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Participation of women with disabilities in local government decision making structures: Unpacking the Silent Voice.
A qualitative study conducted in Lusaka, Zambia.

Thesis submitted in partial fulfilment of the requirements for the
Master of Science in Welfare Policies and Management.

By

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Dedication

I dedicate this thesis report to my family for their unwavering support and all the women with disabilities.

Acknowledgements

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Declaration

This thesis has not been submitted for any Degree Programme at any other University.
The study is the sole and independent work of the author.

Abstract

Research problem: Participation of each and every person in governance system is a fundamental human right and a basic condition for democratic tenets in society regardless of their physical and socio-economic status in society. Persons with disabilities and women in particular have historically been stigmatized, discriminated and excluded in various decision making processes at global, regional, national and local levels. There is dearth literature focusing on the participation of women with disabilities in local decision making structures in Zambia hence this study.

Aim: This study aims at exploring the experiences of women with disabilities with regards to their participation in local government decision making structures in Lusaka, Zambia. The study is anchored on three theoretical perspectives: feminist intersectionality, the social model of disability, and participatory development. These theoretical perspectives are complementary and provide insights to the study.

Methods: A qualitative study design was adopted. Fourteen women with disabilities, four professionals and two local politicians were purposively recruited and interviewed using in-depth audio recorded semi-structured interviews. Additionally, data was also collected by reviewing the relevant documents to the context of gender, disability and Zambia.

Findings: Findings of the study demonstrate that women with disabilities encounter various socio-cultural, economic, attitudinal and physical environmental obstacles with regards to their participation in decision making structures within their localities. The emerged participation obstacles following the responses from interviewees include: negative attitudes towards women with disabilities, poverty, discriminatory traditional beliefs, inaccessible infrastructure and limited social network. However, participation opportunities do exist for them to participate in decision making processes as provided for by different pieces of legislation and policy guidelines. However, there is a gap between the existence of the legal and policy framework and actual implementation of participation opportunities. This gap perpetuate the exclusion of these women in decision making structures in their localities.

Keywords: *Women experiences, Disability, Participation, Local government, Decision making.*

List of acronyms

CSO	Central Statistical Office
CDFC	Constituency Development Fund Committee
DATF	District Aids Task Force
DDCC	District Development Coordinating Committee
DDMC	District Disaster Management Committee
DSPC	District Sub Planning Committee
DPOs	Disabled People's organization
GDP	Gross Domestic Product
GRZ	Government of the Republic of Zambia
HSSREC	Humanities and Social Science Research Ethics Council
ILO	International Labour Organization
LCC	Lusaka City Council
MNDP	Ministry of National Development Planning
SISGP	Swedish Institute Scholarships for Global Professionals
UN	United Nations
UDHR	Universal Declaration of Human Rights
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UNDP	United Nations Development Programme
WDC	Ward Development Committee
WHO	World Health organization
ZAFOD	Zambia Federation of Disability Organization
ZAPD	Zambia Agency for Persons with Disabilities

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Chapter One

Introduction

Participation in decision making is firmly imbedded in international law and established in the Universal Declaration of Human Rights, that every person has the right to participate in the governance issues of his or her country, directly or through chosen representatives (UN, 2015; Gutmann and Thompson, 2004). Participation in decision making provides a platform where various stakeholders can present their felt and actual needs and decide on the course of action which can address their needs (Chambers, 2008). In order to promote and enhance participation of various stakeholders in decision making processes, professionals working for different institutions are expected to ensure that local people are incorporated in planning and implementation of various development initiatives (Chambers, 2008; Greenwood and Levin, 2007). The Zambian government introduced decentralization policy in 2002 in its quest to promote participation of citizens in decision making and improve service delivery. Introduction of decentralization in service delivery empowers local authorities to plan and implement various development programmes, projects and activities (Local government Act, 2019). Therefore, this study was conducted in Lusaka, Zambia to explore the experiences of women with disabilities with regards to their participation in established local government decision making structures. The study aims at exploring participation obstacles and opportunities which exist in decision making structures.

My interest in disability issues developed in 2009 whilst I was working as a social worker (intern) at Chainama Hills Hospital which provides a variety of services to mental patients. The interest increased when I joined Zambia Federation of Disability Organizations as Paralegal Officer in 2012 where I was entrusted with responsibilities of resolving human rights violation cases for persons with disabilities through mediation and litigation. The interest became stronger when I joined the Department of Social Welfare as a Social Welfare Officer responsible for facilitating and

administering social welfare services to different vulnerable groups including women and persons with disabilities. In my line of duty, I observed how women and persons with disabilities have been oppressed, stigmatized and discriminated against and continue to experience high poverty levels as compared to other groups. It was for this reason that I became more interested to explore and understand how the intersection of gender and disability affect women with disabilities with regards to participation in local government decision making structures.

The research problem

According to the Universal Declaration of Human Rights (2015), each and every human being has rights and fundamental freedoms. Article 21 (1) of the declaration stipulates that every person has the right to take part in the governance affairs of his or her country, directly or through chosen representatives. Worldwide, there has been a call for equal participation in governance systems and development agendas at international, national, regional and local levels. Various stakeholders such as researchers, policy makers, human rights activists and donor agencies recognize equal participation in decision making processes as an effective tool for empowering and addressing the needs of the marginalized people (Waheduzzaman, 2010; Chambers, 2008; Greenwood and Levin, 2007).

United Nations (2016) recognizes participation as a fundamental human right principle and a basic condition for a democratic society which allows different categories of groups to play a role in their own development and ensure that their actual needs are taken into account. Historically, vulnerable groups such as women and persons with disabilities, have been in many cases excluded from taking part in decision making processes (UN, 2019). Exclusion of women and persons with disabilities amounts to violation of a right to participation in issues which concern and affect them (UNCRPD, 2006). Just like any other group in society, persons with disabilities are entitled to all the rights and fundamental freedoms including the right to participate and be part of the decisions which impact them.

Persons with disabilities are the most vulnerable group yet there are the most discriminated and excluded in decision making processes in different societies (European Commission, 2009). According to the World Bank-World Health Organization Report (2011), one billion people worldwide have some form of disability, with 80 percent living in low income countries. The report further indicates that Persons with disabilities experience unequal opportunities to participate in society because of discrimination, inaccessibility and poverty. The experience is worse for women because of gender discrimination and other disabling obstacles (WB-WHO, 2011). Livneh et al. (2014) observe that persons with disabilities in different cultures and societies face various forms of stereotypes, prejudices, stigmas and discriminatory practices than those without disabilities. Poverty rates experienced by persons with disabilities are high than those experienced by able bodied people due to unequal access to health care, education, employment opportunities and transport and communication facilities (UN, 2016). This has resulted in them experiencing poor health outcomes, lower education achievements and less economic participation than people without disabilities (WHO, 2011).

Predominantly, persons with disabilities in developing countries are more vulnerable than those in developed countries (WB-WHO, 2011) due to high socio-economic inequalities caused by inadequate policies, negative attitudes, inadequate provision of services, inaccessibility to physical environment and stigmatization when it comes to consultation and involvement in decision making processes (UN, 2016; Chapman and Carbonetti, 2011; Emmett and Alant, 2006). Discrimination in decision making processes is worse for women with disabilities than their male counterparts due to gender, socio-cultural, structural and power relation issues (Sépulchre et al. 2018; Museva, 2012; Shirin, 2009). Women with disabilities face stigma, isolation, invisibility, punishment and generally are on the receiving end of negative attitudes on the part of the community (Shirin, 2009). This is echoed in the preamble of the United Nations Convention on the Rights of Persons with Disabilities (2006: 2) which recognizes that: *women and girls with disabilities are often at greater risk, both within and outside the*

home, of violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation.

In the case of Zambia, there is a wide disparity in terms of available disability prevalence rates. World Health Organization Report (2011) estimates Zambia's disability prevalence at 15 percent whilst Zambia's 2010 census report shows that disability prevalence was at 2 percent. On the other hand, the 2015 National Disability Survey in Zambia indicates 7.2 percent as a current disability prevalence in the country. The survey shows that there are more females with disabilities than their male counterparts (9.1 percent and 7.7 percent respectively). This study adopted the disability statistics by World Health Organization Report (2011) because it covers a wide range of disabilities and is also consistent with the statistics of other development countries which share similar socio-economic characteristics with Zambia.

Despite the fact that the contribution of women in development plays a crucial role especially at the community level (Sépulchre et al. (2018), women in Zambia have a limited voice in development discourse and barely participate in decision making processes¹ (Kalinda and Chirwa, 2015). The combination of discrimination experienced by persons with disabilities and gender bias towards women makes women with disabilities significantly marginalized and invisible in many development initiatives and their voices are silent or limited in the area of decision making (UN, 2019; Kalinda and Chirwa, 2015; ILO, 2013; Shirin, 2009).

Over the years, the Zambian government has formulated and enacted policies and laws with the aim of enhancing the participation of women and persons with disabilities in decision making structures at various levels. The key policies and piece of legislation include National Disability Policy 2015, National Gender Policy 2014 and the Persons with Disability Act No.6 of 2012 respectively. While the Disability Policy aims at providing equal opportunities for persons with disabilities to participate in all

¹ See the full article by Kalinda and Chirwa (2015) entitled *women's participation in key decision making institutions in Zambia: case of three arms of government: legislature, executive and the judiciary.*

developmental processes without being discriminated and excluded, the provisions of Gender Policy aim to ensure the attainment of gender equality in the development process by providing equal opportunities for women and men to actively participate and contribute to their fullest ability and equitably benefit from national development. On the other hand, the Persons with Disability Act seeks to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. The National Strategic Implementation Plan on Disability 2017-2021 provides an important framework to enhance coordination among institutions tasked with implementation of policy provisions. These key policies have been incorporated into the Seventh National Development Plan 2017-2021 and Vision 2030 with emphasis on citizen participation in decision making processes (Ministry of National Development and Planning, 2017).

Despite huge strides in policy and legal frameworks, the country has not responded adequately to the needs of women with disabilities, who still encounter obstacles in realizing their social, economic, cultural and political rights (ILO, 2013; Aide and Loed, 2012). This is largely due to the lack of equal opportunities and means to participate fully and effectively in decision making processes (Kalinda and Chirwa, 2015). The United Nations Zambia Tour Report (2016) demonstrates that persons with disabilities are merely informed or barely consulted on issues which affect them without being accorded an opportunity to actively decide on the course of action of particular development initiatives. These consultations are usually done at the national level and invisible at the local level. Due to limited voice in decision making on issues which concern them, women with disabilities often find challenges in accessing essential resources and services such as health care, education, housing and water and sanitation which are key in improving their well-being (Yoshida et al., 2014, Lewis, 2004; Smith et al., 2004).

Few studies (Yoshida et al., 2014; Mutoloki, 2012; Lewis, 2004 and Smith et al., 2004) on women with disabilities have been conducted in Zambia. However, a detailed search

of literature shows that a study specifically focusing on participation of women with disabilities in local government decision making structures in the Zambian context is lacking hence the need for this study in this area. This study was undertaken under the field of Social Work which is concerned with helping the vulnerable groups facing challenges in their lives which compromise their general wellbeing (Nooyo, 2000). Therefore, the study is relevant in contributing to the knowledge on intersection of gender and disability issues in general and issues pertaining to participation of women with disabilities in established local decision making structures in particular. The findings of the study are expected to be of help in informing policy makers and various professionals such as social workers and planners to reexamine existing disability and gender participation processes, strategies and mechanisms as well as enhancing awareness raising against disability and gender discrimination in Zambia.

Aim of the study

The study aims at exploring the experiences of women with disabilities from their own perspectives with regards to their participation in local government decision making structures. The study seeks to understand the experiences in terms of participation obstacles and opportunities which exist in decision making processes at the local level.

Research questions

1. What are the experiences of women with disabilities with regards to participation in local government decision making structures?
2. Which obstacles are limiting women with disabilities to participate in local government decision making structures?
3. What are the existing opportunities for women with disabilities to participate in local government decision making structures?

Structure of the thesis

This thesis is organized in seven chapters. Chapter one outlines the introduction to the study, the research problem, relevance of the study as well as the aim of the study and research questions. Chapter two highlights the Zambian study context in terms of its geographical location and population, administration and governance structures, economic situation, policy, legal and institutional frameworks on disability and the study location: Lusaka. Chapter three focuses on reviewing the previous studies whilst chapter four provides the theoretical perspectives which have been adopted to provide insights to the study. Chapter five focuses on research methodological issues and methods including ethical considerations whilst chapter six presents and analyzes the findings of the study. Finally, chapter seven provides the study summary, conclusions and some recommendations.

Chapter Two

Study Context: Zambia

Geographical location and population

Zambia is a landlocked and lower-middle-income country located in the Sub-Saharan Africa region with surface area of 752,614 square kilometers. It shares boundaries with eight neighboring countries: Angola, Botswana, Democratic Republic of Congo, Malawi, Mozambique, Namibia, Tanzania and Zimbabwe: See figure 1. The estimated total population for the country stands at 15.5 million, with 58.2 percent of that residing in rural areas whilst 41.8 percent reside in urban areas (CSO, 2015). It is one of the fastest growing population in the Sub-Saharan region with 2.8 percent growth rate per annum between 2000 and 2010 (CSO, 2010). 51 percent of the population are females and 49 percent are males. The country has 72 ethnic groupings with seven major languages: Bemba, Kaonde, Lozi, Lunda, Luvale, Nyanja and Tonga. English is the official and main language of instruction in schools and public offices. Bemba and Nyanja are widely spoken in urban areas.

Figure 1: Map of Zambia



Source: Alamy stock photo. www.alamy.com

Administration and governance structures

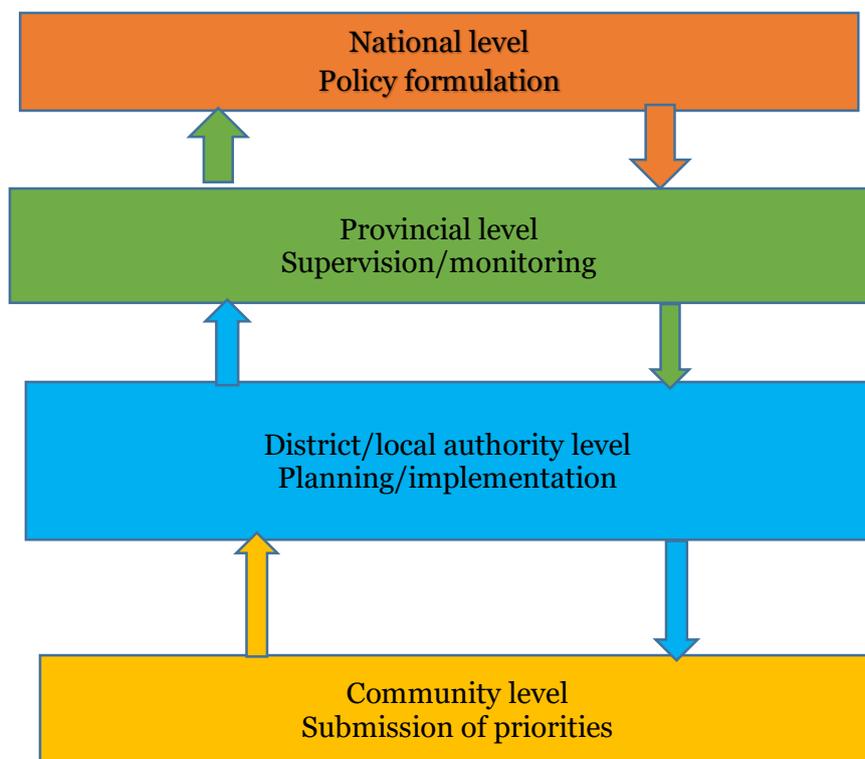
The country gained independence from Britain on the 24th October, 1964. It has experienced three major phases of governance, the multi-party system from 1964 to 1972, one party system from 1972 to 1991 and multi-party system again since 1991 up to date. Administratively, the country is divided into 10 provinces namely; Central, Copperbelt, Eastern, Luapula, Lusaka, Muchinga, Northern, North Western, Southern and Western. These provinces are further subdivided into 105 districts or local authorities/councils (CSO, 2018). The government is comprised of both Central and Local government.

The Central government is responsible for national policy formulation, providing regulatory frameworks and guidelines on service delivery (MNDP, 2017). The key decision making structures at Central government level include the Executive/Cabinet which is presided by the democratically elected President; Parliament/National Assembly which is presided by the Speaker of National Assembly and the Judiciary which is presided by the Chief Justice. The Local Government Councils are headed by the Mayor in case of a City/Municipal Councils and Council Chairperson for Town Councils. Local government is mandated to provide services to the public in their respective locations or jurisdictions (Local government Act, 2019). These councils are required to plan, budget, prioritize and implement development programmes and projects at the district and sub-district levels (Local government Act, 2019; Constituency Development Fund Act, 2018).

There are established decision making structures at the district and community levels where different stakeholders are expected to participate in decision making processes. At the district level, the established local authority decision making structures include District Development Coordinating Committee (DDCC), District Sub Planning Committee (DSPC), District Disaster Management Committee (DDMC), District Aids Task Force (DATF) and Constituency Development Fund Committee (CDFC). At the sub-district or community level, there is Ward Development Committee (WDC) which

is the lowest local government decision making structure. According to the local government Act, these structures are designed to be represented by various stakeholders which include: local councilors, civil society organizations, professionals, traditional leaders, persons with disabilities, clergy and in some instances gender focal point persons. These committees are mandated to plan, budget and prioritize allocation of resources for development programmes such as provision of water and sanitation, health care, education and agricultural services among others (Local government Act, 2019; Constituency Development Fund Act, 2018).

Figure 2: Decision making structures in Zambia



Economic situation and social services

The Zambian economy heavily depends on copper exports to generate most of its foreign exchange revenue (CSO, 2015). Because of this, the country has remained susceptible to high risk of external commodity price fluctuations. Economic growth is driven by capital-intensive sectors and has had limited impact on the welfare of the general citizenry. Despite macroeconomic stability, interest rates have remained high,

and in the last five years, domestic debt has been going up (UNDP, 2019). Over 60 percent of the people depend on subsistence agriculture as their main source of livelihood (CSO, 2018). The economic growth which stood in the range of 6 to 7 percent between 2006 and 2013 slowed down in 2015 and reduced to 2.9 percent (CSO, 2015). Poverty levels and vulnerability have remained high in the country with 54.4 percent of the population living below the national poverty line (\$1.90) and 40.8 per cent of the population being extremely poor.

Social services such as education, health and water and sanitation are mainly provided by the government and complemented by non-governmental organizations. Primary education is provided freely but secondary and tertiary levels are not free (Ministry of Education, 2008). Government provide limited bursaries to vulnerable secondary and university students. Water and sanitation in urban areas is provided by the government through regional water and sewerage companies. Improved sources of water such as boreholes and wells which account for 48 per cent of drinking water are also provided despite being inadequate (UNDP, 2019). Around 80 per cent of households use pit latrines: 95 per cent in rural areas and 65 per cent in urban areas (UN, 2011).

Health services are provided at various levels starting from the Health Posts, Health Centres, first level hospital, second level hospital and third level hospital (Ministry of Health, 2012). Basic health services are provided with minimal user fee charges but people pay more for specialized treatments. Social protection programmes such as Social Cash Transfer, food support and empowerment programmes are being provided to vulnerable people such as orphans and vulnerable children, the aged, women and persons with disabilities.

The provision, access and use of the basic social services is mainly inadequate and faced with numerous challenges. There are few schools, health facilities and improved sources for clean drinking water (UNDP, 2019). The impact of such inadequacy is particularly felt more by persons with disabilities who have challenges of mobility and other accessibility related issues (UN, 2016).

Policy, Legal and Institutional Frameworks on Disability and Gender

As stated above, the Zambian government has formulated National Disability Policy 2015 and Gender Policy 2014 in order to ensure that disability and gender issues are mainstreamed in all development initiatives. In 2012, the government enacted the Persons with Disability Act No. 6 of 2012. This Act seeks to domesticate the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The Act aims to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. Article 20 (2) (e) in the Disability Act provides for the persons with disabilities to be represented in decision making processes. Furthermore, Article 21 (2) (c) of the same Act provides for women with disabilities in particular to have equal opportunities to participate in decision making processes to ensure their full development, advancement and empowerment².

Disability and gender issues are handled by different institutions. Ministry of Community Development and Social Services is responsible for formulation of disability and social protection policies. The Zambia Agency for Persons with Disabilities (ZAPD) acts as an advisory board to the Ministry of Community Development and Social Services on disability issues. The Agency is responsible for coordinating and supervising all organizations and institutions dealing with disability issues in the country. It monitors how disability issues are handled by different ministries and organizations. Zambia Federation of People with Disabilities (ZAFOD) is a national non-governmental umbrella/mother body of all Disabled People's Organizations that are representing and advocating for different interests of persons with disabilities. The main goal is to advocate for the promotion and protection of rights for persons with disabilities.

² See Article 20(2) (e) and 21 (2) (c) of Disability Act No. 6 of 2012. Available online at: <http://www.parliament.gov.zm/sites/default/files/documents/acts/The%20Persons%20with%20disabilities%20act%2C%202012.PDF>

Study location: Lusaka

Lusaka is Zambia's capital and largest city which is the heart of the country's economic activities. According to 2010 census, the population for Lusaka stood at 1,747,152 which was the highest in the country as compared to other districts. 49.2 of the population were males whilst 50.8 were females. English is the main language spoken among the working class, but Nyanja is the widely spoken local language followed by Bemba. Lusaka has been selected for the study because it has the highest number of full-fledged local government decision making structures in comparison with other local authorities in the country. For instance, Lusaka has 33 Ward Development Committees found at the community level dotted around the city and seconded by Kitwe and Ndola with 28 Ward Development Committees respectively (CSO, 2010). The city of Lusaka has mixed population with diverse socio-economic, cultural and ethnicity backgrounds (Chirwa, 2017). There is equally a mixture or diverse types of disabilities in Lusaka. Majority of Disabled People's Organizations with good membership are also found in Lusaka. It hosts 12 offices for Disabled People's Organizations which are non-existence in other districts. See figure 3 below for the view of Lusaka Central Business Centre:

Figure 3: Lusaka Central Business Centre



Source: zambiatourism.com

Chapter Three

Research Studies

Various studies (Sépulchre, M. et al., 2018; Pinilla-Roncancio and Alkire, 2017; Adjei-Amoako, 2014; Yoshida et al., 2014; Museva, 2012, Mutoloki, 2012; EU, 2009; Shirin, 2009; Lewis, 2004; Smith et al., 2004) have been carried out to explore and investigate on issues pertaining persons with disabilities in various areas such as politics, employment, entrepreneurship, education, health and governance. These studies have been conducted both in developed as well as developing countries. The findings of the studies have revealed varied challenges in different contexts which affect persons with disabilities to enjoy their human rights and freedoms to the fullest just like those without disabilities. Nevertheless, some findings indicate some of the attained positive scores in ensuring that persons with disabilities enjoy their rights to the fullest in all spheres of their lives. Global and localized studies present a picture of marginalization which many persons with disabilities experience in different parts of the world but more predominant in low income countries.

Therefore, this chapter discusses different studies that have been conducted in the area of disability, gender and participation in various spheres of life. The studies discussed in this chapter have been conducted in different parts of the world by international and regional bodies such as United Nations and European Union as well as individual scholars from different disciplines. The studies are presented and discussed according to global, continental (Africa) and country (Zambia) levels, starting with global to country level.

Strategy for searching the literature

Literature was searched by using University and other institutions' websites. Books: hard copies and e-Books, peer reviewed articles, reports and journals were accessed from Lund University Library and other international, regional and local institutions databases. Other literature was obtained from other databases such as Google Scholar, JSTOR and Web science. Different Zambian pieces of legislation and policies which

are not found on websites were obtained from various institutions and ministry offices.

Previous studies

People with disabilities and their families have been recognized as a high risk population and are particularly likely to be poor and deprived of most needed essential resources and services for their wellbeing (UN, 2016). A study by Pinilla-Roncancio and Alkire (2017) conducted in 11 countries (Cambodia, Cameroon, Chad, Colombia, Dominican Republic, Ecuador, Egypt, Gambia, Mexico, Uganda and Yemen) by using quantitative data, demonstrate that persons with disabilities and their families face difficulties in obtaining optimum levels of income. The data obtained using the Global Multidimensional Poverty Index (Global MPI) and Demographic Health Survey from 11 respective countries shows that the income challenges which they face have additional indirect, direct and opportunity costs and characteristics that increase their vulnerability to become poor or chronically poor. Apart from income constraints, it was revealed that persons with disabilities usually have a reduced set of functioning, a feature that limits the type and quality of opportunities they have access to and the final functioning that they can achieve. The findings of the study are in line with World Health Organization Report (2011) which indicates that, persons with impairments in general face extra costs and barriers in their access to health care services and are socially excluded from education and employment and have to assume direct, indirect and opportunity costs, which negatively affect their income and consumption. Extra costs are usually incurred due to inevitable demand of extra requirements such as assistive devices which enhances their functionality.

The study done by European Commission in 2009 analyzed and interpreted information on the situation of women with disabilities in Europe in light of United Nations Convention on the Rights of Persons with Disabilities. Gathered evidence at European and national level across 33 countries (the 27 EU Member States, three EEA Members-Iceland, Liechtenstein, Norway and three EU Candidate Countries-Croatia, Macedonia and Turkey) indicate that women with disabilities remained under-

represented in democratic and decision making processes. It was discovered that there were few women with disabilities holding decision making positions or being part of decision making bodies. Despite being under-represented in democratic processes and decision making, women with disabilities equally encounter challenges in entering the Labour market, accessing education and training, social protection services, access to justice and protection from abuse and access to health care services. These barriers are attributed to inaccessible physical environment, negative attitudes and inadequate specialized professional to handle them. Inaccessible buildings due to lack of ramps, hand rails and lifts hindered them to have access to essential services provided in those places.

Sépulchre et al. (2018) conducted a study which adopted an intersectionality approach to explore the experiences of Active Citizenship of women with disabilities in nine countries which include Czech Republic, Germany, Norway, Serbia, the United Kingdom, Italy, Ireland, Switzerland and Sweden. The findings from semi-structured life-course Interviews with 104 women with disabilities revealed that experiences and practices pertaining to Active Citizenship were influenced by combination of womanhood and disability. These targeted countries have advanced and formidable welfare systems and disability issues have been incorporated in the legal and policy frameworks as compared to developing countries such as Zambia. However, the findings of the study demonstrate that women with disabilities are discriminated and excluded from active citizenship participation in education, politics and civil society, family care, intimate relationships and Labour market. Discrimination and exclusion results in women with disabilities having low levels of education which in turn affected them in engaging effectively in different spheres of their lives. Despite scoring some level of achievements in enabling women with disabilities to participate in various aspects, the study indicate that there were still disparities and existence of unequal opportunities for women with disabilities to participate. These women are considered as people who deserve to be helped and be on the receiving end.

A study done in North West Province of Cameroon by Shirin in 2009 involving 24

participants and 12 key informants through semi-structured interviews, focus group discussions and observations indicate that women with disabilities were often excluded from accessing churches, hospitals, schools and market places. The buildings were inaccessible for them and they equally could not manage to walk on their own to these places. Discrimination against women with disabilities started in their homes which made it difficult for them to progress in life. Family members' negative attitudes towards them made it difficult for them to engage in some productive activities. They were considered to be incapable and not worthy to do certain things or granted certain opportunities such as education for them to be empowered. They equally faced difficulties with movements because there was no public or accessible transportation system as most of people walk or use taxis to get to their destinations. Their mobility was affected due to poor roads, lack of assistive devices and financial constraints which could not allow them to pay bus or tax fare. This entails that these women with disabilities were confined in the same environment and could not make any move on their own for them to access certain services. Even attending meetings which concern them was a challenge due to mobility issues.

Museva (2012) carried out a study using a feminist theoretical perspective to investigate the level of participation of women with disabilities in economic empowerment programmes in Gweru district of Zimbabwe. The study which intended to find out community views on participation of women with disabilities and to examine barriers that limited their participation in economic programmes demonstrate that there was lack of consultation and little attention was given to issues affecting women with disabilities. The solicited information through interviews from thirty respondents in Gweru Urban and some Leaders from Government, Non-Governmental Organizations and Community Leaders shows that women with disabilities were regarded as 'aid cases' with the assumption that they were unproductive and could not engage in any economic activity. They were considered as recipients of donations from various well-wishers. Socio-cultural norms and traditions also created barriers for them to freely participate in economic programmes just like those without disabilities.

Women with disabilities were perceived as people who are worthless and deserve to just wait for assistance to come their way. This signifies that their mental abilities to make sound decisions and be involved in economic activities was questionable by those who are able bodied.

A study to understand the experiences of disability and inclusive development with regards to facilitating factors and barriers to participation was carried out in Ghana by Adjei-Amoako in 2014. The study which was based on qualitative, participatory techniques and workshops was conducted in both rural and urban areas in Eastern region and Accra Metropolis. The information collected through semi-structured interviews from 26 disabled men and women, 21 professionals working in non-governmental organizations and institutions, and nine strategic informants show that disabled people's everyday experiences were embodied, attitudinal, physical and institutional arrangements. This entails that persons with disabilities were excluded from participation because of the effects of body impairments, such as deformities and pain, negative perceptions on their capabilities and an inaccessible built environment and public services.

In Zimbabwe and Zambia, it was discovered that most of the microcredit initiatives that have received international attention for alleviating poverty in marginalized groups did not include women with disabilities in their programs (Lewis 2004). The investigation of their participation in this area demonstrates that the stereotypes and discrimination elements of those who provide microfinance services made it difficult for women with disabilities to participate. Due to negative perceptions, women with disabilities were perceived to be incapable of engaging in any economic activity.

Yoshida et al. (2014) conducted a qualitative study by using intersectionality approach to explore the experiences of both men and women with disabilities who were HIV positive in Lusaka, Zambia. The adoption of intersectionality perspective was intended to discover the new insights that could inform HIV, disability and rehabilitation efforts among women and men. The findings of the study from semi-structured interviews with 21 participants demonstrate that people with disabilities experience multiple

constraints in accessing HIV prevention, treatment, care and other supportive services. The encountered challenges varied in terms of intensity depending on intersection with other characteristics such as gender, socio-economic status and trajectory of HIV. It was further discovered that disability and HIV led to stigmatization and discrimination. Members of the society as well as health professionals and other service providers stigmatized and discriminated against people with HIV and disabilities. This was worse for women with disabilities due to differences in social roles.

A qualitative study of 10 women with disabilities in Kazungula and Livingstone districts in Zambia indicate that lacking of assistive devices for the blind, interpreters or translators for the deaf, infrastructure to facilitate movement or access to buildings for those who are physically disabled made it difficult for them to access essential services such as health care facilities, education and water and sanitation (Mutoloki, 2012). Lack of assistive devices proved to be one of the major hindrance for their mobility and access to information. It is further shown that, due to poor education among women with disabilities, it is difficult for them to compete favorably in different spheres of their lives with those who are able bodied. This situation aggravate the vulnerable situation and limit them further in engaging in economically productive activities which can improve their living standards.

Another qualitative study pertaining to the situation of women with disabilities with regards to their encountered barriers in accessing safe motherhood and reproductive health services was carried out in Lusaka, Zambia (Smith et al., 2004). The study consisted of 24 women with disabilities and 25 safe motherhood/reproductive public sector health service providers. The findings from the in-depth audio recorded interviews reveal that women with disabilities encounter various social, attitudinal and physical barriers to accessing safe motherhood and reproductive health services. These barriers are attributed to stigma and physical inaccessibility to health facilities. These women were excluded from reproductive health sensitization programmes because of the assumption that they are sexually inactive hence no need for them to access reproductive health services. The study further indicate that the strong desire women

with disabilities have for children and affection increase their vulnerability to sexual exploitation. On the other hand, the assumption by health service providers that women with disabilities were not sexually active led to their exclusion from accessing reproductive health services which in turn increased their vulnerability to contracting HIV and other sexually transmitted infections. Traditional beliefs on transmission of disabilities also created concrete barriers for their integration in ante-natal clinics.

Summary

The findings of these studies have demonstrated that people with disabilities are more likely than those without disabilities to experience social exclusion, stigmatization and discrimination, which results in unequal access to social, cultural, political, and economic resources and services. For women with disabilities, gender inequities have contributed to multiple barriers which hinder their participation in various spheres of their lives (Collins, 2016). Additionally, the studies provide insights on how issues pertaining gender, disability, participation and other categories are being debated and discussed in development processes in different geo-political contexts. Some of the reviewed studies are inspiring to this study in terms of adopted methodological approaches and theoretical perspectives. Most of the reviewed studies were qualitative in nature and therefore insightful to this study. The methods of data collection: semi-structured interviews used to collect data and theoretical approach: feminist intersectionality by S epulchre et al (2018), Adjei-Amoako (2014), Yoshida et al. (2014) and Shirin (2009) inspire the methods and one of the theoretical perspective: feminist intersectionality for the current study. It is equally worth noting that some studies such as EU (2009) and Pinilla-Roncancio and Alkire (2017) used various sources of secondary data to conduct their studies. This inspires the second method of data collection: document review which has been equally adopted in this study.

Chapter Four

Theoretical Frameworks

This chapter presents and situates disability, gender and participation into theoretical perspectives. Three theoretical perspectives: feminist intersectionality, the social model of disability, and participatory development have been adopted for this study to provide a rich conceptual framework for exploring and understanding the experiences of women with disabilities with regards to their participation in local government decision making structures.

Feminist Intersectionality Perspective

Intersectionality in feminist theory has been mainly used to analyze and describe the experiences of individuals within the system of interlocking hierarchies or identities such as race, class, age, gender, ethnicity and disability and how they create multiple forms of discrimination (Collins, 2016). The concept of intersectionality was coined by Crenshaw (1989), who argued that there was need to explore and investigate the multidimensionality of experiences black women encountered rather than considering race and gender as a mutually exclusive categories of experience and analysis. Crenshaw focused on the black women in the United States and how other social categories such as socio-economic status created triple form of oppression and exploitation. This further triggered other feminist disability scholars such as Morris (1993) and Keith (1992) to focus their attention on the situations of women with disabilities which were mainly overlooked by both disability and feminist researchers. The intersection of gender and other social identities aggravate the vulnerable situation of women and expose them to all forms of repression, exclusion, oppression, stigmatization and discrimination. The contemporary intersectionality feminist scholars such as Collins (2016) and Lykke (2010) apply the concept of intersectionality to understand how various social categories or identities intersect and produce multiple forms of discrimination, exploitation and oppressions. For instance, Lykke (2010: 50), argues that intersectionality is a theoretical and methodological tool which

can be used to *analyze how historically specific kinds of power differentials and/or constraining normativities, based on discursively, institutionally and/or structurally constructed sociocultural categorizations such as gender, ethnicity, race, class, sexuality, age/ generation, dis/ability, nationality, mother tongue and so on, interact, and in so doing produce different kinds of societal inequalities and unjust social relations.*

Intersectionality perspective is crucial in assessing and understanding how gender and disability intertwine and produce a double discrimination which worsens the levels of stigmatization, exclusion, oppression, inequalities and exploitation. The low socioeconomic status (CSO, 2015) for persons with disabilities has placed them in a category of lower class in Zambia just like in many other developing countries. Intersectionality concept is useful in considering how their socio-economic class impact on participation in decision making processes. It provides a lens through which the lives of women with disabilities have been affected by different intersecting identities which perpetuate their marginalization, stigmatization and being trapped in the vicious cycle of poverty. Additionally, an intersectionality approach allows for an exploration of different variables that intersect with one another to determine the power dynamics at both the family and societal levels (Collins, 2016; Crenshaw, 1989), and how these power dynamics impact on women with disabilities.

Despite having some shortcomings such as lacking clarity in meanings and interpretations and clearly defined identities such as meaning of disability, the intersectionality feminist theory is appropriate and suitable for thorough analysis of gender and disability study of this nature. It provides a lens and foundation on which the lived experiences of women with disabilities (Collins, 2016) in the area of participation in decision making can be better understood. However, in order to provide a better understanding of the disability concept in this study, the social model of disability theoretical perspective is adopted. The social model of disability complements and provides an understanding of disability concept which is merely mentioned in feminist intersectionality perspective.

The Social Model of Disability

The social model of disability is premised on conceptions and prejudices that society has towards persons with disabilities. The social model of disability, theorized principally by Oliver (1990) a disability rights activist in the field of sociology, has been developed in the Global North mainly in United Kingdom and United States of America. The social model of disability asserts that disability is a socially constructed problem which results in exclusion, discrimination and stigmatization of persons with disabilities. The concept of disability according to social model externalizes the disability by locating the source of "difficulty or obstacle" in a person's environment and social sphere rather than in the person's diagnosis of body impairment (Dirth and Branscombe, 2017; Oliver, 2012). Disability is understood as being caused by existing of external perceptions and barriers and not body impairment. The social model illustrates how society imposes barriers and constraints in addition to the presentation of a diagnosable condition (Oliver, 2012). The model provides a lens for analyzing and understanding how the physical, socio-cultural and political barriers can be removed in order for persons with disabilities to enjoy their full and effective participation in all spheres of their lives on an equal basis with others (UNCRPD, 2006).

The social model of disability is relevant and useful in this study for analyzing physical, attitudinal and cultural barriers (Barnes and Mercer, 2005), that impede women with disabilities to participate in decision making processes. The model is useful for illustrating how women with disabilities are perceived and treated within the Zambian development strategies and mechanisms aimed at enhancing and promoting participation in decision making processes. The model in this study serves as an analytical tool for unraveling environmental barriers and negative social attitudes that are more pernicious impediments to inclusive policies (Dirth and Branscombe, 2017). This model is also connected to Universal Declaration of Human Rights which seeks for removal of barriers so that every person can have equal opportunities to participate in issues which affect them.

Nevertheless, the social model of disability has been criticized by other scholars. For

instance, Justin and Samuel (2016) and Lorella (2004) have argued that the social model of disability does not give any account on the element of impairment. It fails to address impairment as an observable attribute of an individual that is an essential aspect of their lived experience. Justin and Samuel (2016) further argues that social model does not account for differences and identities among individuals with disabilities such as gender, race and socio-economic status. Therefore, the social model of disability is complemented by the participatory development perspective which provides an account of how different groups of people with different characteristics can be included in planning and decision making on issues which concern them.

Participatory Development Perspective

Participation is a concept that is often cited, but seldom defined and widely used in a variety of fields. It is considered to be critical in development agendas though variations in its definition exist. Flower and Wirz (2000) categorizes participation as being applied in four different ways which include information sharing, consultation, decision making and initiating action. According to the World Bank (1999), participation is the inclusion of the general public in any activity of any country. Rifkin and Pridmore (2001) conceptually defines participation as the equal participation between men and women at all levels of decision-making, policy development, development planning and management especially of development program where effective participation is of utmost importance.

Various participatory development scholars and activists (Chambers, 2008; Greenwood and Levin 2007; Guttman and Thompson, 2004; Cornwall, 2000) have argued that involvement of all stakeholders when making decisions for various development programmes, projects and activities is crucial in poverty reduction policies and strategies. Chambers' (2008) experiences in various development programmes in Kenya, India and Sri Lanka sparked the need for community participation in development programmes few decades ago. He further observed that, with the priority

of poverty reduction coupled with accelerating change in many dimensions, people living in poverty have come to matter more than ever hence the need for their involvement in decision making processes. For example, Greenwood and Levin (2007) argues that participation of local and vulnerable people is vital in co-generating socially robust knowledge which is relevant in planning, implementation and evaluation of development programmes. Therefore, the concept of participation is useful in assessing and understanding how important the participation of women with disabilities is in decision making processes.

Stakeholders' participation in decision making processes enhance and promote the inclusion of diverse views and voices in the governance system with adherence to democratic tenets and human rights (Guttmann and Thompson, 2004). In this vein, the participation approach provides an understanding of how the Zambian government is creating opportunities for various stakeholders including women with disabilities to participate in local government decision making structures and voice out on issues which affect them. Additionally, Chambers (2008) asserts that local people are knowledgeable and experts in issues which affect them hence the need to involve them in decision making for their actual needs to be reflected in development initiatives. This is helpful in assessing and understanding the participation strategies and mechanisms under local government decision making structures which provide opportunities for women with disabilities to express and present their actual needs which may be overlooked by those without disabilities if left in their hands. This is consistent with Cornwall (2000) argument who indicates that participation in priority setting, project design and implementation takes into account the actual needs of the affected people. This entails that women with disabilities should not just be merely informed or consulted on issues which affect them but must actively be part of decisions being made in development initiatives at national, regional and local levels. Drawing from these three theoretical approaches on gender, disability and participation, the adopted theoretical underpinnings complements each other in order to better explore and understand the participation experiences of women with

disabilities in local government decision making structures. These perspectives are used as a lens and pillars of research questions on participation of women with disabilities in decision making processes. The feminist intersectionality illustrates the combination of disability, gender and power dynamics and how they impact on women with disabilities whilst the social model of disability helps in understanding the socio-cultural and physical factors that may be affecting women with disabilities. Participatory development focuses on how the women with disabilities should be considered as a group which understands its needs better and therefore be given an opportunity to participate in decision making processes through different mechanisms put in place for them to express their views and needs.

Chapter Five

Research Methodology

The research questions and theoretical perspectives of the study discussed in the previous chapters inform the research methodology within a qualitative research strategy. Therefore, this chapter outlines and describes the philosophical assumptions which inform the study, adopted research design, data collection methods, participants' inclusion/exclusion criteria, characteristics of the participants, entry point and gatekeeping issues, selection methods and sample size, ethical considerations, issues related to reflexivity and positionality, analysis of data and some of the encountered limitations during the study.

Pernecky (2017) observes that the overall credibility of research largely depends on the adopted philosophical assumptions. He asserts that philosophical assumptions can be used to understand what there is, what can be known about it, and whether the statements and propositions truly describe the world as it is. Philosophical assumptions provide different lenses on how a researcher can conceive and execute the research (Leavy, 2017). Porta and Keating (2008) outlines four philosophical paradigms: Positivism, Post-positivism, Interpretivist and Humanistic. Each of the four paradigms hold a different ontological and epistemological perspective as well as form of knowledge which can be obtained under each one of them. For instance, existence of reality range from objectivity (positivism) to subjectivity (humanistic) whereas form of knowledge range from natural laws (positivism) to emphatic knowledge (humanistic).

The study adopted Interpretivism paradigm because of its focus on understanding social reality from the standpoint of those experiencing it (Gimbel, 2016; Thanh and Thanh, 2015). Interpretivism aims at understanding subjective knowledge in its contextual form (Porta and Keating, 2008). This entails that people attach subjective meanings to their social world and that these meanings are shaped by their knowledge, experience and socio-cultural factors (Chirwa, 2017). Interpretivism was useful in situating the studied group in a Zambian historical, political, structural and

socio-cultural setting and sought interpretations from their own perspectives and understandings (Bryman, 2016). It allowed them to construct their lived participation experiences in local government decision making structures.

Research Design

The adopted Interpretivism paradigm motivates the adoption of qualitative research design in this study. The underpinnings of Interpretivism are consistent, relevant and suitable for qualitative research design which focuses on conducting an inquiry aiming at discovering how human beings understand, experience, interpret, and produce the social world (Creswell, 2013). Key (1997) notes that qualitative research design produces more in-depth and comprehensive information which seeks to understand people's interpretations, perceptions and lived experiences. The study specifically employed qualitative phenomenological approach (Creswell, 2013).

Phenomenological approach, which was founded in the early 20th century by Edmund Husserl and Martin Heidegger, focuses on exploring the lived experiences of one or more individuals in everyday life situations. Pernecky (2017) notes that phenomenological approach is oriented towards studying the structures of conscious experience as they manifest in people's minds. This approach also resonates well with the research questions which are focusing on exploring and understanding how women with disabilities experience the issues pertaining to their participation in decision making structures such as perceived obstacles and existing participation opportunities.

Data Collection Methods

Data was collected by using both primary and secondary sources. Primary data was collected using qualitative interviews. The qualitative methods of data collection were inspired by the qualitative phenomenological approach which requires in-depth inquiry (Mason, 2018; Creswell, 2013; Bhattacharjee, 2012). Mason (2018) and Kvale (2006) observes that qualitative interviews are sensitive and powerful in investigating

the experiences of private and public lives of different categories of people. Adam (2015) argues that in a situation where a researcher need to have in-depth inquiry and have an opportunity to probe the participants for better understanding, semi-structured interviews are suitable as compared to structured interviews.

Interviews

Face-to-face qualitative in-depth *semi-structured interviews* were employed to collect the data. The length of interviews ranged between 25 to 45 minutes for each interview. Semi structured interviews with open ended questions contained in the *interview guide* were used and allowed the researcher to be flexible and probe for further clarification on issues which were raised by the interviewees (Creswell, 2013; Bryman, 2016). It also allowed the participants to freely express themselves. The interviews with women with disabilities were conducted in the disabled people's organization premises and their respective homes depending on their preferences.

Interviews with other stakeholders: local politicians, professionals and disability advocates were conducted in their respective offices. Local politicians were interviewed because they are involved in policy formulation and making of *by-laws* whilst professionals were interviewed because they are involved in planning and interpretation of different government policies and guidelines. Disability advocates were interviewed because they engage in advocacy for the rights of persons with disabilities and ensure that their rights are upheld and adhered to. Interviews with professionals were conducted in English whereas interviews with women with disabilities were conducted in English, Nyanja and Bemba depended on which language they were comfortable with. Language was not a challenge for me because I understand and speak the two local languages without problems. All interviews were audio taped after seeking permission from each interviewee. One interview of a woman with hearing impairment was conducted in writing because there was no sign language interpreter to translate. Semi-structured interviews were complemented by secondary sources through document reviews.

Document reviews

Different documents (Hogan, 2013) were reviewed in order to understand issues on the ground pertaining to gender, disability and participation in decision making processes. The documents which include international conventions, journals, government policies, pieces of legislation and other official government documents provided secondary data for the study. The documents were selected based on their relevance to the context of the study (Prior, 2003). The documents were obtained from the databases of international, national, regional and local institutions. Some of the reviewed documents include:

- Local government Act No. 2 of 2019
- National Disability Policy 2015
- National Gender Policy 2014
- National Decentralization Policy 2002
- United Nation Convention on the Rights of Persons with disabilities document
- Zambia's Seventh National Development Plan 2017-2021
- Zambian Disability Survey Report 2015
- Zambian Disability Act No. 6 of 2012

These documents were mainly used because they provide guidelines and regulations on how persons with disabilities ought to be involved in various decision making processes and enjoy their fundamental inherent rights and freedoms.

Entry point and gatekeepers

In order to have access to the research participants, the researcher went through Zambia Federation of Disability Organizations (ZAFOD). The Federation permitted the researcher to conduct the study under its umbrella. ZAFOD is the National Non-governmental umbrella/mother body of all the 12 existing Disabled People's Organizations (DPOs) in Zambia. Conducting the research under ZAFOD made it easy to have access to Disabled People's Organizations which have membership of targeted

women with disabilities. Undertaking the study under ZAFOD instilled confidence and trust in the researcher by the participants knowing that he was coming from their mother body organization. Being under Zambia Federation of Disability Organizations also made it easy for the researcher to engage and have access to other professionals from Lusaka City Council, Zambian National Association of Women with Disabilities, Association of Blind Women in Zambia and Zambia Agency for Persons with Disabilities.

Inclusion/Exclusion Criteria for participants

The criteria used to include participants in the study was based on a particular types of disabilities. Therefore, this study included only those women with different types of physical and sensory disabilities between the ages of 18 to 65 years old. These were women who have been certified by medical personnel in conjunction with Zambia Agency for Persons with Disabilities as having a permanent disability. These women were drawn from Disabled People's Organizations in Zambia with a possibility of being selected or appointed to participate in decision making structures because of their membership. Local politicians, professionals working for government and disability organizations were also included in order to capture their perspectives on the participation of women with disabilities in local government decision making structures. Their inclusion in the study was necessary because of their involvement in policy making, implementation and advocacy respectively.

Selection methods and sample size

This study employed the combination of purposive and snowball sampling methods. Purposive sampling which involves choosing participants who have certain qualities or experiences that would be essential for the research (Creswell, 2013), was used to recruit fourteen women with different types of physical and sensory disabilities. The age of interviewed participants ranged between 29 and 62 years old. Participants were purposively selected from different socio- economic statuses, residential areas, occupation, marital status and level of their education. Recruitment of women with

varied characteristics was done in order to obtain data on a wide range of experiences from which commonalities and differences would be identified if any. The recruitment of women with disabilities was done through local Disabled People's Organizations. Purposive sampling was appropriate and ensured that the selected women were relevant to the study ³ (Mason, 2018; Bryman, 2016; Creswell, 2013).

Snowball sampling was also used to complement purposive sampling for further identification of targeted participants. This helped in identifying more women with disabilities who had similar characteristics by using initial recruited participants (Bryman, 2016). After an interview, I would ask the participant to help me in identifying another potential participant who met the study criteria. The snowball sampling method helped me to identify more participants in shortest possible time and proved to be effective. It also made it easy for me to quickly win the confidence and trust of the participants after being referred to them by persons they knew. Two local politicians: councilors, two professionals working for the government and two officers from disabled people's organizations were equally recruited purposively and interviewed.

The sample size: fourteen women with disabilities, four professionals and two local politicians was feasible and sufficient enough for the six months allocated time for this qualitative study (Mason, 2018). The sample size allowed me to conduct an in-depth qualitative exploration which is usually time consuming and labor intensive if more sample is used (Adams, 2015). The study involved a detailed analysis and not necessarily generating a large amount of data hence the justification of the small sample size. The idea of having a small sample size in this qualitative study is also supported by various researchers such as Bryman (2017) Malterud, et al (2016) and Marshall et al (2013) who support using small samples especially in situations where the targeted participants are hard-to-reach, in this case women with disabilities.

³ See detailed information on purposive sampling in the Books by Creswell (2013) *Qualitative Inquiry and Research Design*. Page.154-156, Bryman (2016) *Social Research Methods*. Page 407-410 and Mason (2018) *Qualitative Researching*. Page 73-74.

Additionally, the reviewed studies discussed under literature review above also used small sample sizes which ranged from 10 to 30 participants.

Characteristics of participants

The interviewees consisted of fourteen women with a wide range of physical and sensory disabilities. Physical disabilities included paraplegia, muscular dystrophy and amputations whilst sensory disabilities included hearing and visual impairments. The age range was between 29 and 62 years old. These women were selected from various residential areas: Libala, Chilenje, Woodlands, Bauleni, Kanyama, Garden house, Matero, Kaunda Square, Kabwata, North mead, Kalingalinga and Mtendere. Many of these women acquired their disabilities before reaching the age of 10 years. The marital status of the interviewed women ranged from single, married, divorced and widowed. In terms of level of education, these women had varied levels of education ranging from primary, secondary and tertiary levels. These women were involved in various occupations which include: teaching, accounts, secretarial, administration, tailoring and other business ventures. Other women were not involved in any occupation and depended on family members and other people and institutions to meet their needs whilst others were still studying in colleges.

Data analysis

The analysis of the collected data on experiences of women with disabilities with regards to their participation in local government decision making structures was done using qualitative thematic analysis method. This method enabled me to identify, analyze and report the patterns (themes) which were generated from the collected data (Bryman, 2016; Braun and Clarke, 2006). I opted to analyze the data manually due to power outages and sluggish internet connectivity which posed a challenge in using a software. Considering that I had to analyze the data manually, I started transcribing the interviews the second day of my data collection activity. This enabled me to start identifying and categorizing the themes in the early stages of the interviews and further identification of new ones as I continued with interviews.

All the audio recorded interviews were transcribed into text verbatim using the actual language used during the interview. Those interviews conducted in local languages were later translated into English by a qualified translator. Data analysis began with a detailed review of each transcript while repeatedly listening to the recorded interview audio to ensure that nothing was missing in the transcribed text verbatim. The results were presented using text verbatim from transcribed audio interviews. Data collected through interviews and documents was presented and analyzed together.

Ethical considerations

Considering that this study was targeting one of the most vulnerable, sensitive and marginalized group in society, I had to ensure that they were protected from various psychological, social and physical risks (Mason, 2018; Bryman, 2016). I was mindful of the sensitive nature of the study and its anticipated potential impact on them. It was for this reason that the study was subjected to ethical scrutiny and review before it was finally approved. Therefore, this study was approved by the School of Social Work at Lund University through my supervisor and University of Zambia Humanities and Social Sciences Research Ethics Committee domiciled at the University of Zambia: *See appendix B*. The study ensured that ethical issues were given adequate attention in order to avoid any possible risks to the targeted study participants (Mason, 2018). Qualitative study approaches are mainly associated with various ethical boundaries which researchers ought to take into account throughout the research process (Weiss, 1998). This study adhered and upheld confidentiality, privacy and anonymity, informed consent and free will participation as explained in the subsequent sections:

Confidentiality and anonymity

All the collected data was kept and used for scholarly purposes only. All the information given by participants was not shared with other people except my supervisor and the examiner (Mason, 2018). All data was stored in a password encrypted files in my personal laptop with restricted access. I tried to make sure that interviews were conducted in the absence of other people. Nevertheless, there were

two incidences which compromised confidentiality after the participants requested to be interviewed in the presence their mother and the husband respectively. The identities of the women remained unknown throughout the whole research process (Bhattacharjee, 2012). I erased all the identifiers such as names and residential addresses from the transcripts to ensure that the identities of the participants remained unknown. I therefore adopted the use of *letters* during analysis and report writing.

Informed consent and voluntary participation

As emphasized by various research scholars (Mason, 2018; Bryman, 2016; Creswell, 2013) concerning the importance of informed consent and voluntary participation in any research undertaking, I provided both written and verbal information to the participants before conducting any interview: *See appendix C*. The information provided contained the aim of the study and the procedure of the interviews. I had to explain in local languages for those participants who do not understand English for them to understand before making a decision to participate in the study or not. This enabled them to make informed decisions voluntarily without being coerced (Bryman, 2016; Krumholz, 2010; Wiles et al, 2005).

Those who accepted to participate in the study were requested to sign the written statement before the interview: *See appendix D*. Considering that the study focused on women who could have been married or being taken care of by other family members, in certain situations informed consent was extended to relevant family members such as husbands and parents due to cultural, economic, social and power relations. There was one situation where the participant excused herself to go and seek consent from the husband who was taking some rest in the bedroom.

However, ethical decision making were ongoing and relational based on the issues which were encountered during the research process. I equally endeavored to avoid invoking the anticipated emotions, embarrassment and anxiety by being careful and avoiding the usage of derogatory, demeaning and sensitive words during interviews

(Mason, 2018).

Positionality and Reflexivity

Positionality refers to power and social relations between a researcher and the participants which may have influence on the research (D'Silva, 2016). He further notes that positionality can affect research outcomes and interpretations, because one's position within the social world influences the way in which you see it. In this study, my gender, socio-economic status and education could have affected my interaction with the participants which may unconsciously influence the research (Goar, 2008). Additionally, O'Brien (2011) explains that the issue of being an insider or outsider may influence the views of the participants and how researchers view their study participants. On the other hand, reflexivity refers to *the continuous process of self-reflection that researchers engage in to generate awareness about their actions, feelings and perceptions* (Darawsheh, 2014: 561). Therefore, this required me to be willing to consider how my background, personal values, perceptions and experiences may affect my observation and analysis.

Being male and studying a Master's Programme in Sweden automatically put me in a certain position which had the potential to influence my interaction with participants. In order to avoid being influenced by my position (male and researcher), personal values, perceptions and experiences, I endeavored to reflect on them throughout the whole research process (D'Silva, 2016). I tried to remain objective by detaching myself from being over empathetic and feeling pity for them as it is usually the case in the Zambian context. In this study, I was both an insider and outsider. I was an insider because I am a Zambian who is conversant with the socio-cultural context of the research place. Despite this posing a high risk of subjectivity (Chirwa, 2017), being an insider helped me to be accepted and interact with participants using local languages according to expected norms and values. Being a Zambian also helped me to reflect and avoid being influenced by values, norms, beliefs and perceptions of which I am part of. On the other hand, I was an outsider because I am male, a researcher and has no form of disability. In this case, I ensured that I respected the participants in a

dignified manner. I ensured that I dressed appropriately and used appropriate language (Myers and Newman, 2007) befitting the socio-cultural context.

Reliability and validity of the study

Reliability is the consistency of results produced by repeated measurements whereas validity refers to the extent the measurement measures the object that it intends to measure (Rossi et al, 2004). The two concepts are entrenched in positivist paradigm which makes them common in studies which are quantitative in nature. Nevertheless, reliability and validity can be applied to studies that are qualitative in nature like this one (Yin, 2003; de Vaus, 2001). In order to ensure the credibility and quality of this study, the explored variables were clearly highlighted from the onset. Furthermore, a variety of methods which follow a systematic process were used during data collection and analysis. Data was collected by using interviews (semi-structured) which followed a systematic approach and generated rich first-hand information. Data was also collected systematically by reviewing the peer reviewed articles and official and approved documents. These methods ensured the credibility of the study as they facilitated the cross checking of the data. Analysis was done by using thematic analysis which has steps to follow when analyzing the data.

Study limitations

Despite the overwhelming support received from different individuals and institutions, some limitations were encountered during the study. The time allocated to undertake the study was limited due to prior activities which needed to be done before commencement of data collection. As per requirement when undertaking a research in Zambia, the researcher had to apply for ethical clearance from Humanities and Social Sciences Research Ethics Committee at the University of Zambia. It took some time for ethical clearance to be approved which delayed the researcher to begin the data collection as planned. The response seeking permission to interview the Lusaka Mayor and Director planning took more than three weeks due bureaucratic processes. Follow ups were made every after two days and the researcher was eventually allocated other

officers to interview instead the intended Mayor and Director of Planning due to the fact that time was running out. Local politicians seemed to be busy and only ended up interviewing them on phone while recording the interview.

In order for the researcher to interview the participants with hearing impairments, there was need to engage the qualified sign language interpreter. Finding a sign language interpreter was a bit of a challenge. This limitation was cushioned by conducting the interviews in writing. Lack enough, the only participant with hearing impairment who was selected was educated and knew how to read and write without difficulties. The other limitation had to do with restricted movements imposed by the government in Lusaka City during the time of data collection. The restriction of movements was in accordance with the government's strategy to curb crime rate in the city where criminals would go round and spray harmful chemicals in people's homes. This instilled fear in people and made them feel uncomfortable seeing strange people in their respective communities. Undertaking the study under ZAFOD cushioned the limitation because participants gained confidence and trust in the researcher knowing that I was coming from the organization which represents their interests. Towards the end of data collection activity, Zambia reported few cases of Corona virus and restricted the movements further. The researcher opted to interview the few remaining participants via recorded phone interview.

The study was conducted in urban setting leaving out the rural setting. This entails that the study did not capture the views of women with disabilities in rural areas who could have slightly different experiences due to high poverty levels and inadequate provisions of services as compared to urban areas.

Chapter Six

Study findings and analysis

This chapter is divided into two sections. The first section focuses on the issue of gender and disability (intersectionality) as well as external environment (social model of disability) and how it affects the participation of women with disabilities. The second section focuses on the issue of participation through the theoretical lens of participatory development and existing legal and policy framework.

Intersectionality and the Social Model

The interviewed women were asked to identify their perceived obstacles which hinder them to participate in decision-making structures within their localities in view of feminist intersectionality and social model of disability underpinnings. The shared experiences by the interviewed women uncovered various categories of participation obstacles which include: negative attitude towards women and more specific women with disabilities, their poor financial status, practiced discriminatory traditional beliefs, physical environmental challenges such as inaccessibility to infrastructure and a limited social network as a result of stigma and discrimination.

Negative perception towards women with disabilities

The interviewed women felt having been often treated in a negative way by members of the society because of their gender coupled with a disability. People in their surroundings consider and treat them as women who are incapable of performing various activities in their own lives and that of communities where they live. A 36 year old woman highlighted how she felt being undervalued because of her gender and disability:

My gender makes people react badly towards me. This is even worse when the issue of my disability comes in. They see me as someone who can't do anything and less of a human being.

(Interviewee C).

The negative perception towards these women led to discriminatory and demeaning treatments from both family and community members which resulted in participation exclusion in decision making. Stigmatization and discrimination starts in the homes where these women are coming from. Family members considered these women as a burden and that they could not contribute anything to the well-being of the family. For instance, a 49 year old woman narrated how her husband and community members considered her to be incompetent of being involved in some activities and being a burden after losing her sight in 2006:

Being a woman and having a disability is a double tragedy. When I lost my sight, my husband told me to go back to my parents. His relatives equally told me to leave the house because according to them, I became a burden and could not manage to perform various duties as woman. Equally, I stopped receiving information on various community development activities where I used to participate. This situation depressed me for some time but I eventually managed to reorganize myself and thank God I am happy again. I proved them wrong because currently I do business and I am the one providing for the family.

(Interviewee H).

The expressed experience above demonstrates how intersectionality of gender and disability propagate oppression, stigmatization and discrimination (Collins, 2016). Family members who are expected to be in the forefront in promoting, protecting and defending the rights of these women in various spheres of their lives were the first ones to stigmatize and discriminate. These negative perceptions are further reinforced by members of the society who have no close relationship with the women. A similar experience was echoed by other interviewees among them a 42 year old woman. She felt being stigmatized because of being a woman who has a disability. She felt that people focused more on her gender and disability and not her capabilities to make sound decisions and perform certain activities:

Many people usually focus on my disability and gender before anything else. People in the community look down upon me and consider me as someone who cannot do or contribute positively to any developmental activity. I usually see my friends who are not disabled being involved in different activities including decision making but I have only been approached once in the last five years if I could attend a meeting organized in my community to discuss water problem issues.

(Interviewee A).

The views of interviewed women show that intersectionality of gender and disability is associated with inability and incapacitation in making sound decisions at individual, family and community level. The expressions resonate with the feminist intersectionality perspective which focuses on analyzing the experiences of individuals within the system of interlocking hierarchies or identities such as class, gender and disability and how these create multiple forms of discrimination, exclusion and oppression (Collins, 2016; Crenshaw, 1989). Having a low status in society concretized the negative perception towards women with disabilities and subsequent exclusion in decision making. The exclusion and discrimination is not mutually exclusive but rather based on multidimensional categories of gender and disability as well as their low social class in society. This combination disadvantages and subject these women to vicious cycle of poverty. Poverty make these women fall under low class status which is another stigmatized and excluded category of people in the Zambian society. This was highlighted by a 50 year old woman who felt that her low class status led to exclusion in decision making processes:

People in my community don't want me to be part of anything including decision making because I am considered as a 'nobody'. My low class status in society makes it worse such that they don't see anything worthy appreciating in me or as someone who has value. It is so heartbreaking where people consider you as a useless person just because I am a woman who has a disability

and struggling to earn a living.

(Interview F).

Negative perceptions towards women with disabilities lead to prejudices and stereotypes which in turn perpetuate and justify these discrimination and exclusion tendencies (Oliver, 2012). The negative attitude further instill the feeling of self-pity in these women which worsen the problem of exclusion from participating. Stigmatizing processes change the self-perceptions that the women have on themselves. They internalize these perceptions in an inferiority complex and get convinced being unworthy to be involved in decision making. For instance, a 29 year old woman expressed how she feels undeserving and unworthy to be part of decision making structures in her community:

Look at me, who can listen and take me serious even if I was to be involved in decision making? Let those who are better and knowledgeable make decisions for us. I am just fine being at home than going out there.

(Interviewee K).

The views on self-pity due to negative attitudes towards women was confirmed by the interviewed professional staff. The professional felt that negative attitudes towards the women with disabilities made them feel undeserving hence shunning away from participating in decision making processes:

Negative perception towards women with disabilities has created inner problem of self-pity. They feel they cannot do it because of their disability. I have observed that in many occasions they shun away from participating even when an opportunity is accorded to them due to low self-esteem. We have been trying to ensure that they are incorporated in decision making but we need first to get rid of the spirit of inferiority complex which is in them.

(Professional Staff 1).

The interviewed women also mentioned how members of society perceived and considered them as 'charity cases' and that they deserved to be assisted by others. This perception reinforced their vulnerable situation and further inhibited them from being productive members of society. Being considered as a charity cases entails that everything needed to be done for them including accessing certain essential resources and services. They are mostly confined in their homes. The attitude of those surrounding them shows that these women are not good enough to make productive and progressive decisions which can contribute to development initiatives. They are perceived as people who are passive and feeble minded. A 30 year old woman explained how she was considered as a charity case and not someone with mental capabilities with potential to make productive and sound decisions:

More often I am being considered as a person who should be decided for by others and just wait for things to be done on my behalf. This happens to me at home and out there when I go to access some services. I have no voice in issues which I feel are important to me as someone with a variety of requirements in life. It is very unfortunate and it feels really bad to be treated as a 'nobody' but just a receiver of either bad or good things. This mentality of treating us as charity cases is everywhere and even practiced by professionals who provide services to the public. I am mentally stable and even knowledgeable about many issues, why should someone perceive me as a charity case? It's so dehumanizing.

(Interviewee E).

However, some interviewed women felt that they were fairly treated by members of the society regardless of their gender and disability. These women have other resources and belong to the middle class. They had equally attained College and University education and had knowledge and better understanding of disability rights and fundamental democratic tenets. A 37 year old woman explained how she felt being treated fairly by family members as well as other people in society:

My family and members of the society treat me like any other human being. In few cases where I feel that someone is trying to take advantage of my disability and probably use a derogatory words I rebuke and sensitize them on disability issues for them to appreciate diversity. No one can take advantage of me because I know my rights and I will always ensure that my rights are respected by anyone including those in different authorities.

(Interviewee M).

The experiences of being stigmatized, discriminated against and excluded in various activities including participating in decision making structures because of negative perceptions are consistent with some of the localized studies by scholars from different disciplines. Studies by Adjei-Amoako (2014), Yoshida et al. (2014) Museva (2012), Shirin (2009) and Smith et al. (2004) demonstrate that persons with disabilities frequently encounter discrimination and exclusion in various spheres of their lives because of negative perception towards them by members of society including those working in public institutions. There is a strong negative perception on capabilities of persons with disabilities. However, this study went further to uncover how negative perceptions affect these women's self-esteem and confidence which was not the case in other aforementioned studies.

Poverty

The interviewed women indicated that their poor financial status hinder them from participating in established local decision making structures. Having financial constraints was attributed to low levels of education, unemployment and exclusion in various socio-economic empowerment programmes in comparison with other people. For instance, a 34 year old woman complained of being financially unstable due to lack of employment despite having qualifications as a secretary:

It is not easy for me to attend decision making meetings in my community because I have no transport money to use. The place where meetings are held

from needs one to use a vehicle. The little money I get from my small business of tailoring goes to buying food in the house. I am a qualified secretary but I have failed to find employment for me to have stable source of income. It is a challenge to be a woman with a disability because employers think that I can't perform to their expectations.

(Interviewee B).

The above expression shows that women with disabilities are discriminated in areas of employment and income generating ventures. The historical discriminatory attitude by employers make it difficult for the women to have stable and reliable income which can help them meet their various needs. Poor financial status contributed to challenges of being part of decision making processes. A 32 year old woman narrated how her poor financial status forced her to become and a dependent:

I have always wanted to attend meetings and be part of various activities which can bring about development within and outside this community but I can't because I need money for me to be able to do that. I don't have any source of income and I just depend on my mother who is also struggling to provide for the family. Now where do I get the money to go for meetings and register my views on a number of issues which affect me? It's not an easy thing.

(Interviewee J).

Interviewed women mentioned that most of the meetings called upon to plan and decide on various community development programmes and projects required them to meet their own transport costs. Transport costs were high especially that these women in some cases needed to go with someone to be helping them:

Whenever I want to go somewhere, I usually go with my cousin who helps me push the wheel chair. In that case I need money for two people to go for meetings, so where do I find the money to pay for two people when I can hardly

pay for myself without my cousin. I feel it's just even wasting money to go for such meetings because when I come back I need to eat again, so where do I find the money for all that?

(Interviewee L).

The interviewed women mentioned that most of decision making meetings such as those organized by Ward Development Committee never provide transport logistics for its members. Most of the members in these Ward Development Committees were community members who were struggling to meet their needs. On the other hand, it was revealed that decision making structures at the district level such as District Development Coordinating Committee, Constituency Development Fund Committee and District Disaster Management Committee which are mostly comprised of government workers and local councilors provide transport logistics during decision making meetings to the members. A 49 year old woman who has worked for government for nine (9) years observed that decision making meetings at community level were not supported financially whilst those at the district level were funded despite being comprised of people who are already paid by the government:

I have been working for the government for the past nine years and I have observed that most of the decision making meetings at the community level are not funded but those at district level receive funding. The unfortunate thing is that the members at the district level are civil servants who are already paid by the government but most members at the community level do not even work. This makes it worse for women with disabilities who are already bombarded with many challenges when it comes to attending such meetings due to financial constraints.

(Interviewee H).

The above expression on financial constraints affecting women with disabilities was in the same vein echoed by a Leader of Disabled People's Organization who explained

how difficult it was to provide transport money and other necessities for its members to go and represent women with disabilities in various decision making structures:

Our Association is struggling to survive and does not receive funding anymore yet we need to function and continue advocating for the rights of women with disabilities which includes the right to participation. Most of our members are struggling are very poor. They hardly manage to buy food. Due to this impoverished state, they fail to attend decision making meetings where our views are needed because we cannot afford to meet their transport costs. I have been trying within my personal means to provide transport but this is not sustainable, and as you may know most of our members are not employed hence they have no source of income.

(Disability staff 1).

The expressions of the interviewed women is evident enough that poverty which leads to their poor financial status affect their mobility. Having a disability and being financially constrained makes their mobility a bit more challenging than those who are able bodied. They cannot easily move from one place to another including attending decision making meetings. Their poor financial status cannot allow them to hire a taxi which is more convenient for them than public buses. One of the interviewed woman explained how taxis were conducive for her but unaffordable:

A taxi is more convenient and suitable for me than a public bus but it's very expensive. I can sit comfortably in a taxi because there is enough space and I can even park my wheel chair nicely but I have challenges with space in these minibuses. The only problem is that taxis are quite expensive and I can't afford.

(Interviewee G).

The above statement demonstrate some of the challenges associated to financial challenges which women with disabilities are grappling with on daily basis. Financial challenges are external to the body impairment and thereby becoming an obstacle

which affect a number of issues in the lives of the women including being actively involved in decision making. The social model of disability indicates how the existence of financial constraint in addition to the presence of already diagnosable condition hampers their effective participation. Maximum and effective participation can only be attained if they are financially able to meet transport costs and procurement of assistive devices which enhances their functionality.

The interviewed women further expressed concern over expensive assistive devices. It was discovered that most of assistive devices were unaffordable to these women. The assistive devices are crucial in supporting their mobility, reading and listening. The availability of these devices enhances their functionality and effective engagement in various discussions and deliberations. The government of the Republic of Zambia through the Ministry of Health is mandated to provide *appropriate assistive devices* to all persons with disabilities in accordance with the provisions of Persons with Disability Act No. 6 of 2012 clause 28 (1) (a) but this has not been the case. This situation force these women to assume the responsibility of acquiring the needed assistive devices which are being sold by private business companies at high prices. For instance, a 52 year old woman complained of how expensive assistive devices were for her to buy them:

I have challenges with mobility due to defective calipers and a wheel chair. Even if I want to go for a decision making meeting, the question is how do I get there without a wheel chair or calipers? These things are expensive, I need to spend about five thousand Zambian Kwacha (276 USD) to buy calipers and about one thousand Zambian Kwacha (55 USD) to buy a standard wheel chair, now where do I get that money? Its better I just stay home.

(Interviewee I).

Similarly, the interviewed professional staff explained on the issue of inability to purchase assistive devices by persons with disabilities due to inadequate or lack of financial resources. The professional staff indicated how difficult it was for persons with

disabilities to participate effectively in decision making due to expensive assistive devices:

Most of persons with disabilities have completely no source of income to enable them procure assistive devices. Some years back government used to provide these assistive devices but it stopped a long time ago. This has now been left in hands of persons with disabilities to buy for themselves. As you may be aware women with disabilities are very vulnerable and experiencing extreme poverty such that they can't afford procuring the assistive devices which they need for them to function optimally and actively participate in decision making processes.

(Professional staff 2).

Additionally, the interviewed women felt that they were financially constrained due to the fact that they were in many instances left out from accessing empowerment and social protection programmes such as women and citizen economic empowerment funds which can boost their financial status. The processes, procedures and eligibility criteria for most of empowerment programmes were discriminatory and segregated against women with disabilities. These women are vulnerable and do not have some of the requirements demanded by the empowerment programmes such as collateral in form of assets. These requirements contribute to their continued low financial situation. A 62 year old woman narrated how she was left out of empowerment programme because she did not meet the eligibility criteria of having an asset as collateral:

I hear of women empowerment programmes but I have never been considered for that. I hoped that if I receive something then I will be able to invest in tailoring business but that never happened. I wanted to apply for some funds so that I can boost my small business but I was told to provide collateral for me to be given the money. So I failed to access the funds because I don't have any

asset to provide to them apart from the good business idea which they can't accept on its own.

(Interviewee N).

Benefiting from empowerment and social protection programmes were associated with politics. Those who are actively involved in politics especially the ruling party benefited more from empowerment programmes than others. This disadvantages women with disabilities to benefit because they are mostly not active players in politics. For example, a 47 woman felt that empowerment programmes were highly political and accessible only to those with connections and affiliated to a ruling political party:

These empowerment programmes are political. Those in power give those whom they feel can contribute positively to their political party. Now, look at me, they do not see anything beneficial in me because I can't be of any help to their party hence the exclusion from the empowerment programmes.

(Interviewee B).

A study by Pinilla-Roncancio and Alkire (2017) conducted in 11 countries (Cambodia, Cameroon, Chad, Colombia, Dominican Republic, Ecuador, Egypt, Gambia, Mexico, Uganda and Yemen) produced similar findings. Their findings equally demonstrates that persons with disabilities find it difficult in obtaining optimum levels of income which causes additional indirect, direct and opportunity costs and characteristics that increase their vulnerability to become poor or chronically poor. However, there are variations in terms of the causes of poor financial status in these studies which range from low levels of education, unemployment and lack of access to empowerment funds like it is in the case of this study. Poverty, gender and disability are intersecting and leaving these women excluded from the contexts where they can influence their situations.

Discriminatory traditional beliefs

Interviewed women mentioned how frequently they were being excluded in social and economic activities because of long term standing discriminatory traditional beliefs. Traditional beliefs in Zambia have historically played a role in distinguishing the expected roles for men and women at the household and societal level. One woman explained how men were considered to be superior with vast experiences in life situations than women:

All men are considered to be powerful and superior with the ability to run the affairs of a home and national matters. Women are expected to take care of children at home, cook food for the family and inform the men of what is missing at home. We are not expected to question certain things. All we have to do is to submit to men and do what they tell us to do.

(Interviewee C).

These historical traditional beliefs have continued to be used to legitimize stigmatization and excluding practices towards women. Stigma is even worse when a woman has a disability. The beliefs perpetuate the oppression and exploitation of women especially those with disabilities. These traditional beliefs are blind to consideration of good ideas and opinions from women. Interviewed women expressed having been unable to participate in decision making structures owing to the fact that decision making was considered as a preserve for men not women. Traditionally, decision making at all levels in Zambia is dominated by males due to power relations and women are expected to be in the background. This was highlighted by a woman who felt that decision making was a preserve for men and not women:

I have always wanted to take part in decision making especially on issues which affect persons with disabilities in this community. Now you know how it is, I have to struggle if I want to participate because our culture demands that decision making should be done by men not women. Though things have

slightly changed over time, but the elements of these beliefs are still practiced to some extent.

(Interviewee G).

The cause of disability is traditionally justified by a belief that anyone with a disability has a curse or being punishment for having done something against the tradition. This traditional belief make it even worse for women who are discriminated because of being women. The expressed views from the interviewees demonstrate how society consider them to be unworthy in any undertaking. A 37 year old woman shared how her family members and the community at large stigmatized and discriminated against her on the assumption that her disability was as a result of being bewitched by someone because of her late father's misconduct:

I don't have a voice in anything here at home and out there in the community. People believe that am cursed because of my disability which they believe was caused by the misconduct of my late father. The tag of being cursed and especially that am a woman makes my life difficult. I can't make any decision of my own but my uncle does for me. I am not allowed to even go out there in the community because my family may feel embarrassed if am seen by others out there.

(Interviewee M).

The above expressed view validates the feminist intersectionality perspective in that the obstacle to participate in decision making are justified by traditional beliefs with particular focus on gender as well as the cause of disability which reinforces stigma and exclusion. The experiences of these women are also in conformity with the social model of disability which asserts that prejudices that use traditional belief systems as arguments exclude women from decision making structures. It is evidenced through the experiences of interviewed women that traditional beliefs can hinder women with

disabilities to enjoy their fundamental rights and freedoms, and to participate in society and development on an equal basis with others.

Inaccessibility to infrastructure

Inaccessible infrastructure is another concrete obstacle to participation. The views of women show that most of the buildings were inaccessible to persons with disabilities to attending meetings and accessing various social services. A 58 year old woman expressed how she struggled to enter the venue for the meeting which was called upon to deliberate on distribution of relief food in her community:

My nephew pushed me on a wheel chair from here up to the nearby school which was the venue for the meeting. Upon reaching there, we discovered that there were only stairs which were a bit high and my wheel chair could not pass through. My nephew could not lift me together with the wheel chair. It had to take one of the people who came to attend the meeting to assist my nephew in lifting me to finally enter the room where the meeting was held. That was the last meeting I attended and never went back due to that humiliating experience. That is being inconsiderate.

(Interviewee D).

The interviewed women, professionals and disability advocates acknowledged that most of the buildings were inaccessible due to lack of ramps, hand rails and lifts which can be easily used to access a building. These inaccessible buildings act as external environmental barriers that are more pernicious impediments to involvement of persons with disabilities in many areas of life (Dirth and Branscombe, 2017; Oliver, 1993). The architectural design of some buildings in Lusaka hinder persons with disabilities to go in, worse still for those who are using wheel chairs and clutches. A concern was raised by a 30 year old woman who encountered challenges in accessing the premises of local authority offices on several occasions due to lack of ramps and the lift:

You know what! On four different times I failed to go in the premises of local authority offices. I went there to air my views on how us women with disabilities have been neglected and left out in community activities which equally concern us. The particular office I intended to visit is on the second floor and there are no ramps at the entrance and even when you get to go through up to the reception, again there is no lift to take you to the second floor. The lift has not been working for some years now. There are times when I have been invited for meetings but I just decide to stay home because of the challenges I go through.

(Interviewee E).

The above statement was attested by the professional staff. The professional staff acknowledged the absence of ramps and lifts in many public buildings including some of local authority offices:

Yes, it is true that some buildings in Lusaka are inaccessible to persons with disabilities. This for sure pose a challenge for them to access certain services they need including attending meetings where they can possibly register their ideas and concerns. Nevertheless, the Planning Department is doing its level best to ensure that all approved buildings to be constructed take into account issues to do with provisions of ramps and lifts. As for local authority offices, something is being done already to ensure that the premises and offices are accessible to persons with disabilities through provision of ramps and lifts.

(Professional staff 2).

Decision making meetings in various communities and central business center are usually held in buildings which are inaccessible to persons with disabilities. It is therefore imperative to remove the environmental barriers by ensuring that all buildings are accessible through provision of ramps, hand rails and lifts so that persons with disabilities can have equal opportunities to participate in issues which affect them by being part of decision making structures.

Interviewees further indicated how more elementary infrastructure such as toilets were also difficult to access in public buildings. The design of toilets discriminate against certain types of disabilities especially those who need some kind of support when using them. This was clear from the response given by a 42 year old woman who went to attend the meeting and later decided to use the toilet:

I really suffered to use the toilet because it was too high for me since and I had left the wheel chair outside because the door was too small. I crawled to the toilet pan but failed to sit on it due to height and lack of hand rails. I had to call someone who was nearby to come and help me. Imagine such kind of embarrassment, it is so discouraging.

(Interviewee A).

Inaccessibility to infrastructure was not only limited to public buildings but also the roads and presentation formats of information. Interviewed women mentioned that most of the designs of roads had no provisions where persons with disabilities using wheelchairs can freely move without being disturbed. Persons with disabilities are forced to share the roads with motorists which is not safe for them and poses a danger to their lives. This was highlighted by one of the interviewed woman:

There are times when I would want to go and attend meetings but it is tricky for me because I fear for my life sharing the roads with motorists. These roads have no provisions for us who are bound to wheel chairs. The authorities responsible for construction of roads do not consider the safety of us who are using wheel chairs.

(Interviewee N).

Equally the format in which information was presented was inappropriate for those who are visually impaired thereby exacerbating their exclusion from actively participating in decision making processes. The interviewed women indicated that information pertaining to development issues was rarely provided in braille thereby

making it a difficult for visually impaired people to have access to information which can enable them to be well informed and contribute positively and effectively in decision making processes. All these views from women resonate with social model of disability which locates disability in external environmental factors rather than diagnosed body impairment.

The findings on inaccessible infrastructure have some similarities with the findings of the studies carried out by Adjei-Amoako (2014) in Ghana, Mutoloki (2012) in Zambia and the European Union (2009) in the 27 EU Member States, three EEA Members and three EU Candidate Countries. The three aforementioned studies show that inaccessible infrastructure such as buildings and roads made it difficult for disabled people to have access to various essential services. However, the degree of inaccessibility prevailing in Zambia cannot be compared to that of European Countries where issues of accessibility are intensified and incorporated in robust legal provisions.

Limited Social Network

Social network has proved to be an effective way of interacting with people and have access to information on various issues. Interviewed women indicated that they had few friends within and outside their residential areas. There were only few people they could easily interact with and share information on various issues. The limited social network is as a result of stigma from people. People do not want to associate themselves with persons with disabilities as they do not expect any favor or help from them. One interviewed woman said that:

People feel that I have nothing to offer them so they would not waste their time associating with someone whom they think is of no help. They would want to associate with those who are mobile and go out for social events.

(Interviewee A).

Stigma makes women with disabilities to be confined in their homes which in turn affects their friendship with other and creation of big and dependable social network.

They felt being indoors was the best option for fear of being ridiculed and embarrassed by others. Their confinement limit them to have access to information on various issues including participation and other activities in their localities. For instance, a 53 year old woman explained how she never received information pertaining to local government decision making structures and other development related issues:

Most of the times I am just at home. I have few people I interact with so I rarely receive information on what is happening in this community in as far as decision making issues are concerned. The few friends I have are from church and we don't meet much often and even when we meet we only talk about church issues. So in short I don't receive information on what is going on around here otherwise I would have taken keen interest to be part of such decision making processes.

(Interviewee L).

Another interviewed woman similarly shared how her disability makes it difficult for her to have access to information:

My disability hinders me to build a good social network where I can easily be informed on certain issues. Even the small number of friends I have don't share information regularly. Quite alright I read about these things on social media but when it comes to actual dates of formation and selection of members for such decision making structures I don't receive that information.

(Interviewee A).

The above expressed views on limited access to information due to limited social network was attested by the local politician (councilor):

You know we share information on various development issues through different channels such as emails, whatsapp and community representatives. So you will find that our friends (women with disabilities) do not belong to these

communication groups thereby missing a number of development activities which are taking place. However, as a Ward Councilor I have been trying to ensure that all stakeholders including women with disabilities receive information on all development activities in this Ward.

(Ward Councilor).

Better social networks are better placed to influence the authorities. Limited social network leave these women uninformed and having scant knowledge on various issues which are key in decision making processes. This situation perpetuate their vulnerable situations of being unable to access certain essential services and resources which are key in improving their living standards.

Participatory Development Perspective

This section focuses on the question of 'participation possibilities' which are created by existing policy and legal framework in the Zambian context. The findings are presented and analyzed in line with participatory development theoretical perspective. The section begins by looking at the existing legal and policy framework. This is followed by presentation and analysis of the views shared by both the professionals and the interviewed women pertaining participation opportunities.

Legal and Policy Framework

Legal and policy framework emerged as the main theme when a question was asked on some of the existing possibilities for women with disabilities to participate in local decision making structures. Zambia has different pieces of legislation and policies which are aimed at promoting and enhancing the participation of persons with disabilities in decision making processes as highlighted in chapter two. For instance, the Persons with Disability Act No. 6 of 2012 has clear provisions pertaining to issues of participation by persons with disabilities. Article 20 (2) (e) of the Act promotes the participation by making sure that policy measures are ensuring representation of persons with disabilities in all national and local decision-making positions. Article 21

(2) (c) further specifies the need for women to participate in decision making by ensuring that women with disabilities have equal opportunities to participate in all aspects of life and to ensure the full development, advancement and empowerment of women with disabilities.

All the provisions of the Persons with Disability Act have been incorporated in various development agendas such as Seventh National Development Plan 2017-2021 and Vision 2030. It is evident that these legal and policy provisions provide participation opportunities for women with disabilities at various levels which include national and local decision-making structures. The provisions of the existing legal and policy framework are reflected in the participatory development theoretical perspective which asserts that local people and vulnerable groups need to be involved when planning and deciding on various development programmes and projects which concern them (Chambers, 2008).

Professionals and Politicians' Perspective on Participation

The interviewed professionals and politicians were of the view that the existence of the Persons with Disability Act and other related policies such as Disability, Gender and Decentralization policies provide possibilities for women with disabilities to be part of decision-making structures in their respective communities. The Act as well as policies provide guidance on how disability and gender issues should be mainstreamed in different development initiatives at local and national level. Development plans should be products of various concerns from all stakeholders including those groups that are commonly outside government institutions. One of the interviewed professional staff felt that there were adequate legal and policy framework in place which aimed at enhancing participation for persons with disabilities in decision making processes in the country:

In general, we have a good laws and policies in place aimed at promoting participation in decision making processes for disabled people in our country. We have both a policy and an Act with progressive provisions in support of

considering disabled people in decision making at all levels of governance system. All these provisions are gradually being considered by different institutions and ministries. I feel these policies together with Persons with Disability Act provide a great opportunity for disabled people to participate in decision-making.

(Professional staff 1).

The availability of legal and policy framework to support the participation of women with disabilities in local government decision making structures was echoed by a local politician who felt that different policies were in place to ensure that participation was promoted and enhanced:

The combination of Disability, Local government Act and Gender policy provide enough opportunities for women and persons with disabilities to be part of decision making structures. This is also in line with vision 2030 whose objective is never to leave anyone behind. The local government has made sure that decision making structures such as Ward Development Committees are formed and functioning in all the 33 Wards in Lusaka.

(Ward councilor).

However, the interviewed professionals equally acknowledged that gaps existed when it comes to implementation of the provisions of the law and policies: one interviewed professional from disability movement mentioned some of the gaps which existed in as far as participation is concerned regardless of having a good legal and policy framework in place:

Despite having the adequate laws and policies on paper, gaps exist on the ground in terms of implementation. There are many reasons causing this and one of them has to do with inadequate funding by government to ensure that these provisions are implemented according to the provisions of the law and

policy guidelines. Lack of funding affect the realization of existing participation opportunities for women with disabilities.

(Disability staff 2).

Another interviewed professional echoed the above narration and indicated that structures such as Ward Development Committees were established in all the communities but these needed financial resources for them to be fully functional and incorporate all the stakeholders:

All the necessary participation structures have been formed and existing in all the communities in Lusaka district but we need resources for them to function properly and ensure that all groups are represented in these decision making structures. Our desire is that each and every group should be represented in these structures so that we can real issues to address as a nation originating from the ground.

(Professional staff 2).

The views by those interviewed demonstrate that having a good legal and policy framework in place does not guaranteed actual realization of their provisions. There is need to ensure that all the necessary requirements are in place in order to achieve the desired results of involving person with disabilities in decision making structures. Lack of funding to the decision making structures perpetuate the exclusion of women with disabilities which is against participatory development perspective which asserts that actual needs of the people can best be met if actual people who feel the need are part of decision-making process so that they can register their concerns (Chambers, 2008; Greenwood and Levin 2007).

Views of women with disabilities on participation possibilities

The views from interviewed women show that there were possibilities for them to participate in established local decision making structures. They frequently cited the

existence of Persons with Disability Act as the means to their inclusion in existing decision-making structures. A 58 year old woman explained how possible it was for her to participate in decision making structures because of support from certain provisions enshrined in the Disability Act:

For sure I know there are opportunities for me and other persons with disabilities to participate in established decision making structures because of the Act which is in favor of our involvement in decision making. So even if authorities may not want us to participate but the Act which is law forces them to find ways and means of including us. They have no option but to adhere to the provisions therein.

(Interviewee D).

The above statement was echoed by a 49 year old woman who believed that the government had done a good job by enacting the law:

I know I can participate because the government has come up with the law which is supporting my participation. Even the local government Act provides for inclusion of a person with a disability in Ward Development Committees. So this means that as people with disabilities we have opportunities to take part in decision making as provided by the law.

(Interviewee H).

However, interviewed women also felt that the possibilities of participating as a result of the existing legal and policy framework were not yielding positive results. They felt that all these were just politics at play. This can be demonstrated by complaints expressed by interviewee:

These politicians are playing with our minds. A good law has been enacted but where is the money so that we see the results and goodness of the law. This is not fair to persons with disabilities because we also need our voices to be heard

by participating in issues which affect us. Why coming up with a law which they can't implement? It doesn't make sense at all.

(Interviewee M).

The above complaint was similarly expressed by other women among them a 62 year old woman:

What is the purpose of having policies and laws which are not working? Yes I have an opportunity to participate in decision-making but that comes with many things. These politicians are just allocating resources where they are benefiting and have continued making decisions on our behalf. Our rights to participation are not respected.

(Interviewee N).

Participation opportunities can only yield intended results if it is followed with allocation of resources to strengthen the participation strategies and mechanisms. This study shows that the formal structures do exist, however, other obstacles have to be overcome. These existing formal structures have to be accompanied by concrete measures that facilitate the mobility of these women and that also show them respect as human beings with inherent dignity and human rights. Lack of resource allocation to decision making structures is an institutional discrimination which leads to exclusion of these women in decision making processes.

Chapter Seven

Study summary, conclusions and recommendations

The study sought to explore the participation experiences of women with disabilities in established local government decision making structures in Lusaka, Zambia. Three research questions were asked in order to have a better understanding of experiences women with disabilities have in light of participation in decision making structures in their localities. The focus was on understanding the existing participation obstacles, and participation opportunities created by legal and policy framework.

The study was anchored on three adopted theoretical perspectives: feminist intersectionality, social model of disability and participatory development. Feminist intersectionality provided a lens in understanding how the intersection of gender and disability affect participation whilst social model of disability provided an understanding of how external factors (environmental and attitudinal) hinder the participation in decision making. Further, participatory development perspective provided an insight on the necessity of participation in decision making by various stakeholders and the role of government to ensure that all groups are represented in decision making processes.

The study adopted qualitative design which captures in-depth understanding of people's perceptions and experiences in life. Qualitative methods of data collection were used. Fourteen women with different types of physical and sensory disabilities, local politicians (councilors), professionals and leaders from Disability People Organizations were purposively selected and interviewed through semi-structured interviews. Documents provided information on the contexts of gender, class, disability, legal and policy framework and the socio-cultural and economic situation in Zambia.

The results show that women with disabilities encounter various obstacles with regards to participation in local government decision making structures. The emerged categories of participation obstacles following the responses from the interviewees

include: negative perception towards women with disabilities, poverty, discriminatory traditional beliefs, inaccessibility to infrastructures and limited social network. However, the results also demonstrated that there were participation opportunities which are provided by legal and policy framework. Nevertheless, the legal provisions and policy guidelines have not yielded intended results of including persons with disabilities in decision making structures due to lack of other necessities such accessible public infrastructures and financial resources which are crucial in strengthening and actualizing the implementation of participation strategies.

Conclusions

The findings of this study have unraveled various obstacles that have been affecting women with disabilities with respect to participation in decision making in established structures within their communities. The obstacles emanate from socio-cultural, economic, political and institutional/structural arrangements. These obstacles have a negative effect on achieving a good governance and sustainable development aimed at reducing poverty among various vulnerable groups including women with disabilities. The tenets of good democracy and respect for human rights for women with disabilities can be best achieved by ensuring that they are effectively involved in decision making so that their actual needs can be presented and addressed as they are. This can lead to their improved and enhanced general well-being. It is evident that the experiences of women with disabilities are similar but there is a difference on how they get affected because of different types of disabilities. The commonalities converge because of gender and disability stigmatization, discrimination and stereotype in both daily and public lives contexts. The challenges encountered by women with disabilities are multifaceted and need a holistic approach in order to ensure that they have equitable access to social services and essential resources which are key in improving their well-being.

Recommendations

The findings of the study have revealed some gaps in the area of participation in local government decision making processes. The findings uncovered certain factors that have been impeding the effective participation of women with disabilities. In view of the findings, this thesis makes the following recommendations:

- Policy makers should devise deliberate participation measures which will allow women with disabilities to have specific slots in local decision making structures.
- The government of the Republic of Zambia through the Ministry of Health should consider allocating resources which will be used to purchase the assistive devices for persons with disabilities.
- Information dissemination should be presented in appropriate formats including braille so that those who are visually impaired can easily have access to information.
- The government should consider allocating resources under Zambia Agency for persons with disabilities for conducting accessibility audit for public buildings and making necessary adjustments.
- There is need to fund local government decision making committee meetings so as to ensure that even those who are financially constrained can be attending the meetings.
- Government and other stakeholders should consider coming up with empowerment programmes for women with disabilities.
- Different stakeholders should continue sensitizing the public on disability issues

Bibliography

- Adams, W. (2015). *Conducting Semi-Structured Interviews*. 10.1002/9781119171386.ch19.
- Adjei-Amoako, Y. (2014) 'Experiences of disability and inclusive development in Ghana : facilitating factors and barriers to participation'. Available at: <https://search.ebscohost.com/login.aspx?direct=true&db=edsndl&AN=edsndl.oai.union.ndltd.org.bl.uk.oai.ethos.bl.uk.657597&site=eds-live&scope=site> [Accessed: 22 January 2020].
- Barnes, C. and Mercer, G. (2005). Disability, work, and welfare challenging the social exclusion of disabled people. *Work, Employment & Society*, 19(3), 527–545.
- Bhattacharjee, A. (2012). *Social Science Research: Principles, Methods, and Practices*. Available at: https://scholarcommons.usf.edu/cgi/viewcontent.cgi?article=1002&context=oa_textbooks [Accessed: 30 December 2020].
- Braun, V. and Clarke, V. (2006), 'Using thematic analysis in psychology', *Qualitative Research in Psychology*, 3(2), pp. 77–101. doi: 10.1191/1478088706qp063oa.
- Bryman, A. (2016) *Social research methods*. Oxford: Oxford University Press.
- Central Statistics Office (2018). *Zambia in figures*. [Online]. Available at: <http://www.zamstats.gov.zm/phocadownload/Dissemination/Zambia%20in%20Figure%202018.pdf> [Accessed: 20 December 2019].
- Central Statistics Office (2018). *Zambia National Disability Survey 2015*. [Online]. Available at: <https://www.mcsw.gov.zm/wp-content/uploads/2018/01/Zambia-Disability-Survey-2015.pdf> [Accessed: 3 December 2019].
- Central Statistics Office, (2015). Living Conditions Monitoring Survey Report. Available at:

https://www.zamstats.gov.zm/phocadownload/Living_Conditions/2015%20Living_Conditions%20Monitoring%20Survey%20Report.pdf [Accessed: 7 January 2020]

Central Statistics Office (2010). Zambia 2010 Census of Population and Housing. Available at: <https://unstats.un.org/unsd/demographic-social/census/documents/Zambia/PreliminaryReport.pdf> [Accessed: 7 December 2019].

Chambers, R. (2008). *Revolutions in development inquiry*. London; Sterling, VA : Earthscan.

Chapman, A. R. and Carbonetti, B. (2011) 'Human rights protections for vulnerable and disadvantaged groups : the contributions of the UN Committee on Economic, Social and Cultural Rights', *Human Rights Quarterly*, 33(3).

Chirwa, M. (2017) *Experiences of Parenting Children with Disabilities*. A Qualitative Study on the Perspectives of Mothers of Children with Disabilities in Zambia. Available at: <https://core.ac.uk/download/pdf/157620208.pdf>. [Accessed: 28 January 2020].

Collins, P. H. and Bilge, S. (2016) *Intersectionality*. Cambridge: Malden, MA: Polity press.

Cornwall, A. (2000). Beneficiary, consumer, citizen: perspectives on participation for poverty reduction, Sida.

Crenshaw, K. (1989). Demarginalizing the intersection of race and sex: A black feminist critique of antidiscrimination doctrine, feminist theory, and antiracist politics. *University of Chicago Legal Forum*, 1989(8), 139–168.

Creswell, J. W. (2013). *Qualitative inquiry and research design : choosing among five approaches*. Thousand Oaks: SAGE Publications.

- Darawsheh, W. (2014) 'Reflexivity in research: Promoting rigour, reliability and validity in qualitative research', *International Journal of Therapy & Rehabilitation*, 21(12), pp. 560–568.
- De Vaus, D. A. (2001). *Research Design in Social Research*. London: Sage Publications.
- Dirth, T. P. and Branscombe, N. R. (2017) 'Disability Models Affect Disability Policy Support through Awareness of Structural Discrimination', *Journal of Social Issues*, 73(2), pp. 413–442. doi: 10.1111/josi.12224.
- D'Silva, M. U. *et al.* (2016) 'Reflexivity and Positionality in Researching African-American Communities: Lessons from the Field', *Intercultural Communication Studies*, 25(1), pp. 94–109.
- Eide, A. H. and Loed, M. E., (2012). *Living conditions among people with activity limitations in Zambia* (National Representative Study) Oslo: SINTEF.
- Emmett, T. and Alant, E. (2006) 'Women & Disability: Exploring the Interface of Multiple Disadvantage', *Development Southern Africa*, 23(4), pp. 445–460. doi: 10.1080/03768350600927144.
- European Commission (2009). *Study on the situation of women with disabilities in light of the UN Convention for the Rights of Persons with Disabilities* (VC/2007/317). Birmingham, Vincent house.
- Flower, J. and Wirz, S. (2000) 'Rhetoric or reality? The participation of disabled people in NGO planning', *Health Policy & Planning*, 15(2), pp. 177–185. doi: heapol/15.2.177.
- Gimbel, E. W. (2016). Interpretation and objectivity: a gadamerian re-evaluation of max weber's social science. *Political Research Quarterly*, 69(1), pp. 72-82.
- Goar, C. (2008). Experiments in black and white: Power and privilege in experimental methodology: In Tukufu Zuberi & Eduardo Bonilla-Silva (Eds.), *White logic*,

white methods: Racism and methodology (pp. 153-162). Lanham, MD: Rowman and Littlefield Publishers.

Government Republic of Zambia (2019). Local Government Act No. 2 of 2019. Available at:
<http://www.parliament.gov.zm/sites/default/files/documents/acts/The%20Local%20Government%20Act%20No.%202%20of%20%202019.pdf> [Accessed: 30 November 2020].

Government Republic of Zambia (2018). The Constituency Development Fund Act No. 11 of 2018. Available at: <http://www.parliament.gov.zm/node/7851> [Accessed: 2 December 2019].

Government Republic of Zambia (2017), National Disability Implementation Strategic Plan 2017-2021. Available at:
https://www.un.org/development/desa/disabilities/wpcontent/uploads/sites/15/2019/10/Zambia_DISABILITY-STRATEGIC-PLAN-2017-2021.pdf [Accessed: 24 January 2020].

Government Republic of Zambia (2015). National Disability Policy: *Empowering Persons with Disabilities*. Lusaka: Ministry of Community Development and Social Services.

Government Republic of Zambia (2012). *Persons with Disabilities Act No.6 of 2012*. Available at:
<http://www.parliament.gov.zm/sites/default/files/documents/acts/The%20Persons%20with%20disabilities%20act%2C%202012.PDF> [Accessed: 15 November 2019].

Government Republic of Zambia (2006). Vision 2030. *A prosperous Middle-income Nation By 2030*. Available at: https://www.mndp.gov.zm/?wpfb_dl=89. [Accessed: 27 February, 2020].

Government Republic of Zambia (2002). The National Decentralization Policy: "Towards empowering the people". Available at: https://thereddesk.org/sites/default/files/zambia_national_decentralisation_policy_1.pdf [Accessed: 10 December 2019].

Greenwood, D. J. and Levin, M. (2007). *Introduction to action research: social research for social change*. (2nd. ed.). Thousand Oaks, London: SAGE.

Gutmann, A. and Thompson, D.F. (2004). *Why Deliberative Democracy?* Princeton: Princeton University Press.

Hogan, S. (2013). *Understanding Discourse Analysis?* Paper Produced for Doctor of Practice Students. Academia.edu.

International Labor Organization (2013) *Women with Disabilities-Focus on: Disabled Women Entrepreneurs in Zambia*. Available at: https://www.ilo.org/wcmsp5/groups/public/---africa/---ro-addis_ababa/---ilo-lusaka/documents/publication/wcms_313411.pdf [Accessed: 16 November 2019].

Justin, A. H. and Samuel, H. (2016). Disability Discourse: Overview and Critiques of the Medical and Social Models, *Quest*, 68:2, 193-206, DOI: 10.1080/00336297.2016.1143849.

Kalinda, R. and Chirwa, M. (2015). Women's Participation in key decision making institutions in Zambia: Case of three arms of government: Legislature, Executive and The Judiciary. *Journal of Societal and Cultural Research*, 1(3), 128-137.

Keith, L. (1992). Who cares wins? Women, caring and disability. *Disability, Handicap and Society*, 7(2), 167-175. <http://doi.org/10.1080/02674649266780191>.

Key, P.J. (1997) *Research Design in Occupational Education*. San Francisco: Oklahoma State University. Available at:

<http://www.okstate.edu/ag/agedcm4h/academic/aged5980a/5980/newpage21.htm>. [Accessed: 12 January 2020]

- Krumholz, H. M. (2010). Informed Consent to Promote Patient-Centered Care. *JAMA Internal Medicine*, 303(12), pp.1190-1191.
- Leavy, P. (2017). *Research Design: Quantitative, Qualitative, Mixed Methods, Arts-Based, and Community-Based Participatory Research Approaches*. New York: The Guilford Press.
- Lewis, C. (2004), *Microfinance from the point of view of women with disabilities: lessons from Zambia and Zimbabwe*. Available at: http://web.worldbank.org/archive/website01030/WEB/IMAGES/CINDY_LE.PDF [Accessed: 27 November 2019].
- Livneh, H., Chan, F. and Kaya, C. (2014) 'Stigma related to physical and sensory disabilities', in Corrigan, P. W. (ed.). *The stigma of disease and disability: Understanding causes and overcoming injustices*. Washington, DC: American Psychological Association, pp. 93–120. Doi: 10.1037/14297-006.
- Lorella T. (2004). The Social Model of Disability: A Philosophical Critique', *Journal of Applied Philosophy*, 21(2), p. 141.
- Lykke, N. (2010) *Feminist Studies: A Guide to Intersectional Theory, Methodology and Writing*. Routledge advances in feminist studies and intersectionality; 1. London: Routledge.
- Malterud, K., Siersma, V. D. and Guassora, A. D. (2016). Sample size in qualitative interview studies: guided by information power. *Qualitative Health Research*, 26(13), pp.1753-1760.
- Marshall, B. et al (2013). Does sample size matter in qualitative research? A review of qualitative interviews in IS research. *Journal of Computer Information Systems*, 54(1), pp.11-22.

- Mason, J. (2018) *Qualitative researching*. (3rd.ed.). Los Angeles: Sage Publications Ltd.
- Ministry of National Development Planning (2017), *Seventh National Development Plan 2017-2021*. Available at: <http://extwprlegs1.fao.org/docs/pdf/zam170109.pdf> [Accessed: 25 February 2020].
- Ministry of Gender and Child Development (2014). *Natiobal Gender Policy 2014*. Available at: <http://extwprlegs1.fao.org/docs/pdf/zam152916.pdf> [Accessed: 15 December 2019].
- Ministry of Health (2012). National Health Policy: '*A Nation of Healthy and Productive People*'. Available at: <http://dspace.unza.zm/handle/123456789/5116> [Accessed: 22 December, 2019].
- Ministry of Education (2008). National Policy on Education: '*Educating Our Future*'. Lusaka: Institutional Suppliers Limited.
- Morris, J. (1993). Feminism and disability. *Feminist Review*, 43, 57–70. <http://doi.org/10.2307/1395069>.
- Museva, L. (2012). *The Level of Participation of Women with Disabilities in Economic Empowerment Programmes in Gweru District*. Available at: <https://pdfs.semanticscholar.org/5f84/8ec23f7fbc4e1f1ea026a9dc7ac1e4397b2c.pdf> [Accessed: 18 November 2019].
- Mutoloki, T. N. E. (2012). *A study of socio-cultural barriers and human rights of women with disabilities in Livingstone and Kazungula districts of Zambia*. <https://nmbu.brage.unit.no/nmbuxmlui/bitstream/handle/11250/187818/14.05.12%20Final%20master%20thesis.pdf?sequence=1&isAllowed=y> [Accessed: 12 January 2020].

- Myers, M. D. and Newman, M. (2007). 'The qualitative interview in IS research: Examining the craft', *Information and Organization*, 17(1), pp. 2–26. doi: 10.1016/j.infoandorg.2006.11.001.
- Noyoo, N. (2000). *Social Welfare in Zambia*. Lusaka: Multimedia.
- O'Brien, E. (2011). The transformation of the role of "race" in the qualitative interview: Not if race matters, but how? In John, H. Stanfield, II (Ed.), *Rethinking race and ethnicity in research methods* (pp. 67-93). Walnut Creek, CA: Left Coast Press.
- Oliver, M. (1990). *The Politics of Disablement. Critical texts in Social Work and the Welfare State*. London: McMillan Press.
- Oliver, M. et al (2012). *Social work with disabled people*. (4th.ed.). New York: Palgrave Macmillan.
- Pernecky, T. (2016). *Epistemology and metaphysics for qualitative research*. London: SAGE.
- Pinilla-Roncancio, M. and Alkire, S. (2017). 'How poor are people with disabilities around the globe? A multidimensional perspective.' *OPHI Research in Progress* 48a, University of Oxford.
- Porta, D. D. and Keating, M. (2008). How many approaches in the social sciences? An epistemological introduction. In D. D. Porta, & M. Keating, *Approaches and Methodologies in the Social Sciences: A Pluralist Perspective* (pp. 19-39). New York: Cambridge University Press.
- Prior, L. (2003). *Using Documents in Social Research*. London: SAGE Publications.
- Rossi, P. H. et al (7th Ed.) (2004). *Evaluation : a systematic approach*. London:Thousand Oaks, CA Sage.
- Rifkin, S.B. and Pridmore, P. (2001). *Partners in Planning: information, participation and empowerment*. London and Oxford: Macmillan/TALC

- Sépulchre, M. et al (2018). Gendering Active Citizenship: Experiences of women with disabilities. In: Halvorsen, R. et al, (Ed). *Understanding the lived experiences of persons with disabilities in nine countries*, (pp 156-173). New York: Routledge.
- Shirin. K, (2009). *Women with disabilities in the North West province of Cameroon: resilient and deserving of greater attention*. *Disability & Society*, 24:4, 517-531, DOI:10.1080/09687590902879205.
- Smith, E. *et al.* (2004) 'Barriers to Accessing Safe Motherhood & Reproductive Health Services: The Situation of Women with Disabilities in Lusaka, Zambia', *Disability & Rehabilitation*, 26:2, 121-127, DOI: [10.1080/09638280310001629651](https://doi.org/10.1080/09638280310001629651)
- Thanh, N. C. and Thanh, T. (2015). The interconnection between interpretivist paradigm and qualitative methods in education. *American Journal of Educational Science*, 1(2), pp.24-27.
- United Nations Development Programme (2019). Inequalities in Human Development in the 21st Century Briefing note for countries on the 2019 Human Development Report Available at: http://hdr.undp.org/sites/all/themes/hdr_theme/country-notes/ZMB.pdf [Accessed: 11 January 2020].
- United Nations (2019). *Women with Disabilities in Political and Public Leadership: Towards Beijing+25* UN Women, United Nations, New York, 12 June 2019. Available at: <https://www.un.org/development/desa/disabilities/wp-content/uploads/sites/15/2019/07/Declaration-towards-Beijing25.pdf> [Accessed: 19 December 2019].
- United Nations General Assembly (2016). *Report of the Special Rapporteur on the rights of persons with disabilities*. Available at: <https://www.ohchr.org/EN/Issues/Disability/SRDisabilities/Pages/Reports.aspx> [Accessed 29 November 2019].
- United Nations Human Rights Council (2016), *Report of the Special Rapporteur on the rights of persons with disabilities on her visit to*

Zambia, A/HRC/34/58/Add.2, available at:
<https://www.refworld.org/docid/58b00b5c21.html> [accessed: 10 February 2020]

United Nations (2015), *Universal Declaration of Human Rights*. Available at:
https://www.un.org/en/udhrbook/pdf/udhr_booklet_en_web.pdf. [Accessed: on 16th December 2019].

United Nations Development Programme (2011). Zambia Human Development Report 2011 Service Delivery for Sustainable Human Development
http://hdr.undp.org/sites/default/files/nhdr_zambia_2011_en.pdf

United Nations Convention on the Rights of Persons with Disabilities (2006). A/RES/61/106, Annex I. Available at:
<http://www.refworld.org/docid/4680cd212.html> [Accessed: 13 December 2019].

Waheduzzaman, W. (2010). *Value of people's participation for good governance in developing countries*. Transforming Government: People, Process and Policy. 4. 386-402. 10.1108/17506161011081345.

Wiles, R. et al (2005). Informed consent in social research: A literature review. *National Centre for Research Methods Review Papers*, NCRM/001.

World Bank (1996). *Participation Sourcebook*. Washington, D.C.: The World Bank.

WHO-WB, (2011). *World Disability Report*. Malta, World Health Organization and World Bank.

Yin, R. K. (2003). *Case study research design: design and methods*. Thousand Oaks: Sage Publications.

Yoshida, K. *et al.* (2014) 'Using intersectionality to explore experiences of disability and HIV among women and men in Zambia', *Disability & Rehabilitation*, 36(25), pp. 2161–2168. doi: 10.3109/09638288.2014.894144.

Zambia Federation of Disability Organizations' website 2020. Available at:
<https://www.zafod.net/about-2/> [Accessed 12 January 2020].

Appendices

Appendix A: Introduction letter



LUND
UNIVERSITY

2/12/2020

Department of Political Science
Jakob Gustavsson
Director of Studies

To Whom It May Concern

Oscar Lwiindi, born June 20 1984, is a full time student in the master degree programme MSc (Two Years) in Welfare Policies and Management at Lund University, Sweden.

Oscar Lwiindi is currently writing his master's thesis with the working title "Participation of women with disabilities in local government decision making structures" and has by his supervisor been encouraged to visit the Republic of Zambia for data collection.

Oscar Lwiindi is serious, curious and very independent, and has demonstrated excellent analytical skill during his previous studies.

We hope you or the organization you represent can assist him in his pursuit for completing his master's degree.

If you have any further questions with regard of his background or qualifications, please do not hesitate to contact me.

Ex officio

A handwritten signature in blue ink, appearing to read 'Jakob Gustavsson'.

Jakob Gustavsson
Director of Studies

Appendix B: Ethical approval letter



THE UNIVERSITY OF ZAMBIA

**DIRECTORATE OF RESEARCH AND GRADUATE STUDIES
HUMANITIES AND SOCIAL SCIENCES RESEARCH ETHICS COMMITTEE**

Telephone: +260-211-290258/293937
Fax: +260-211-290258/293937
Zambia
E-mail drgs@unza.zm

P O Box 32379
Lusaka,

HSSREC 2020 – Feb- 003a

Approval of Study

24th February, 2020

Dear Mr Lwindi Oscar

Reference is made to your submission requesting approval of the study “Participation of Women with disabilities in Local Government Decision making Structures”.

The University Of Zambia Humanities And Social Sciences Research Ethics Committee IRB resolved to approve this study and your participation as Principal Investigator for a period of one year.

Review Type	Expedited Review	Approval No. 2020-Feb-003a
Approval and Expiry Date	Approval Date: 24 th February, 2020	Expiry Date: 23 rd January, 2021
Protocol Version and Date	Version- Nil	-
Information Sheet, Consent Forms and Dates	• English.	Approved
Consent form ID and Date	Version	Approved
Recruitment Materials	Nil	Approved

Yours faithfully,

A handwritten signature in black ink, appearing to read "Dr. Jason Mwanza", written over a horizontal line.

Dr. Jason Mwanza

BA, MSoc, Sc., PhD

CHAIRPERSON

The University Of Zambia Humanities and Social Sciences Research
Ethics Committee IRB

Appendix C: Participants Information Sheet

Title of the research

The Participation of Women with Disabilities in Local Government Decision Making Structures in Lusaka: Unpacking the silent voice.

The researcher

My name is Oscar Lwiindi and I am working as a Social Welfare Officer in the Ministry of Community Development and Social Services under the Department of Social Welfare. I am currently pursuing a Master of Science Programme in Welfare Policies and Management at Lund University in Sweden.

Aim of the study

The aim of the study is to explore the experiences of women with disabilities with regards to their participation in local government decision making structures. The study seeks to understand the challenges and opportunities embedded in decision making structures, processes and strategies under Lusaka City Council.

Participation in the study

Participation in this study is purely voluntary. Anyone who decides to participate in the study will be requested to sign the consent form. In an event where you feel that you cannot continue as a participant in this study, you are free to withdraw even without providing a reason. You are also at liberty not to answer all the questions if you feel like.

Confidentiality and Anonymity

All the data gathered during the interviews will not be shared with any person. Your names, signature and residential address which will be provided in the consent form will be erased to ensure that you are protected and unidentifiable.

Risks and benefits

There could be questions which may trigger your emotions or anxiety. In an event where you feel that the question is affecting you psychologically, you are free to say so and will skip the question. Do not hesitate to tell me if any question or word make you feel embarrassed or emotional. There are no expected direct benefits to the participants but the findings of the study may be helpful and used by policy makers and other stakeholders to inform and devise gender and disability participation strategies, processes and mechanisms which will be beneficial to women with disabilities. This may enhance the respect of human rights and adherence to democratic tenets.

For any clarity you can contact:

Oscar Lwiindi

lwiindioscar@gmail.com

Phone #: +260 977 233 896; +46 704 395 241

Or

Norma Montesino

norma.montesino@soch.lu.se

Tel: +46 46 222 93 89

Appendix D: Informed Consent Form

The researcher has given me the information sheet.

The researcher has explained to me in writing and verbally the purpose and procedure of the study.

The possible risks and benefits of the research have been explained to my satisfaction

I have had the opportunity to ask questions and they have been answered to my satisfaction

I agree that the researcher can audio-record the interview.

I understand that the information obtained from me will be kept confidential.

The researcher has explained that I have the right to withdraw from the study anytime I feel like and I am not obliged to give reasons.

I consent voluntarily to be a participant in this study

Name:

Signature:.....

Date:.....

Appendix E: Interview guide for women with disabilities

Background information

1. Tell me about yourself briefly?
2. Are you married? If yes, do you live with your spouse?
3. Who is a breadwinner for your household?
4. How many children do you have?
5. How far did you go in your education?
6. What do you do for your living?

Disability experience

1. How do family members and community treat you?
2. Do you feel that they focus on your disability and not a person like any other?
3. How do people react towards you being a woman with a disability?
4. Do you depend on others to perform certain activities? If yes, what kind of assistance do you require?
5. How has this condition/state of disability impacted on your access to social services?
6. Does your surroundings make it easy or difficult for you to have access to health care, education and water and sanitation facilities?
7. Do you need to use any form of assistive device? If yes, do you have it?
8. Who provide the assistive device?

Participation in local government decision making structures

1. Have you ever been selected/appointed to be part of any local government decision making structure?
2. What is your perception on the possibilities of you being involved in local government decision making structures?
3. Do you feel that the combination of your gender and disability affect your participation in decision making structures?

4. Do you think your views and concerns are considered and respected during decision making processes?
5. What opportunities are there for you to participate in local government decision making structures?
6. What obstacles have you encountered with regards to participation in local government decision making processes?

Appendix F: Interview guide for professionals

1. What is your view on participation of women with disabilities in decision making processes?
2. What participation strategies are in place for women with disabilities to be involved in decision making?
3. What is the role of your organization with regards to participation of women with disabilities in decision making?
4. What obstacles are there for women with disabilities to participate in decision making
5. Are there any deliberate measures to ensure that women with disabilities are actively involved in decision making in their localities?

Appendix G: Timeline for study activities

Activity	Jan	Feb	March	April	May	June
Writing research proposal						
Ethical approval						
Making appointments with stakeholders						
Meeting various stakeholders						
Data collection and transcribing						
Data analysis and report writing						
Thesis submission						
Thesis Defense						