics for further discussion, each example provided is an expression of my informants situated accomplishment.

7.2 Life Events

To account for the lived experience of the embodied selves of my informants through their various life events, is deterministic. However, it does provide a basis to understand the *capability sets* available to my informants. Moreover, it may also provide a basis to understand to what degree the hegemonic cultural power influence the lives of my informants. As argued by Sen (1993), the capability of an individual reflects the alternative *combinations of functionings* that an individual can achieve, and from which an individual can choose one collection. However, it is of importance to keep in mind that there are individual differences with regard to how much individuals let structural barriers and external expectations, control their actions and behavior, but also how they let it affect their *sense of place* and *sense of self*.

7.2.1 Traditional Belief Systems – Disability and Witchcraft

Despite the fact that Uganda is a very religious country, as mentioned in Chapter 4 section 4.3.1, *traditional belief systems* are still of great importance to its inhabitants. Owing to difficulties retrieving any written information about the traditional belief system in the Buganda region in which Kampala is located, I base these statements on a book about witchcraft in the Basoga region (Cultural Research Centre, Diocese of Jinja 2003), a neighboring region of Buganda. In addition, I use oral sources, in particular my assistant Lydia. *Witchcraft* is often considered to be the primary cause of misfortunes. It is feared so much that when someone visits a home and is given, for example, an alcoholic beverage, the host is required to nip from it first so as to remove the witchcraft. This fear of witchcraft is due to the belief that everybody is a potential witch on account of jealousy, envy or enmity. However, the power of witchcraft usually affects people in the witch's own family or surroundings.

All of my informants, at the micro level, but Elizabeth became impaired before the age of 10 due to disease or illness, or accidents. The reason why witchcraft is of importance to understanding the lived experience of the embodied selves of my impaired informants, is that several of my informants blame witchcraft, and in particular '*talo*', as the reason for their impairments. '*Talo*' is related to witchcraft in central Uganda, in particular to the Buganda region. It is not a concrete object but rather an abstract concept. They believe that '*talo*' is something you can step on, and may result in someone becoming ill, and even disabled. This is done by a person with evil intentions, and is often related to jealousy. Several of my informants came from families where the fathers had several wives; polygamy, and they accounted of rivalry and jealousy between the different wives of their fathers, in particular with regard to producing a boy child. Charles, a walking impaired man, said that, '*I believe that I became bewitched by my step-mother because she had produced a baby girl*'. All of my informants who believe themselves bewitched blame their step-mothers. Accordingly, even though my informants can account for the disease or accident that made them impaired, they still believe that witchcraft was the underlying force that made it happen. As explained by the Executive Secretary of the National Council for Disability (NCD), '*Even if you are shot, and everybody can see the bullet, your grandmother will still say that you are shot because you are bewitched*'. As disability to a large extent is connected with witchcraft, it is regarded as something dangerous and negative. However, for my informants to live in a society where their physical presence is regarded as the negatively '*other*', it may be easier to cope with, and

accept, their status if they have someone to blame for their misfortunes. This is also argued by Major et al. (2003) who state that *attributions* to discrimination, such as the stigmatizing label of disability, is most likely explained by external causes rather than internal. This is because it can help the person discriminated against to protect his or her self-esteem.

7.2.2 Education – An Object of Value

Despite the fact that Sen does not provide a set of essential *capabilities*, as criticized by Ruggeri Laderchi et al. (2003), I choose to focus on my informants' access to education as an important *object of value*. This is because access to education may enhance the opportunity and freedom of my informants to act as *agents of change* in their own lived experience of their embodied selves. Employment represents another object of value to my informants. However, I choose not to focus on that in this chapter because access to education may enable my informants to choose type of employment as part of their *plan of life*. My informants come from various socio-economic backgrounds, but none of them can be regarded as having a high socio-economic status. Only one of my informants, Lincoln, has a university degree, but as has been recognized in Chapter 6 section 6.2.3.1, he represents an exception from the norm as he has been able to *transgress* both socio-economic and socio-cultural structural barriers in order to achieve his degree. As such, Lincoln represents an individual that does not let external factors control his actions. On the other hand, one of my informants with whom I had an informal conversation, Abraham, had no education at all. Abraham grew up in a rural area with no family, and according to himself, he was brought to Kampala by a sympathizer who gave him some money to start a small business. As such, Abraham's capability set was limited, and he let himself be dependent on sporadic help from outsiders because he was disabled, and he did not experience himself as capable to formulate a plan of life. The rest of my informants had various levels of education, from dropping out of school after primary school, such as Vincent, to dropping out of college, such as Elizabeth. There were different reasons for them to have left their education. One reason was lack of financial resources. Another reason was that their families had learned about vocational options for PWDs, which they had identified to be of greater relevance to the PWDs in order for them to enhance their opportunities of independent living and access to employment. A third reason, such as for Elizabeth, was the belief that an impaired person cannot study. However, as identified by the social model of disability, liberation from disability is about not conforming to a pre-defined notion of normality. Accordingly, with education as object of value, my informants could have increased their freedom to lead their lives liberated from the label of disability.

7.2.3 Friendship – A Place as Locale

Another life event that may provide an understanding of the *lived experience* of my informants is their social lives. Having friends during childhood represents an important *place as locale* to my informants. Through the interaction with friends, my informants have various lived experience with the *hegemonic cultural power* and its definition of what is regarded as ‘in place’ and ‘out of place’. However, my informants represent different strategies on how to cope with external structures and expectations with regard to their embodiment. Such individual differences can be related to different *tendencies of attribution*, meaning to what extent an individual focuses on external factors as opposed internal. Only one of my informants, Elizabeth, accounted of completely losing her friends when she became visually impaired. As identified in section 7.4, the consequence was that she developed a sense of inferiority and a feeling of being ‘out of place’. On the other hand, Asha and Lincoln had friends who helped them with various tasks. However, while the help Lincoln got from his friends made him capable of transgressing the various structures in the society in order to liberate himself from the disability experience, Asha still felt different and ‘out of place’. An explanation for the difference between Asha and Lincoln is complex. However, it may be explained by individual differences with regard to the level of *power from within* as identified by Rowlands (1995). Hence, the more *power from within* and confidence an individual possess, the more negotiating power toward external structural barriers. Although the rest of my informants had friends, they also experienced to be teased about their impairments, and I have identified individual differences with regard to how they dealt with it. According to Michael, he used to be bullied when playing with his classmates at school. However, his strategy for overcoming the bullying was to befriend them through jokes. Eria, on the other hand, used to be called ‘*mulema*’, meaning ‘lame’, when playing with his friends. As to show them that he was just as able as any one of them, he tried to manage any of the activities that his friends did. Despite having some friends, many of my informants spent most of their childhood years together with their mothers. Even though this represented a safe haven with regard to not feeling ‘out of place’ due to their impairments, many of their fathers had several wives; polygamy, and they experienced to be teased by their step-mothers and their children.

7.2.4 Marriage – Another Place as Locale and an Object of Value

Marriage is, as friendship, an important *place as locale*. If an individual’s capability set does not hold a collection of functionings that individual can choose from in order to achieve self-respect and to be socially integrated, that individual is regarded to be *capability-poor* (Sen

1999; Burchardt 2004). As I will come back to in section 7.5, there are certain roles and identities an individual have to perform in order to be regarded as ‘normal’ and ‘in place’ in a society. Marriage is an important role in the life event of my informants in order for them to feel ‘in place’. This is because marriage constitutes part of the socio-cultural expectations to what it is to be an adult (Stone 2001). As such, marriage represents an *object of value*, with regard to achieving self-respect and social integration. Whether or not there are any particularities with regard to socio-cultural expectations to marriage in a city, such as Kampala, I cannot answer for. Accordingly, I can only account for my informant’s thoughts and dreams about the topic, which mostly come from rural areas but reside in Kampala.

Out of all of my informants at the micro level, five of them were married. All of my married informants were men, and the rest of my male informants who were still single, planned to get themselves a wife, or several, when they felt ready to do so. All of my female informants, on the other hand, were single, even though both Asha and Elizabeth had children. As identified in Chapter 5 section 5.2.2, there appears to be a gender difference with regard to access to marriage as a *place as locale*. However, even though my male informants were able to marry, they did experience negative attitudes both from the women and the women’s relatives. As Vincent put it,

‘I got my wife through a friend. He took me to her place, and he talked to her. My wife accepted to marry me, despite her parents who tried to discourage her. However, she tried to run away from me before the wedding’.

Considering the negative attitudes of relatives with regard to marrying an impaired person, such as Vincent spoke of, Eria, who was still not married, was worried about meeting the family of a potential wife, *‘If I fell in love with a woman, it would be difficult to be introduced to her parents because of my disability’*. Despite the fact that my male informants meet with difficulties when getting married, they are able to do so, and as such, marriage represents a *functioning achievement* in their capability sets. The women, on the other hand, can be regarded as capability poor with regard to this particular object of value. As Norah, a visually impaired woman stated, *‘I dream of getting a man and to get married, but I think I cannot because of my disability’*. Asha, a walking impaired woman, who already had two children with two different men, said that, *‘I dream of marrying a man who loves me and cares about me. However, in the beginning of each relationship, these men promise to marry me, but they eventually do not. It hurts me’*. Hence, the difference in opportunities for men and women in order to become married is an indication of differences in the lived experience of the

embodied selves of my informants. Although not all of my informants dreamt of marriage, such as Elizabeth who emphasized independence rather than marriage, the lack of opportunities for my other female informants to become married, might have had an influence on their *sense of selves* and feeling of being ‘out of place’ in Kampala.

7.3 Living in Kampala – A Sense of Place

According to my informant Lincoln, PWDs in the city are better off than those residing in rural areas, in particular with regard to financial assets. However, as identified in Chapter 6 sections 6.2.2.2 and 6.2.2.3, traditional belief systems and expected daily activities make it difficult for my informants to live in rural areas. Asha, a walking impaired woman exclaimed about living in Kampala, *‘I like Kampala because this is where I can do business, and I cannot stay in the village because I cannot manage to dig’*. As such, most of my informants, especially those working in the informal sector in the New Taxi Park area, acknowledged that if they had a choice, they would choose not to stay in Kampala. As Rashid explained,

‘I feel good about being in Kampala because it has everything like business. As I am a business man, it is good, because everyone comes to Kampala to buy their goods and services. However, if I could go to my home area to do business, I would’.

Accordingly, Kampala represents a *place of opportunity* for conducting business or getting money, even for Vincent, the walking impaired beggar who originally came from Lira, a town up north. When talking of Kampala, Vincent stated that, *‘I am tired of being in the streets of Kampala even though I see it as an opportunity for getting money. If God does something good for me, he gets a good place for me to do business in Lira’*. Apparently, Kampala represents an opportunity to gain an income for my informants. Hence, my informants can manage to make a living for themselves. However, if barriers within the places of socio-cultural, socio-economic, and also the physical and built-up environment of rural areas were removed, my informants would prefer to live in the villages where they origin from and where they have their families. Furthermore, Kampala is not only a place of economic opportunities. As acknowledged by Elizabeth and Lincoln, people in Kampala are more sympathetic and sensitized to the impaired body than in rural areas, which imply a place of greater opportunities to participation within the socio-cultural structures. However, Elizabeth had an ambiguous *sense of place* of Kampala, as the city, to her, also represented a *place of fear*. As accounted for in Chapter 5 section 5.3.4, Elizabeth experienced to almost become raped in the outskirts of Kampala.

7.4 Disability – A Tragedy?

The notion of impairment and disability as a tragedy is the basis for the *medical model of disability* which sees disability as an individual problem and focus on the normalization of deviance by all means (French and Swain 2004). Following from this is the assumption that an impaired person cannot enjoy an adequate quality of life. It is further assumed that an impaired person wants to be what is considered ‘normal’ by the hegemonic culture. The personal tragedy view of impairment and disability is accordingly forming a basis of the social identity of the non-disabled people. This is because identity is about establishing recognition and difference with others. Hence, the impaired persons represent ‘the others’ (Hetherington 2000). As the hegemonic culture, i.e. the non-disabled people, identify the impaired persons as ‘the others’ giving them an involuntary identity label, it might have significance on how the PWDs understand themselves and their own lives. Hence, for someone being non-disabled to become impaired, such as Elizabeth who became visually impaired in her late teens, as mentioned in section 7.1, it may be experienced as a tragedy (French and Swain 2004). Elizabeth had an inherited disease which caused her gradual loss of sight. Throughout her studies of economics at college, she experienced more and more trouble with her sight. Nonetheless, she said that, *‘I never wanted people to identify me as a blind person. It was only when I stopped reading print things had to come out. I felt very small being called blind’*. Elizabeth had to leave her education and was brought back to her village. She continued,

‘I wanted to continue with my education but I could not, and I thought it was the end of my life. After losing my sight, I also lost my friends. They could no longer see me as their close friend. I developed a kind of inferiority inside me. Now that I am blind, I am not of any use, not of any importance. Sometimes I even tried to poison myself. I tried three times’.

Elizabeth had lived her life as an able-bodied. She was halfway through her college education and had dreams for her future. Elizabeth was part of the hegemonic able-bodied culture thinking about PWDs as the negatively ‘others’, a stigmatized label. Suddenly she was not only one of the ‘others’, she was also, in her own opinion, without any opportunities. For Elizabeth, the experience of becoming disabled was a tragedy. However, her life and lived experience of her embodiment changed. Through contact with her interest organization, she received counseling to accept impairment as part of her life, and she had also been given access to education for persons with visual impairments. Anyhow, Elizabeth was continuously struggling to overcome her own prejudices to the involuntary identity label of

disability. However, Elizabeth's life continued although not in the direction she hoped for before becoming visually impaired.

The notion of a *non-tragedy view on disability* challenges in many ways the dominant hegemonic culture. According to French and Swain (2004), the idea that PWDs may experience lives of equal satisfaction and worth is by many denied as unrealistic and posed as a lack of acceptance. As such, the tragedy model of disability is in itself disabling as it denies PWDs to have another lived experience than tragedy. Although the identity label of disability may be a given and involuntary label (Panelli 2004), it does not necessarily imply tragedy. As mentioned above, identity is about establishing recognition and difference. However, it is also a process of self-recognition, belonging, and identification with others (Hetherington 2000). To a large extent, the identity label of disability has resulted in the exclusion of PWDs from various places of participation. Consequently, as mentioned in Chapter 6 section 6.2.3.3, all but one of my informants from the New Taxi Park area, had joined together in trading associations. The people in these associations had not only used the label of disability to organize themselves. The women had also chosen to group together as their interests were not properly taken care of in the mixed gender associations. Hence, my informants had used the identity label of disability and gender in a process of self-recognition through the identification with others. As a result, they experienced a sense of belonging. Instead of viewing disability as a tragedy, they had taken advantage of the given identity label. Consequently, they had enhanced a *sense of self* and through that become able to help and support each other. This can be related to Rowlands' (1995) third dimension of *empowerment*, which is about working together in order to achieve a greater impact than what an individual could have managed alone. See further elaboration of empowerment and the lived experience of the embodied selves of my informants in section 7.6.

All of my informants but Elizabeth became impaired before the age of 10, and none of my informants were born with their impairments. Several of my informants, at some level, struggle with accepting their impaired bodies and the feeling of being 'out of place' in various contexts. However, it seems to be more difficult, and a feeling of tragedy due the stigmatizing label of disability, to become impaired later in life than during childhood. In the words of Lincoln, one of my most confident informants,

I no longer think about my disability because I have come to believe that this is part of life. The only thing is to try to learn how to live with it. If it has come, it has come, and I cannot do

away with it. The only solution is to live with it, and I never regret that. I only now struggle to live positively with my impairment’.

Lincoln’s attitude and understanding of his lived experience of his disability is extremely positive, and it does not represent all of my informants who became impaired before the age of 10. However, it highlights that a tragedy view of disability does not include the embodied experience of all PWDs.

7.5 Body Perfect?

What is human perfection? Human perfection has, according to La Fontaine (2003), been long sought after, and the idea of human perfection is related to physical, emotional, sensorial, and intellectual states. The idea of human perfection is often regarded as normality, in particular in aesthetic terms. Human perfection and normality are thus related to beauty. However, variation in appearances, practices, and mobility of bodies and what is constituted as perfect and ‘normal’ can only be understood in their specific spatial, temporal, and cultural contexts (Davis 1997). The notion of gender is often related to ideas of perfection and normality (Zitzelsberger 2005). Gender is part of the *binary category* of the biological sex and the socially constructed gender. Gender is performed through notions of masculinity and femininity and is constructed through gender identities, which are learned, recognized, and reproduced through social interaction (West and Zimmerman 1987). Such notions of masculinity and femininity incorporate meanings and expectations about bodies, and are therefore expected to be performed in prescribed ways (Longhurst 2001).

As gender is socially produced, and in order to be identified as ‘in place’ in a certain social context, gender identities have to be performed according to what is defined as ‘normal’ by the hegemonic cultural power. However, the emphasis does not necessarily have to be on whether or not the hegemonic culture defines someone as ‘in place’ but rather whether or not individuals identify themselves as such. Asha, a walking impaired woman, spoke about her embodied experience of self as a disabled woman in Kampala,

‘I feel very bad about my disability. I feel different from other people because I am disabled and other people are able. I feel different because when moving, other people move well and normal, but I cannot. And I love shoes. Women here in Kampala wear such beautiful shoes, but I cannot because I have a paralyzed leg. It makes me feel hurt and disappointed’.

Asha’s lack of mobility makes her feel different from what she refers to as ‘normal’ people, and it makes her feel ‘out of place’. However, Asha’s account of the beautiful shoes expresses

her feeling of not being a woman, hence, not being able to perform the feminine gender identity as she wished for. In relation to Asha's story, the PWDs themselves related to the notion of feminine human perfection as beauty and being able-bodied. This was emphasized by my male informants at the New Taxi Park area. Charles, a walking impaired man, stated that, *'I would prefer a perfect body of my wife, but I could not get it. I am now married to a disabled woman'*. Yusuf, another walking impaired man, on the other hand, had two wives who both were able-bodied. It appears from the stories told by my male informants that being able to marry, and in particular marry an able-bodied woman makes the male PWDs perform their masculine gender identity according to the hegemonic cultural power. Hence, being married makes them feel 'in place' in this particular context. The dream of being married to able-bodied women might, however, account for the reason why it is so difficult for women with impairments to get married.

Although culturally defined, hegemonic notions of masculinity are related to strength, rationality, self-reliance, potency, and action (Robertson 2004). The performance of masculine gender identities is thus not only related to appearances, as discussed above, but also to the ability to perform activities (Panelli 2004). Although there has been a shift from understanding disability as individual failure to societal failure, the definition of disability today is still related to this segregation as, *'Disability is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers'* (DPI 1982). As such, for a man to be considered 'normal' and also to experience himself as such in relation to a masculine gender identity, a man has to be able to be self-reliant and to perform activities in manners considered 'normal'. Yusuf, a walking impaired man, stated that,

'I am a business man. I do not consider myself as disabled because I can do everything for myself. I can do what able people can do, and something the able people cannot do as well. My family did not expect me to be able to take care of my family when I got married. Now I also take care of my mother in the village'.

Being able to provide for himself and his family sustained Yusuf's sense of masculine gender identity because he managed to do what was expected from a man. Accordingly, Yusuf felt 'in place' in relation to the contextual understanding of normality. Although Yusuf regarded himself as being 'normal', he regarded the disabled beggars as 'abnormal' because, *'Those begging in the streets have grown up with the mentality that they are disabled and that they cannot do anything for themselves and that they have to be supported'*. Accordingly, Yusuf

related of own expectations to what is considered 'normal'. Although being disabled, a person has to partake in the society to be self-reliant, and if not, that person is to be regarded as 'out of place'. In order to overcome the stigmatized label of disability that the hegemonic cultural power had given to him, Yusuf redefined the meaning of independence in an attempt to redefine his self-identity through an unfounded belief about his abilities. This is referred to by Krefling (1989) as recasting strategies in an attempt to de-stigmatize the disability. My male informants gave an impression of a more positive lived experience of their embodiment than my female informants. It might be due to the fact that life in Kampala as a PWD is easier for men than women. On the other hand, it might be due to the fact that my male informants might not have wished to be experienced as weak in front of me, a female researcher.

7.6 Empowerment

To imply that the socio-spatial and socio-cultural structures in the Ugandan society, as introduced in Chapter 5, shape my informants *sense of place* and *sense of self*, is a deterministic approach to identity formation. However, as can be identified in Chapter 6, not all of my informants enact the same level of agency with regard to negotiating access to various places of participation. Throughout this chapter that focuses on the lived experience of the embodied selves of my informants, it has been revealed that despite the fact that they are all defined by the hegemonic culture as the negatively 'other', every individual has their own unique coping strategies. Through the notion of intersectionality and situated accomplishment, it has become clear that most of my informants experience in their everyday lives that they are more than their impairments. Although, this experience varies from the different places and social interactions in which they partake. The hegemonic cultural power sets the norm of proper behavior, and my informants compare themselves to that standard in order to feel 'in place' and 'normal'. However, my informants experience to be continuously defined as 'abnormal' and 'out of place' by the hegemonic cultural power due to the omnipresent subject positions of their impaired bodies. Such a process of 'othering' may affect how the PWDs think of, and experience, their *sense of place* and *sense of self*. Hence, it may result in diminishing the level of *power from within* of the individuals. However, individual differences influence how much the individuals let external expectations and structural barriers control their actions, and also how it affects their *sense of self*. As identified in section 7.2.3, such individual differences can be related to different *tendencies of attribution*.

Some of my informants internalize expectations about an ideal view of identity. Consequently, their own ideas and notions of their impairments stigmatize themselves as the negatively ‘other’ and ‘out of place’. Quotations by Asha, Elizabeth and Rashid provide examples of identifying themselves as ‘out of place’:

Asha: *‘I would like to go to the discotheques but I cannot because I feel I cannot fit there. My boyfriend called me up one day and wanted to take me dancing, but I dodged him because I felt that I was not fit to be in such a place’.*

Elizabeth: *‘Before I lost my sight I used to enjoy music. For example, during holidays I could go with my friends to the garden of Sheraton where they organize music festivals. I used to enjoy that music, and sometimes I could even go alone. But now that I am blind, I fear going there alone, yet I feel that I really enjoy music. I fear being laughed at and hearing things like “why does this blind person want to hear?”’.*

Rashid: *‘I would like to go to discotheques and other places of entertainment. I know that we are allowed to enter entertainment places, but when I am there, I feel that I do not fit’.*

These three cases provide examples of what Rowlands (1995) refers to as *power over*, hence an instrument of domination. Asha, Elizabeth, and Rashid have experienced to be systematically denied access to various places of participation. As a result, they have become obedient to the stigmatizing label of disability as the negatively ‘other’. Rashid expressed the knowledge of the opening of the place of participation with regard to the Persons with Disabilities Act (2006) that focus on the removal of discriminatory practices toward PWDs. However, he did not feel capable of nor entitled to occupy this particular place. Hence, Asha, Elizabeth, and Rashid lack the *power from within* in order to be empowered to participate in the mainstream society.

While some of my informants focus on the barriers and what they cannot do, others, on the other hand, focus on the opportunities available and what they can do. Quotations provided below by Michael and Lincoln, are examples of individuals who believe in their own capabilities to act:

Michael: *‘You say that I cannot, but I say that I can. This mentality has pushed me up to now. If not, I would not have been very far. I have managed to become a student. I joined a football team despite the fact that the coach did not believe I could handle the ball. I am also a good music composer. I have two songs. One of the songs is about self confidence, because my life style is all about my confidence’.*

Lincoln: *'Moving around is difficult for me because I am blind. These surroundings are not friendly, but with assistive devices like the white cane, I try to move around. There are so many details, there are so many holes, but I struggle and walk despite those challenges. It is all about gaining confidence that I can walk. Through the help of my friends, I have learned the appearance of the environment, and I have become braver'*.

Apparently, Michael and Lincoln have a higher level of confidence than what Asha, Elizabeth, and Rashid showed from their quotations. Accordingly, the higher level of confidence in an individual, the more *power from within* that individual is able to enact. Consequently, Michael and Lincoln expressed more power related to Rowlands' (1995) second dimension of *empowerment*, which is relational and about the ability to negotiate external barriers and structures.

To be able to understand the individual responses and coping strategies to the socio-spatial and socio-cultural structures of Kampala, there is a need to go further into psychological theories. Although relevant, this has not been the focus of this work. However, it is of importance to acknowledge that despite the fact that my 'basic' informants are all inhabitants of the same community and all being labeled as the negatively 'other', their lived experience of their embodied selves vary from individual to individual. Accordingly, in order to empower the PWDs in Uganda to enable them to participate in the mainstream society, and as such, overcome the barriers, there exists a need to see them as individuals, and not only as a stigmatized category. This is because, as has been identified throughout this chapter, the opening, creation, and changing of places of participation for PWDs does not automatically lead to greater levels of participation.

7.7 Summary

The endeavor of this chapter has been to gain an understanding of the lived experience of the embodied selves of the PWDs in Kampala. The social model of disability, which has been used as an analytical framework throughout this study, emphasizes the removal of structural barriers in order to overcome the disability experience. However, as the goal of the social model represents a utopia in a short-time perspective, overcoming in this chapter has been referred to as a way of living with an impaired body while restoring a positive self-identity. Hence, this chapter has sought to create new references for understanding the lived experience of PWDs by focusing on individual differences.

In Chapter 5 and Chapter 6, the emphasis has been that as long as places of participation are opened for PWDs, they will immediately gain equal opportunities and dignity in the mainstream society. However, PWDs need to feel themselves capable of, and entitled to, occupy the various places. Throughout this chapter, it has become clear that social attitudes, or *place as locale*, and *place as location*, or the physical and built-up environment, influence the lived experience of the embodied selves of my ‘basic’ informants. It has also become clear that there are individual differences with regard to how much the individuals let structural barriers control their actions and affect their *sense of place* and *sense of selves*. Accordingly, the opening and creation of places of participation at macro and meso level may not be enough for PWDs to be able to access society at the micro level. Consequently, there exists a need for PWDs to see themselves as more than a given identity label and to increase the level of *power from within* which is about developing a positive *sense of self* and self-confidence.

Chapter 8

Summaries, Conclusions and Recommendations

The endeavor of this study has been to contribute to the debate on *commonalities* versus *differences* and *diversification* within the topic of disability. Accordingly, the thesis has sought to identify structural *barriers* and *opportunities* for persons with disabilities (PWDs) access to *participation* in the mainstream society of Kampala, Uganda. It has also sought to identify and assess how the barriers are *negotiated* by various agents in order to increase PWDs access to participation. Lastly, it has sought to assess and analyze how the barriers are *overcome* in the everyday lives of PWDs, and also how it affects their embodied experience of self.

The theoretical framework of this study is the *structuration theory* (Giddens 1984) and a complementary approach to *place* as presented by Agnew (1987). The conceptual framework in this thesis comprises, among some, the concepts of capability, participation, power and empowerment, identity, categorization and intersectionality, body, embodiment, impairment and disability. The analytical framework that has been used in this thesis is the *social model of disability*, although with modifications (Oliver 1996a).

The nature of this research is *exploratory*. Hence, it has been conducted following the qualitative research tradition. I have used a *hermeneutical approach* to the ethnographic methodology to be able to link theory and the methods chosen. As the theoretical framework of this thesis is the structuration theory, I have used four *informal conversations* and nine *in-depth interviews* to be able to grasp the lived experience of my ‘basic’ informants at the micro level. At the meso and macro level, I have used seven *key informant interviews*. *Observations* have been used in order to contextualize my findings and to be able to conduct *critical reflexivity* of my position in, and influence on, the field.

8.1 Barriers and Opportunities to Participation in the Mainstream Society

According to the human rights, everyone is entitled to equal rights and human dignity. However, it has been acknowledged that all people do not benefit from the human rights, such as many PWDs. The UN Standard Rules work to promote equalization of opportunities for PWDs. According to the social model of disability, there exists a need to remove discriminatory structural barriers in order to enhance the opportunities of PWDs. The first

research objective of this thesis was therefore to identify what structural *barriers* and *opportunities* to participation that exist in the mainstream society of Kampala, Uganda for the people being categorized as PWDs. To remove discriminatory structural barriers, one has to be aware of the barriers that exist.

8.1.1 Summary and Conclusion

The barriers and opportunities identified were of political, socio-cultural and socio-economic, and physical character. The political structures and the legal framework represent opportunities for PWDs to gain access to the society. They also represent an opportunity for the different interest organizations of PWDs to advocate for further rights of PWDs. However, *lack of implementation* of various laws and policies, and also lack of information of the opportunities available to the PWDs, creates further barriers to the inclusion of PWDs in the mainstream society.

Disability is to a large extent a *stigmatized label*, and PWDs are often regarded as the negatively ‘other’ compared to the notion of the ‘normal’ body. Disability has also often been linked with *witchcraft* hence something negative and dangerous. As such, PWDs have become vulnerable and marginalized members of their societies due to ignorance, superstition, and lack of awareness. There is also a *gendered bias* due to Uganda being a patriarchy, putting women with impairments further down on the hierarchical pecking order than men with impairments. Negative attitudes toward PWDs influence all areas of the society, implying barriers to participation of socio-cultural character.

There exist an interrelation between *poverty* and disability. Disability may be both the cause as well as the consequence of poverty. Poor people have to a large extent limited access to health care services which make them more vulnerable to preventable diseases that may cause impairment. PWDs are regarded to be opportunity or capability-poor. Access to education, health care, employment, land, and information represent barriers to participation for PWDs. Lack of access to land in rural areas is a major incentive for PWDs to move to urban areas in order to gain access to income-generating activities. However, lack of access to education and also need of special facilities, make PWDs appear as a burden to employers in the formal sector rather than a resource.

The *physical and built-up environment* of Kampala represents physical barriers for the mobility of PWDs. The Persons with Disabilities Act of 2006 focuses on the removal of

discriminatory practices with regard to PWDs mobility, such as access to buildings and transport. However, lack of implementation and enforcement of the law leaves the physical environment of Kampala as a barrier to participation of the PWDs.

8.2 Negotiation of Places and Power

Based on the theoretical framework of the structuration theory, structures are the result of social interaction. Hence, structures are negotiable. The UN Standard Rules opt for various agents from *macro*, *meso* and *micro* level to negotiate access to participation in order to gain equalization of opportunities. The second research objective of this thesis was therefore to identify and assess how the barriers to participation are negotiated by various agents to increase PWDs access to participation. Negotiation implies *unequal power-relations*. The various agents have different positions of power and also different means of negotiation. The theoretical framework consisting of a complementary approach to place provides a means of identifying power-relations within various *places of participation*, and also to identify how these are negotiated.

8.2.1 Summary and Conclusions

The barriers and opportunities identified in answer to the first research objective were of political, socio-cultural and socio-economic, and physical character. These characteristics represent structural components of the Ugandan society. The structural components are in this thesis identified as places of participation in which PWDs are either included or excluded. The agents of negotiation were key informants of position at the macro and meso level. At the micro level, my 'basic' informants consisted of the PWDs themselves. At the macro and meso level the means of negotiation were *advocacy*, *capacity-building*, and *awareness-raising*. At the micro level, the means of negotiation were both intentional *social action* and unintentional *social practice*.

During the past two decades, there has been an increased focus on disability issues at a global and regional level. International agents, such as the United Nations (UN) and the African Union, have had a positive impact on the opening of the political place of participation for PWDs in Uganda. PWDs have been included at all level of decision-making, and laws and policies have been amended in order to enhance the opportunities of PWDs. However, throughout this thesis it has been identified a lack of implementation of various laws and policies. Nevertheless, the legal framework is used as a means of negotiation by the agents at

macro and meso level for further negotiations and advocacy, giving them more legitimacy and power. As such, the legal framework is used by the macro and meso level in advocacy work to influence agents in order to open, create or change places of participation, such as education, health care, employment, land rights, information, and accessibility to the physical and built-up environment.

The *hegemonic cultural power* has the power to define the boundaries of proper behavior, meaning those being ‘in place’ and ‘out of place’ in a particular context. The impaired body is an omnipresent *subject position* which to a large extent is regarded to be ‘out of place’ in comparison to the notion of the ‘normal’ body. At the macro and meso level, the various agents work to create awareness in the society and to sensitize the communities on the abilities of PWDs. Being individuals with different coping strategies, the PWDs at the micro level negotiate their subject position of their bodies in various manners. However, the main strategy seems to be to avoid or adapt to the hegemonic cultural power rather than to challenge it.

With regard to negotiation of places and power, there is one trend that stands out and needs to be highlighted. The various agents of negotiation at the macro and meso level work to create better opportunities and access to participation for PWDs at the micro level. However, the trend appears to be advocacy work toward agents at a higher level in the power hierarchy rather than to include the PWDs at the micro level. Even though the advocacy work might result in opening, changing or creating various places of participation, the PWDs need information of the opportunities available to enjoy them.

8.3 Overcoming the Barriers – The Embodied Experience of Self in Kampala

The UN Standard Rules focuses on the equalization of opportunities to participation of PWDs. Chapter 5 and Chapter 6 of this thesis have thus focused on the opening of *places of participation* for PWDs. However, throughout Chapter 7, it became clear that PWDs not only need access to places of participation, but also need to experience themselves as entitled to occupy them. The third, and last, research objective of this thesis was to assess how the structural barriers to participation are *overcome* in the everyday lives of the PWDs. According to the *social model of disability*, overcoming implies a total removal of discriminatory structural barriers. However, overcoming in this study has been used in terms of a way of living with an impaired body while restoring a positive self-identity. The concept of

embodiment puts the mind back into the body, the body back in the society, and the society back into the body. Even though the concepts of attribution, *sense of self*, and identity may imply a psychological study, the concept of embodiment provides a geographical means to understand an individual, its actions and experiences in a specific context of political, socio-cultural and socio-economic, and physical character.

8.3.1 Summary and Conclusions

The *place as location*, meaning the physical and built-up environment, and the *place as locale*, meaning the hegemonic cultural power and traditional belief systems, influences the *sense of place* and *sense of self* of my informants. However, my ‘basic’ informants at the micro level all represent different strategies on how to cope with, and overcome, external structures and expectations to their embodiment. This indicates different *tendencies of attribution*.

Many PWDs are regarded to be capability-poor. This is because they have limited *capability sets*, such as limited access to education, employment or marriage. Hence, many PWDs have limited abilities to pursue a *plan of life*. At the micro level, all of my ‘basic’ informants expressed a need to experience themselves as ‘in place’ and ‘normal’ in a given context. There were various roles and identities that my informants related off in order to identify themselves as being ‘in place’, such as having friends, being able to marry, and the ability to gain an income and to take care of one’s family.

Despite the fact that my ‘basic’ informants all reside within the same urban context and experience to be labeled as the negatively ‘other’, their lived experience of their embodied selves vary from individual to individual. By using the concept of *intersectionality* and the related concept of *situated accomplishment*, it has been shown that the PWDs are more than the involuntary label of disability, hence, creating new references for understanding the lived experience of PWDs. While some of my informants experience disability as a *tragedy*, others use the label to their own advantage through a process of self-recognition and belonging. Consequently, the ability to attribute negative attitudes to external forces seems to increase the level of *power from within* in an individual. Hence, increase the ability of an individual to occupy various places of participation.

8.4 Recommendations

There are several recommendations that can be given in order to enhance the opportunities of PWDs to access participation in Kampala, Uganda. The recommendations given here are at different levels of abstraction, meaning that some are at a theoretical level while others are more practical in character. They are also organized according to the theory of structuration (Giddens 1984), meaning according to the macro, meso, and micro level of the society.

Given the mostly postmodern approach in this thesis, my first recommendation emphasizes the *destabilization of categories*. Categories are social constructions in order to simplify a complex world. The hegemonic cultural power has the power to define the different categories in a given context, or space. Destabilization of categories such as the impaired body being the negatively ‘other’ in comparison to the ‘normal’ body, may enhance the opportunity of individuals and groups of individuals to free themselves from the hegemonic order (McCall 2005). Destabilization of categories may as such gain new appreciation of the lived experience of the embodied selves of the PWDs in Kampala.

At the macro level, and a lower level of abstraction, the government of Uganda is said to give political will to issues of disability. However, even though PWDs have been included in the legal framework, and several laws and policies have been made favoring the rights of PWDs, there is a lack of implementation. Uganda is a poor country with limited financial funds and several marginalized groups fighting over the same resources. However, instead of seeing PWDs as a burden, they should see them as a resource. Given the opportunity of access to education, health care, employment, land rights, and information, PWDs could work to increase the socio-economic development process. Accordingly, both at the macro level and at the meso level, implying both NGOs and also the private-public sector, there could be organized *sheltered workshops* in order to open the place of participation of formal employment to PWDs.

Given the presence of chronic illness as a causal factor of impairment, there exists a need for greater attention to *preventive measures*, which includes both strengthened delivery of health care and medical treatment (Bury 1996). Accordingly, at both the macro and meso level, instead of only focusing on those already impaired, there should perhaps be an increased focus on awareness-raising of the population with regard to causes of impairment, and how these may be prevented.

At the meso level, the interest organizations of the PWDs, at least in Kampala, function as administrations. A recommendation for change is to use these organizations as arenas for the PWDs to meet and to get *access to information*. The creation of such arenas might give the PWDs a place for identification with others, and help to enhance the *sense of self-recognition* and sense of belonging. Accordingly, such arenas might increase the level of *power from within* of the PWDs.

The most important recommendation based on experience gained throughout this process is that the agents at the different levels; macro, meso and micro, should all start to *cooperate*. Instead of using the participation of the interest organizations as a means of legitimizing the PEAP process, they should be fully included. However, as for the interest organizations, they should include the voices of the PWDs to a higher degree than that which exist today. Their common goal is to increase the PWDs' level of participation. Hence, they should be included in order to be able to define and pursue their own *plan of life*.

8.5 Limitations

Throughout this study, several limitations have been mentioned and discussed, in particular in Chapter 1 section 1.5 and Chapter 3 section 3.8. This section will accordingly present a brief yet complete list of limitations of this study:

- Qualitative research approach: A quantitative approach might have provided a different understanding of disability in Kampala
- Restricted literature on disability in Africa: Possible Eurocentric approach
- Time: Fieldwork set between June 11 and August 6, 2007. Lack of time to build trust and rapport. Lack of time to return to informants for discussion of findings to enhance trustworthiness of study
- Outsider status of researcher: White, Norwegian academic woman. Limited overview and understanding of local culture, language and context
- Assistant: Possibility of lost information in translation
- Urban bias
- Public sphere bias as opposed to private sphere of my informants
- Limited access to informants based on self-selection. Restricted selection: Types of impairment were visible. All informants were of African origin. White informants might have provided another understanding of disability in Kampala

- Possible expected and misrepresented answers from informants. Answers might give a more positive understanding of the lived experience of impairment than other PWDs might have
- Restricted selection of analytical variables: Exclusion of different age-brackets, socio-economic status, sexuality

8.6 Recommendations for Further Research

There are several recommendations for further research that can be given based on the experience I have gained throughout this work. This work has focused on two types of impairment. Commonalities and diversities in the lived experience of type of impairment vary from category to category, and individual to individual, and as such, I would recommend a focus on other *types of impairment*. Another recommendation related to the lived experience of PWDs, is to focus on *rural areas* as opposed to the urban area that has been the study area of this work. Rural areas represent other socio-economic, socio-cultural, and physical structures. Hence, one may identify other barriers and opportunities to participation than those in an urban context. *Socio-economic status* and *sexuality* are two important dimensions in the lived experience of any individual. Hence, to include these categories in the study of the lived experience of PWDs might be fruitful. This research has been conducted using the theory of structuration and only one in-depth interview with each informant. A more *participatory approach* might enhance an understanding of the lived experience of the everyday lives of PWDs.

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Appendices

Appendix 1A

In-Depth Interview Guide – Persons with Disabilities

I am a Master student of development from Norway. The objectives of my research are to try to identify what barriers and opportunities that exist for the participation of persons with disabilities in society in Kampala. I am a student with no funding so I have unfortunately nothing to offer you, so I understand if you are busy and cannot help me. Your participation is voluntary and everything that you tell us will be treated confidentially. That means that nobody will be able to recognize you in the finished product. You can at any time withdraw, and do not feel obliged to answer to any question. The interview will take approximately 45 minutes.

Background

- Sex, age and disability
- Can you please start with just telling me about your life while growing up.
 - o Where do you come from? Parents → Work and education? Grown up with your family? Where do you live? Still with your family? Marital status? Children?
 - o School? Job/Income?
 - o Access to health care? Hospital or clinique?
- Connected to interest organization. How? Motivation? What do you get out of it?

Experience of physical landscape

- Describe yesterday. Movements and activities. Typical day? If not, how?
- For persons with disabilities, it may be difficult to get around. How do you experience that?
- Are there places you would like to go that you feel you cannot due to your disability? Where? And how would you get there if you could? What do you feel is stopping you?

Experience of social interaction/attitudes

- Do you feel that your childhood was a good childhood? Can you exemplify this with a story?
- Do you know some PWDs who from their parents might have experienced difference in treatment between themselves and their siblings? In what way?
- While growing up, who did you spend your time with?
- What did you do? And what activities did you like to do to have fun?
- What do you think is the reason of your disability?

Experience of being disabled in Kampala – Sense of place – In place/out of place

- What is it like to live in Kampala? Do you feel like you belong here? Or would you like to live somewhere else? Where?
- What is it you like about Kampala? What do you not like so much?
- Do you feel safe in Kampala? Are there places where you feel safer than others in Kampala? Where? Why? Exemplify.
- How do you experience your disability? Do you think about it?
- Do you feel different from other people? How? Exemplify.

- Do you feel that your disability limits your abilities to do what you would like to do? Or become?
- Have you dreams about what you want to do with your life? Or what you would do if you did not have a disability?
- Do you think it is easier to realize your dream here in Kampala than in a village? Exemplify.
- What was it like to be disabled in Uganda 10 years ago? Have you experienced any changes? Can you give any examples?
- Do you do anything yourself to change your life-situation?

Do you have any questions for me? Do you still accept that I use this information in my research? Would it be ok if I come back another time? Thank you very much for your time and participation!

Appendix 1B

Key Informant Interview Guide – Interest Organizations

I am a Master student of development from the Norwegian University of Science and Technology. The objectives of my research are to try to identify what barriers and opportunities that exist for the participation of persons with disabilities in mainstream society in Kampala, Uganda. I also try to identify how these are negotiated and overcome in the everyday lives of the persons with disabilities and of other agents working the cause of the pwd's. The interview will take approximately 45 minutes.

Background of organization

- Can you please start by telling me about the history of your organization. Was there a specific cause that made someone initiate the start of this organization? What happened?
- Can you tell me about the work of your organization? Towards the disabled? Other NGOs? Government?
- Do you cooperate with other NGOs and international interest organizations? How does this cooperation function? Do they influence your work and focus?

Focus of disability

- What are the main causes of disability in Uganda?
- What is being done to reduce the number of disabled in Uganda?

Barriers/opportunities

- What opportunities does your organization identify for the disabled in this society?
- How do you work to promote these to the disabled persons, and other relevant agents? Who are these other agents?
- What does your organization identify as the barriers for disabled persons to participate in this society?
- How do you work to remove these barriers? Towards the disabled persons themselves? Towards the society in general? Towards the government, or other relevant administration?
- Do you identify any differences between men and women with regard to access to participation in the mainstream society?

Financing

- How is this organization being financed? Are there instances where you can apply for money? Which ones?
- How do you prioritize the money you receive? Are there any conditionalities to the money you receive?

Specific implementations

- What was the situation 10 years ago regarding persons with disabilities access to participation in mainstream society?
- What has happened/been changed during this last decade through your work?

Thank you for your time and cooperation!

Appendix 1C

Key Informant Interview Guide – Macro Level

My name is Mette and I am a Master student of development from the Norwegian University of Science and Technology. The objectives of my research are to identify what barriers and opportunities that exist for the participation of persons with disabilities in mainstream society in Kampala. I also work to identify how these barriers are negotiated and overcome in the everyday lives of the persons with disabilities and of other agents working the cause of the PWDs. The interview will take approximately 45 minutes.

Position

- Tell me about your position as an MP
- What is the focus of your work? How do you work? What are your responsibilities?

Focus on disability

Your government has ratified several international conventions working towards promoting the rights of persons with disabilities, among some the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities and the Human Rights.

- What exactly has been done in order to implement these conventions into action?
- What has been the result of these implementations?
- What do you identify as the main obstacles while working for persons with disabilities?

Opportunities/barriers

- What opportunities for disabled persons to participate in mainstream society do you identify? How do you work to promote them? Toward whom?
- What barriers for disabled persons to participate in mainstream society do you identify? How do you work to remove these?
- I focus on participation in the society with regard to the physical landscape, attitudes within the society, and the empowerment of the PWDs themselves. I find in the 'Persons with Disabilities Act of 2006' that the government work to eliminate any discrimination against PWDs. What do you do/has been done to create access to participation in these areas?

Financing

- How much money is given to the work for this specific group?
- Who does the work? What work is done?
- Is there a competition about the resources? How are they prioritized?

Perspective of change

- What was the situation 10 years ago regarding persons with disabilities access to participation in mainstream society?
- What has happened/been changed during this last decade?

Thank you for your time and cooperation!

Appendix 2

List of Informants

Macro Level:

1. Minister of State of Disability and Elderly Affairs:
Honorary Sulaiman Kyebakoze Madada
2. Executive Secretary of National Council for Disability:
Mr. Jack Mirembe
3. Member of Parliament:
Honorary Margaret Baba Diri

Meso Level:

4. City Council in Nakawa Sub-division:
Mr. Kalule Ssalongo
5. National Union of Disabled Persons of Uganda (NUDIPU):
Mr. Martin Ssenoga
6. National Union of Women with Disabilities in Uganda (NUWODU):
Ms. Beatrice Guzu
7. Uganda National Association of the Blind (UNAB):
Mr. Ronald Luyima

Micro Level (by Pseudonyms):

8. Male – Walking Impaired – Student:
Michael
9. Male – Walking Impaired – Beggar:
Vincent
10. Male – Walking Impaired – Street Vendor:
Rashid
11. Male – Walking Impaired – Street Vendor:
Eria
12. Female – Walking Impaired – Street Vendor:
Asha
13. Female – Walking Impaired – Student:
Norah
14. Male – Visually Impaired – Teacher:
Lincoln

15. Female – Visually Impaired – Student:
Elizabeth

16. Female – Visually Impaired – Student:
Beatrice

Informal Conversations (by Pseudonyms):

17. Male – Walking Impaired – Street Vendor:
Abraham

18. Male – Walking Impaired – Street Vendor:
Jack

19. Male – Walking Impaired – Street Vendor:
Charles

20. Male – Walking Impaired – Street Vendor:
Yusuf