A Thesis Submitted for the Degree of PhD at the University of Warwick

Permanent WRAP URL:

http://wrap.warwick.ac.uk/101764/

Copyright and reuse:

warwick.ac.uk/lib-publications

Experiences of Parenting Children with Disabilities

A Qualitative Study on the Perspectives of Mothers of <u>Children with Disabilities in Zambia</u>

Masauso Simon Chirwa

Thesis submitted as fulfilment of the requirements for the Degree of Doctor of Philosophy in Social Work and Social Policy

University of Warwick
Centre for Lifelong Learning

September 2017

Dedication

To the mothers of children with disabilities who remain unsung heroes despite the enormous work they do in caring for their children with disabilities.

Acknowledgements

Declaration

This declaration states that this thesis and the research on which it is based are the sole work of the author. This thesis has not been submitted for a degree at another university.

Abstract

This thesis sought to provide new insight into the lives and experiences of mothers of children with disabilities in the rural (Kaoma) and urban (Lusaka) settings of Zambia. A detailed literature review revealed that there is a dearth of research that has focused on the views of mothers parenting children with disabilities within the Zambian social and cultural context. Qualitative, biographical interviews were undertaken with thirty mothers whose child had a disability significant enough to qualify for intervention services at the time of the interviews. This study drew on a framework using insights from the social model of disability, feminist intersectionality and the social empowerment model. The methodology was informed by interpretivism, social constructionist grounded theory, feminist intersectionality theories, and data analysis was carried out concurrently with data collection.

Findings revealed that disability is still surrounded by stigma and prejudice. It was associated with punishment and bad omen. The diagnosis of a child's disability had an impact on mothers as it resulted in a liminal (suspended) state and a biographical disruption as they had to reorient their lives. Mother-blame was common and they were often ostracised by their significant others and the communities. Divorce was common especially among first-time mothers whose child had cerebral palsy. Divorce was an unexpected disruptive event that had socioeconomic impact on mothers. They had to bear the burden of caregiving in the absence of support from their partners. Some gave up their employment because of the demands associated with caregiving resulting in financial deprivation. Mothers also experienced loss of agency over their future and that of their child. More power was allotted to husbands than mothers with regard to decision making at home.

The study makes a deeper, and more nuanced, contribution to the scarce literature on mothering children with disabilities in Zambia and globally.

Table of Content

List of Figures

List of Tables

List of Abbreviations

ADHI	Archie Hinchcliffe Disability Intervention
AIDS	Acquired Immune Deficiency Syndrome
CSO	Central Statistical Office
DPOs	Disabled People's Organisation
GRZ	Government of the Republic of Zambia
HIV	Human Immunodeficiency Virus
HSSREC	Humanities and Social Science Research Ethics Council
IMF	International Monetary Fund
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
WB	World Bank
W.H.O	World Health Organisation
ZAFOD	Zambia Federation of Disability Organisation
ZAPCD	Zambia Association for Parents of Children with Disabilities

List of Appendices

Chapter One

Introduction: Setting the Scene

Until you have a disabled child, you have no idea of the depth of your strength, determination and resourcefulness- Gertrude (mother of three children)

I am not myself anymore. I was looking forward to becoming a mum but I got more than what I bargained for- Esther (first-time mother of a child with cerebral palsy)

1.1 Introduction

This thesis reports on a small scale qualitative study undertaken in Zambia, to explore the experiences of mothers of children with disabilities in Lusaka and Kaoma. A diverse sample of thirty mothers aged between 22 and 59 years who had children with disabilities shared their lived experiences. Rich data were generated which illuminated the complex range of personal, sociocultural and economic factors related to childhood disability that impacted on mothers' lives. Overall, this research contributes to a nascent area of empirical knowledge about disability in Zambia and it also adds to the international body of research about disability studies.

Disability has been viewed and understood differently historically, and in different cultures and societies. However, throughout the world, every culture has found supporting and looking after people with disabilities a challenging and sometimes controversial undertaking (Kuhn et al., 2006, Hastings, 2003). Recently in many developed countries, there has been an emphasis on de-institutionalising care services, thus, a shift towards community care services (Hamilton-Giachritsis and Browne, 2012, Cambridge and Ernst, 2006). In most developing countries, however, the family, especially mothers, have always cared and continue to care for their members with disabilities (Bourke et al.,

2010, Kuhn and Carter, 2006). With a world population of over seven billion, it is estimated that there are about one billion people with disabilities in the world (WHO-WB, 2011). The population of youth (under 25-years) with disabilities in the world is estimated to be about 10 percent, of which 80 percent are in the developing countries. Furthermore, 93million of the world's children under the age of 15-years have mild to severe disabilities (WHO-WB, 2011, CSO, 2007). In Zambia, the population of persons with disabilities stands at about 15 percent out of the total population of over 13 million (Sakala and Korpinen, 2013, Loeb et al., 2008). As life expectancy and population increase worldwide, and as conditions such as malnutrition and poverty continue to rise in the world, cases of disability will also continue to rise (WHO-WB, 2011). The need for more carers will also increase.

There has been a steady growth of literature on gender and disability in Zambia recently. Recent research has however, sought to understand the intersection of gender and disability (Wickenden et al., 2013, Trani and Loeb, 2012, Lewis, 2004) in terms of adults with disabilities, HIV/AIDS, and a connection between disability and poverty. However, less attention has been paid to the needs of children or their carers. This thesis explores the experiences of mothers of children with disabilities from their own perspectives- who like Gertrude and Esther cited above have diverse experiences of parenting children with disabilities in the context of Zambia. This thesis illuminates the ways in which mothers give meaning to their child's condition and how society perceives such mothers and their children with disabilities over time. The study traces life trajectories of these mothers and highlights how the child's condition impacts on them over time.

This introductory chapter has five sections to provide a context to the study. In the first section, I introduce the setting of the study, Zambia, by giving a historical background of the country. I then discuss what motivated me to undertake the current study. This is followed by a summary of the theoretical framework that informed this thesis. In the fourth section, I describe the methodology that I employed in this research. This chapter concludes with a

section that highlights the structure and the content in each chapter of the study of the thesis.

1.2 Setting of the Study: Political, Socio-cultural and Economic History of Zambia

1.2.1 Demographic Characteristics

Zambia is a landlocked country situated in Southern Africa. The country has one of the fastest growing populations in Southern Africa. According to the Census Population Report of 2010, the population grew at a rate of 2.8 percent per annum between 2000 and 2010 and it now stands at over 13 million (CSO, 2012c, CSO, 2010). The country has a young population as 45.4 percent are aged below 15 years while 20.8 percent of the population is in the age group 15- 24 years, those 15-64 years make up 52 percent, and the 65-years and above constitute 2.6 percent of the population (CSO, 2012c, CSO, 2010). Thirty-nine point five percent of the population lives in urban areas while 60.5 percent are in rural areas. Life expectancy in Zambia is 49.2 years for males and 53.4 years for females, up from 37 and 40 years respectively during the 1990s (CSO, 2012c). There are seventy-three ethnic groups in Zambia, from which there are seven languages, and these are (in alphabetical order): Bemba, Kaonde, Lozi, Lunda, Luvale, Nyanja (Ngoni) and Tonga. English is the official language while Bemba and Nyanja are widely spoken in cities and urban areas (CSO, 2012a; Nooyo, 2000).

HIV/AIDS and malaria have had a devastating effect on both the social life and economy of the country and are still one of the key factors affecting life expectancy. The most affected age group is between 15 and 49 years, which means that the most productive human capital has been affected. In 2010, the overall HIV/AIDS infection rate stood at 14.3 percent (UNICEF, 2008; CSO, 2012b). The infection rate is higher among women than men, and this has been attributed to power imbalance between men and women. The latter are powerless especially in the *'negotiation of relationships'* (UNICEF, 2008: 13).

For example, there is a tendency for some men to have multiple sexual partners (CSO, 2012c, UNICEF, 2008), without adopting practices of safer sex such as condom use. The infection rate is also high among people with disabilities and it has impacted them negatively. For example, Yoshida et al. (2014:2162) argued that *'HIV and AIDS exacerbate existing difficulties facing people with disabilities by; increasing health, welfare and psycho-social needs, providing additional fuel for stigma and discrimination, and further limiting economic opportunities.'* This has called for inclusion of people with disabilities in HIV/AIDS intervention programmes (Parsons et al., 2015, Nixon et al., 2011).

1.2.2 Independent Zambia

There was no unitary state called Zambia before 1911 when the former North-western Rhodesia and North-eastern Rhodesia were amalgamated to form the state that came to be known as Northern Rhodesia (Phiri, 2006, Posner, 2004). The area became a British protectorate, and Britain assumed direct responsibility over the territory (Mvunga, 1980). In the 1923, Northern Rhodesia (Zambia) and Southern Rhodesia (Zimbabwe), and Nyasaland (Malawi) were merged to form a federation of Rhodesia and Nyasaland. In 1963, Nyasaland broke away from the federation, became independent and was renamed as Malawi. In 1964, Britain split Rhodesia into Northern and Southern Rhodesia, the northern part was renamed as Zambia, a name derived from a river called Zambezi that formed the boundary between the two territories (Gewald et al., 2008, Wills, 1985).

Zambia was led to independence in 1964 by the United Independent Party (UNIP) whose focus was to advance economic empowerment of its people. The new government embarked on developing infrastructure that would raise the living standards of the people. The government designed development plans to guide the development of the country (Bigsten and Kayizzi-Mugerwa, 2005, Bates and Collier, 1995). The country's economy was and remains anchored on minerals especially copper. The government inherited the British constitutional model which permitted dissenting views through multi-party

electoral system, but a number of these political parties were inevitably constituted along tribal lines (Ndulo and Kent, 1996). To overcome this, the government introduced one party politics and came up with a national slogan of *'One Zambia One Nation'* (Marten and Kula, 2008) which to this present day is used. The country adopted socialist policies and there was universal provision of social services (Mhone, 2004). The emphasis was also on the role of the family as the primary unit of security and it provided its members with emotional and material support.

1.2.3 Economic Meltdown and its Impacts

The 1960 and 1970s saw Zambia ranked as one of the fastest growing economies with the gross domestic products as high as that of South Korea (Shafer, 1990). The country witnessed improved living standards with major improvements in health and education. However, in the 1980s, copper prices plummeted on the international market. This reduced the funds allocated for social investment plan to almost nil leading to shortages of basic goods. This resulted in the country's economic growth slumping and there was discontent in the country. The public started demanding for President Kaunda's resignation through protests which often turned violent. The people were demanding an end to goods shortage, reintroduction of plural politics and protection of their civil liberties such as freedom of speech and assembly. Following prolonged public demonstrations, President Kaunda gave in to the demands of the people and reintroduced multi-party politics and in 1991 elections were held and there was a change of government. The new government, the Movement for Multiparty Democracy (MMD) discarded socialist policies and adopted the Bretton Woods Institutions (World Bank and International Monetary Fund) supported structural adjustment programme (SAP). Zambia implemented austerity measures aimed at cutting down on government expenditure. Zambia also liberalised the investment climate and privatised parastatal companies (Block, 2002, Kees van Donge, 1998, Baylies and Szeftel, 1992). Taxes were increased, public spending was reduced. All these measures were meant to reduce budget deficit. The new liberal policies,

however, did not result in an upsurge of investments. This resulted in massive job losses (Hill and McPherson, 2004, Bates and Collier, 1995). This led to high poverty levels and it attenuated the living standards of many. The country experienced social dislocation with the emergence of new social problems such as street children, high crime rate, high unemployment and a high level of HIV/AIDS (Cheru, 2002, De Vogli and Birbeck, 2005). There was increased destitution among the vulnerable members of society such as the elderly and the disabled (Craig, 2001, Larmer, 2005).

1.2.4 2001-2011- the New Deal Government

However, Zambia's economic growth picked up significantly post-2000. In 2001 there was a change of government. The new government adopted mixed economy policies. They embarked on public sector reforms aimed at improving service delivery, more resources were allocated to poverty reduction programmes and an emphasis on infrastructure development and diversification of the economy (Oshionebo, 2010, Hill and McPherson, 2004). The country witnessed increased foreign direct investment. The Zambian government established the Zambia Development Agency (ZDA) which was a one-stop-shop for foreign investment (Kragelund, 2009).

Zambia soon became a preferred destination for foreign direct investment. Things were considered to have had improved in that there was an end to goods shortages, there was also a reduction in unemployment and poverty levels (CSO, 2010, Kragelund, 2009). The country moved from being a least developed country to a lower middle-income country. In 2011 there was another change of government with the new government getting more involved in the running of the economy (CSO, 2012a, 2012b).

1.2.5 Legal and Policy Frameworks on Disability and Gender

The government designed the National Development Plans (NDP) in order to sustain the improved socioeconomic indicators which were mainly as a result

of a combination of domestic policies and foreign investment. In this vein, the Vision 2030 and the Sixth National Development Plan were formulated. The country has also signed, and in some instances ratified, both regional and international treaties aimed at promoting equality and human rights among other goals. Various legal and policy frameworks have been adopted that seek to build and strengthen the mainstreaming of gender and disability issues in the development process (CSO, 2012a). For example, both the Vision 2030 and the Sixth National Development Plan recognise the importance of mainstreaming the needs of people with disabilities in all sectors of the economy, in order to improve their living standards. However, there is no disability policy as yet. Issues of disability are addressed in various policies such as the education policy of 1996 (Chirwa, 2011).

Zambia ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2010. The UNCRPD seeks to promote the effective inclusion and participation of persons with disabilities in society (Kanter, 2008). The country also signed the Optional Protocol to the Convention that provides for an individual complaint mechanism (Hendricks, 2007). In line with these international initiatives providing for the domestication of the above international treaties, the Zambian government enacted the Persons with Disabilities Act of 2006 and 2012, and is in the process of formulating a new disability policy. Furthermore, part II section 14 of the Persons with Disabilities Act of 2012 prohibits discrimination and stigmatisation of people with disabilities and their carers (Zambian Government, 2012).

However, studies have shown that people with disabilities and their carers still suffer discrimination. For example, UNICEF's (2008) survey on the situation analysis of children and women in Zambia discovered that women were the primary caregivers of children. The study further revealed that despite enacting the Disability Acts, people with disabilities and their carers are often banished from the mainstream society. This is primarily due to the strongly entrenched socio-cultural norms and traditional beliefs that associate disability with curse. Furthermore, UNICEF states that *families with disabled children face the*

forbidding costs of accessing treatment, which may include indirect costs to the caregivers whose capacity to work and earn a living is severely curtailed' (UNICEF 2008:25).

The above scenario reveals that as much as the Zambian government has made positive strides in mainstreaming disability issues in both legal and policy frameworks, critical gaps still exist. The needs of carers for people with disabilities have not been incorporated into the policy documents thus far. This is a significant concern, considering the important role they play in the lives of people with disabilities. As UNICEF (2008) indicates, caring for the disabled reduces the capacity of those in the caregiving role to engage in income generating activities.

As previously explained, in Zambia as elsewhere, women are the principal carers of children. Despite the important role that women play, they still continue to suffer injustices in terms violation of their rights and inequality in many spheres of society (Banda, 2006). The Zambian government is attempting to address gender disparity through various laws and policies, and to that effect has signed and domesticated international treaties such as the Southern African Development Community Declaration on Gender and Development (SADC-DGD) of 1997, the UN Convention on the Elimination of all forms of Discrimination Against Women (CEDAW), and the Convention on the Rights of Children (CSO, 2012a, 2010, Skjelmerund et al., 2008). SADC-DGD provides 30 percent of the representation of women in decision-making positions. It also states that gender inequality is a result of both laws and social practices (Kiamba, 2008, Baldez, 2006, Sadie, 2005, Banda et al., 2003), and to address this, various policies have been formulated in conformity with the above conventions. For example, the National Gender Policy of 2000 seeks to address, among other issues: (i) the imbalance in power relations between men and women, and the cultural practices that perpetuate this imbalance, (ii) women's limited, and in some cases non-existent, access to social services such as healthcare, education, and employment (CSO, 2012a, Skjelmerund et al., 2008, Milimo et al., 2004).

However, despite the attempts made to promote gender equality, women continue to be deprived of their rights in relation to access to justice despite their rights being violated (EFZ, 2009, Benschop, 2004, Richardson, 2004). Various church mother bodies (the Evangelical Fellowship of Zambia, the Council of Churches in Zambia, and the Zambia Episcopal Centre) noted that despite the country's constitution incorporating the Bill of Rights, *'…there are no women's rights guaranteed in there, and the document does not have an express equality clause'* (EFZ 2009:11). The church mother-bodies further stated that the application of a dual legal (statutory and customary) system perpetuates gender inequality in society. For instance, customary law is unwritten, and thus varies from one culture to another *'…generally and widely, it legalises discrimination against women'* (EFZ 2009:13).

1.3 Rationale of the Study

In this section, I start by introducing myself. I have BA in social work, an MSc in International Social Work and another MSc in Peace and Development Studies. I worked as a teaching and research fellow in the Department of Social Work and Sociology at the University of Zambia. I was engaged in research undertaken by the department and I also taught courses in Social Work and Sociology such as social work, mental health and disability, social work with families and children, social policy analysis and planning, monitoring and evaluation. I was also a visiting lecturer at Linnaeus University in Sweden. I have worked on a range of quantitative, qualitative and mixed-method evaluations, randomised controlled trials and a systematic review both at the University of Zambia and the University of Warwick in the United Kingdom. Recently (January to September 2017), I was part of the team that undertook a study aimed at Enhancing the Employability of Non-traditional Students in Higher Education (EMPLOY) in Europe. The Project was funded by the European Union and consisted of a network of researchers from the University of Algarve, Portugal, the University of Ireland, Maynooth, the University of Lower Silesia, Poland, the University of Seville, Spain, Stockholm University, Sweden and the University of Warwick, United Kingdom. In July 2015, I

provided advanced training to Zambia Monitoring and Evaluation Association (ZaMEA) members in Monitoring and Evaluation with a focus on data analysis using statistical packages (SPSS and Excel). From January to June, 2013, I was a lead consultant on a comparative study funded by Bath University, United Kingdom and HODI that focused on the wellbeing of married women, single mothers and husbands in Chiawa, Zambia. I was also part of the team in September 2013 that conducted a baseline survey for VSO Zambian programme to strengthen the Zambian Ministry of Local Government and Housing towards providing quality services to communities through building governance capacity of Local Authorities and Provincial Departments in Zambia. In June 2012, I participated in a study by GTZ, a Germany Technical Assistance project with other staff from the University of Zambia to carry out a study entitled, The Role of Civil Society on Social Protection in Zambia. My aspect of the study was civil society activism in Zambia. Other studies I have participated in include: evaluation of the Commonwealth Youth Programmes for twenty-one member countries throughout the world in July 2011, another study was an evaluation of a programme implemented by the local Kommun (authority) on fostering youth participation in social activities in an area called Araby within the city of Växjö, Sweden. This study was conducted in April 2011.

A number of these studies contributed to me choosing to explore the lived experiences of mothers of children with disabilities. My interest developed over time based on a study I conducted for my master's dissertation in social work that focused on the views of parents on inclusive school system in Lusaka, Zambia. At that point, my interests were in inclusive education (Chirwa, 2011). Through interacting with and interviewing twenty parents of children with disabilities, I realised that mothers of such children were often neglected and suffered shame in the community and were living in poverty. In my study, it was clear that mothers played a key role in the lives of their children. So, I decided that it would be important to explore their experiences. This was one of the foundations for this research.

Another reason was that in Zambia, like in many other developing countries, mothers are primarily responsible for domestic chores such as caring and rearing children, and preparing food for the family (Bornstein and Putnick, 2012, Schatz and Ogunmefun, 2007, Esu-Williams et al., 2006). Statistics from the Population Census of Zambia 2010 indicate that 99.2 percent of children with disabilities live at home, and 90 percent of carers of these children are mothers while 10 percent are other family members. Further, the report revealed that 90 percent of the household chores were done by women (Day and Evans, 2015, CSO, 2012b). From the above statistics, the majority of the carers are mothers in general. Mothers play a significant role in the lives of their family members, yet their immense contributions have been neglected and marginalised (CSO, 2012a, Chirwa, 2011). Their work goes unnoticed (especially those who care for children with disabilities) among the academics and policy makers as evidenced by lack of research exploring their lives or policy aimed at improving their living standards. This is confirmed by a dearth in literature to understand their experiences. Furthermore, policy documents relating to disability in Zambia are silent on what should be done for the carers of persons with disabilities. Such mothers are set apart from other families either by stigma or by being seen as special and thus either way defined by their identity as mothers of children with disabilities. Therefore, more often than not, people with disabilities become the mother's lifelong responsibility, thus hindering their ability to engage in formal activities such as generating income (CSO, 2012a, Wilson, 2011).

For the above-mentioned reasons, such mothers experience particular challenges such as social isolation and multi-faceted impacts of living in poverty. Thus, this makes it difficult for mothers and their people with disabilities to escape such challenging situations (Chirwa, 2016, Dykens et al., 2014, Park et al, 2002). In addition, the power relations both at household and societal level disadvantage women, as they are placed in a subordinate and subservient position to men (Aterido et al., 2013, McFerson, 2010). For example, in Zambia the nature of most of the women's employment is in the informal sector (CSO 2010). Such women face the challenges of selling in the market and on the

street, raising money for the family and the demand and burden of looking after a child with disabilities. Therefore, they have to juggle between two competing responsibilities. The wages earned from such work are insufficient to raise the socioeconomic status of their family. Furthermore, these mothers often face a stigma of raising a child with disabilities (Read and Harrison, 2002).

The above reasons, coupled with weak social support systems in Zambia make such women lead challenging lives. I considered, therefore, important that their voices are elicited and heard in order to ensure that their needs and those of their children are better met. Hence, in the context of a partial research picture, my study sought to provide the participants with space to talk more fully about their lives. I hope that the information generated from this study will help policy makers in formulating and implementing policies that will assist in uplifting their living standards.

1.4 Theoretical Context

A theoretical framework was developed following a detailed analysis of literature on the subject. This study draws on social model of disability, feminist intersectionality theory and social empowerment model in order to understand how mothers socially constructed their experiences. The theoretical framework is discussed in greater detail in the subsequent chapters.

1.4.1 Social Model of Disability

The social model of disability is important in understanding conceptions of and prejudices against people with disabilities and their carers by society (Simkiss, et al. 2011, Barnes et al., 2002; Goodley, 2000; Shakespeare, 2006). In this study I draw on social model of disability to understand how society perceives people with disabilities and their carers, and how mothers perceive themselves and their disabled child. In this study, social model of disability is enhanced by incorporating the theory of biographical disruption that was developed by Bury (1982) to elucidate how chronic illness can be *'a major kind of disruptive*

experience […] where the structures of everyday life and forms of knowledge which underpin them are disrupted' (Bury, 1982:169).

1.4.2 Feminist Intersectionality Theory

This theory takes into account how different social categories impact on women within a given social context (Parsons et al., 2015, Crenshaw, 1991, 1989). Feminist intersectionality theories are important in examining and analysing how social categories such as ethnicity, age, gender, class, disability, and socioeconomic status are interwoven and put women in the position of vulnerability, and perpetuate oppression and poverty. It is thus, critical to attend to various identities, as intersecting categories on the basis that these are not merely cultural (Carbin and Edenheim, 2013). As a theoretical framework, feminist intersectionality provides greater insight into the personal experiences of women by looking at the various aspects that shape their identities and perpetuate their disadvantage (Tremain, 2013, Cole, 2009).

1.4.3 Social Empowerment Model

Friedmann's (1992) social empowerment model focuses at both income poverty and how lack of access to other bases of social power hinder people's ability to engage in various social activities. This model is orientated towards social change. Every individual has some degree of power, some individuals are in stronger positions than others thus, society is not a level playing field. This fact reveals that there is a close connection between social power and, equality and diversity in society (Staub-Bernasconi, 2010, Thompson, 2007). In relation to social power, this is the centre of every household economy. Poverty is viewed as lack of social power by a household. Social empowerment model is used as lens to understand the living circumstances of mothers of children with disability.

1.5 Aim and Research Questions

The preceding section highlighted the theoretical framework developed from a critical review of literature. The research focus of the study arose from both applying this framework, and also from key findings from empirical research in Zambia and elsewhere, and the gaps identified in the current knowledge base. On this basis, an overarching aim of this study is to explore and make sense of the experiences and desires of mothers parenting a child with disabilities from their own perspectives in Zambia. The study has the following as research questions:

1.5.1 *Main Question:*

- What are the experiences of mothers in respect to parenting a child with disabilities?

1.5.2 *Underlying questions*

- How do mothers view their children's disabilities and the causes of them? And what are their reactions to the child's diagnosis?

- How does having a child with disabilities affect the mothers' in relation to power dynamics at the family and at a societal level?

- What are the mothers' present concerns and sources of support, and what are their future expectations?

1.6 Research Methodology

This thesis employs the methodological approach of biographical research which allows mothers to tell their stories by exploring their past and, present situation and what their future expectations are. The aims of this study are

underpinned by theoretical knowledge base related to perception of disability and caregiving roles. This methodology is in line with the aim and research questions of this thesis. This research is underpinned by an interpretivist perspective and draws on a methodology informed by grounded theory and feminist intersectionality.

1.6.1 Interpretivism

Within the context of this study, an interpretive perspective seeks to give insight into how the participants interpret, and make sense of, their experience (Creswell, 2013, Roberts, 2002). It situates these mothers within the context of the prevailing Zambian socio-cultural, political and economic milieu, not to mention their personal contexts, in order to gain an in-depth understanding of their needs, views and opinions (Gill, 2014, Sloan and Bowe, 2014, Crotty, 1998).

1.6.2 Social Constructionist Grounded Theory

My thesis methodology draws on Charmaz (2014, 2006) constructionist grounded theory. This approach is cognisant of the subjectivity of a researcher and prevailing social conditions and how these can influence research. However, there are variations of grounded theory developed by other scholars (Charmaz, 2014, 2006, Strauss and Corbin 1998) that have remained useful in qualitative studies.

1.6.3 Feminist Intersectionality Theory

This thesis is also informed by feminist intersectionality as it is an important part of feminist inquiry, whose goal is to understand different facets of social oppression (Carbin and Edenheim, 2013). In the context of this study, the participants are not just women but also mothers of disabled children. They are living their lives while coping with a particular nexus of issues that pose unique challenges for each of them. It is therefore, important to look at how their lives

are shaped by different structures in society (MacKinnon, 2013, Crenshaw, 1991).

1.6.4 Inclusion Criteria

The eligibility criteria were; participants were mothers of children with disability, whose children have had impairment for one year or more, serious enough to warrant service provision. As elaborated by (Shih, 2012), the rationale for having a criterion of having had impairment for one year or more is that *'it can take over a year for families to settle into a pattern of adaptation to disability'* (Shih 2012:78). Participants were residents of Lusaka or Kaoma.

1.6.5 Sample Size and Sampling

Thirty mothers aged between 23 and 59 years from across two research sites (Kaoma and Lusaka) were recruited and interviewed. This research employed a combination of purposive and snowball sampling to recruit research participants from a hard to reach group (Simons, 2009, Punch, 1999, Rubin and Rubin, 1995).

1.6.6 Data Collection: Biographical Interviews

Biographical interviews were used in the study. The rationale for using biographical interviews over other forms of interviews was that little is known about mothers' experiences and these interviews gave control to the mothers to look at their present situation in relation to their past, thus allowing them to tell their story within the context of their lived experiences under their own control (Brugar, 2013, Riessman, 2008).

1.6.7 Ethical considerations

I was cognisant that studies such as this one could evoke emotions and can be distressing. Even if new data is generated and analysed in such a way that society can benefit as a whole, it still does not justify causing harm through lack of discernment or sensitivity in the interview process (Wengraf, 2001). This study, therefore, adhered to the University of Warwick and University of Zambia ethics procedure.

1.6.8 Data Analysis

I used grounded theory approach in analysing data in which data collection and data analysis were done simultaneously (Charmaz, 2014, 2006, Corbin and Strauss, 2008). I started by preparing data by transcribing the interviews into text verbatim, using the original language. Then I did a back to back translation into English. Transcribing was an on-going process which started as soon as I finished the first interview. This enabled me to identify themes that I explored further in successive interviews.

1.6.9 Limitations

One of the limitations related the timing when I started fieldwork especially in Kaoma. Fieldwork was undertaken from September to December. This is the time when people do farming. Some interviews were rescheduled while in some instances, participants came late for interviews because they first had to go to their farms. Some interviews were done in a noisy environment especially those that were held outside.

1.7 Structure of the Thesis

The next two chapters focus on literature review. The review includes empirical studies on disability and families. The review further includes a focus on theoretical framework upon which this study was based.

1.7.1 Chapter two: Key Theoretical Themes

This chapter situates disability and gender at a theoretical level and shows how an intersection of the two can disadvantage mothers. It also presents the conception of disability within the context of a social model of disability, feminist intersectionality and social empowerment model. This chapter further highlights the values, beliefs and ideologies that maintain male domination and relegates mothers to the role of caregiving.

1.7.2 Chapter three: Engaging with Literature on Parenting a Disabled Child

This chapter focuses on the main body of literature relating to disability, motherhood and parenting children with disabilities. This chapter draws primarily on empirical studies on motherhood and disability undertaken in various parts of the world, with an emphasis especially on studies conducted in the United Kingdom, East and Southern Africa. Literature from these countries and regions is relevant to this study because of similarities that Zambia shares with them. This chapter further identifies gaps in literature and diversity with regard to gender and parenting.

1.7.3 Chapter four: Methods and Methodology

In this chapter, I reflexively discuss the research paradigm used in the study, and demonstrate its theoretical and empirical appropriateness for the study. A modest participatory element was incorporated within the study and this is reviewed. I also address among other issues, underpinning philosophical

assumptions, methodological and ethical issues. The methods used, and the necessary skills of the interviewer are also critically evaluated in relation to adducing the views of often marginalised participants. The chapter also focuses on the aspects of pre-fieldwork, fieldwork and post fieldwork activities such as data analysis and interpretation. Mothers who took part in the study are introduced in this chapter.

1.7.4   Chapter five: Becoming a Mother of a Child with Disabilities

The next three chapters present findings that emerged from the analysis of data from interviews with the thirty mothers involved in the study. This first findings chapter provides insight into what it means to become a mother of a child with disabilities. The chapter further illuminates how mothers and their significant others reacted to the diagnosis of the child's condition. The chapter highlights both the decisions to seek help and how the decisions were made and the difficulties mothers experienced.

1.7.5   Chapter six: Transitions and Critical Thoughts: Trajectories and Shifting Circumstances over Time

In this chapter, I highlight how the mothers adjusted and adapted to their child's disability over time: it examines the beliefs surrounding disability and how mothers perceived themselves and their child's condition over time. I also explore the impact of the child's disability over time on the relationships of mothers with their significant others, and how this impinged on their own health and wellbeing. The chapter also includes a discussion about the joys mothers derived from parenting a child with disabilities.

1.7.6   Chapter seven: The Present and the Future: The Lifelong Journey of Mothering a Child with Disabilities

Chapter seven discusses how mothers were coping with the challenges associated with raising a child with disabilities. I also highlight the mothers'

expectations for the future. In this chapter, I discuss the role and significance of parent-support groups as well as formal support systems to mothers. I also demonstrate how the mothers perceived these groups and their motivation for joining support groups.

1.7.7 Chapter eight: Motherhood, Mothering and Children with Disabilities Understanding their Experiences using Theoretical Frameworks

This chapter interprets the findings of my study and evaluates them within the context of the theoretical frameworks used in the study. I demonstrate how the use of the three theoretical frameworks (social model of disability, feminist intersectionality and social empowerment model) simultaneously allowed for an in-depth understanding of the lived experiences of mothers. Further, I explain how the use of theoretical perspectives allowed me to reflect on the relationship between social conditions and how these have a bearing on the lives of mothers of children with disabilities.

1.7.8 Chapter nine: Conclusion

This chapter summarises the main findings of the study and highlights the implications of the study. In this chapter, I also claim original contribution of my study to the body of knowledge. The chapter also discusses the limitations of the study.

Chapter Two

Key Theoretical Themes and Issues related to the lives of Mothers

2.1 Introduction

This chapter discusses the role of indigenous knowledge in understanding disability within the Zambian context. It however, focuses mainly on how theories and models of disability developed in the western countries shaped the direction and themes of this thesis. It also draws on a broader research context arising from the extensive literature on the lives of families including mothers of children with disabilities, as a basis for the thesis. This chapter helps identify and frame the research questions for the thesis and establishes the basis for a study which focused on the ways in which disability was theorised and understood within a number of disciplines. The chapter focuses on a framework using insights from different, but nonetheless interrelated and overlapping theoretical underpinnings (as shown in fig.1 below) in understanding the perspectives of mothers: the social model of disability, feminist theories (intersectionality and motherhood), and the social empowerment model.
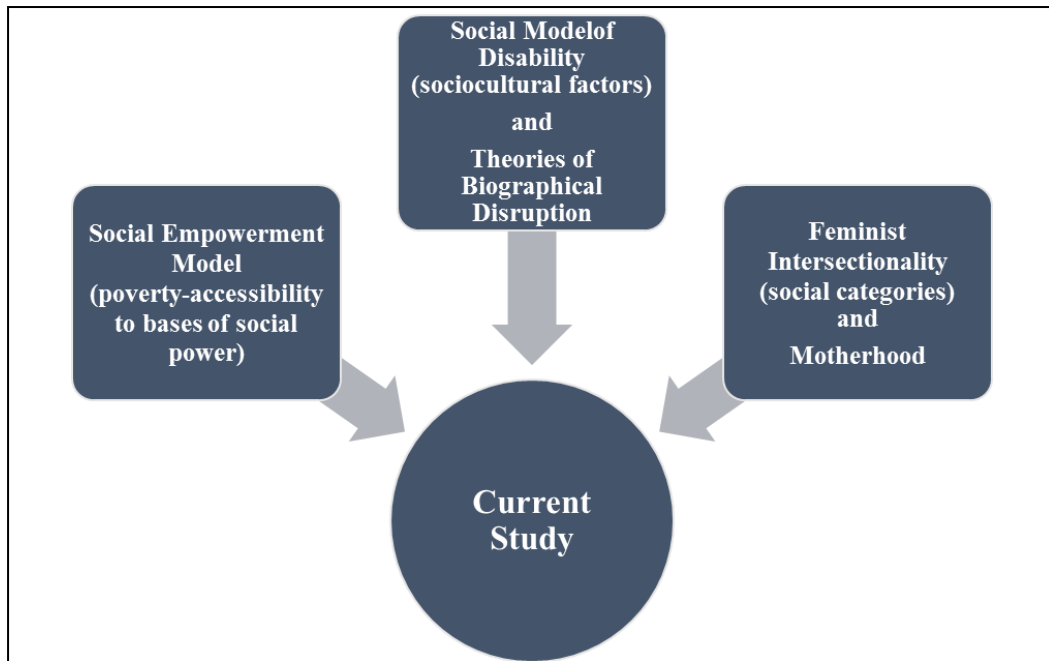
Figure 1: Theoretical perspectives

This chapter will critically evaluate the three theoretical perspectives that have provided a conceptual framework for this study. It will start with a discussion on how the theoretical frameworks derive from the western perspective and will acknowledge the importance of indigenous frameworks and how these contribute to understanding disability. This will be followed by discussion on the social model of disability as an overarching model because it is the foremost approach in theorising disability and caregiving from the socio-cultural perspective, and how carers perceive the disability of their own children. The third section utilises feminist theory. There are two dimensions that will be outlined in relation to the contribution of feminist perspectives. One lies in feminist theorisation of motherhood and the significance of gender to parenting. The other illustrates the more recent contribution of intersectional theorising, and it looks at gender and intersection of different social oppressions. Finally, the chapter looks at how the social model of empowerment can contribute to understanding the relationship between disability and poverty experienced by mothers of children with disabilities that has been repeatedly highlighted in empirical research. This perspective focuses on the relationship between social power and poverty, and illustrates how lack of access to social power hinders

a household's ability to engage in social activities. Each theoretical framework makes a contribution to understanding the lived experiences of mothers. They also resonate with the existing research. The theoretical perspectives complement each other in giving a holistic picture of the living circumstances of mothers of children with disabilities, although each also needs to be critically evaluated.

The rationale for using the above stated theoretical frameworks is to allow a greater depth of understanding of the multi-faceted perspectives of mothers. In addition, an extensive literature review revealed that, to date, no study had used them as an integrated framework to understanding mothering a child with disabilities. Studies have been undertaken that used a social model of disability (Morgan, 2012, Blackburn et al., 2010, Connors and Stalker, 2007, Dowling and Dolan, 2001); feminist perspectives (Edwardraj et al., 2010, Erevelles and Minear, 2010, Davis, 2008) and social empowerment model (Wilson, 2011) but no study has focused on experiences of such mothers using insights from the three theoretical perspectives simultaneously.

2.2 The contribution of Indigenous Knowledge of Disability

The contribution of indigenous knowledge to the framework is also acknowledged. Sarpong (2002) asserts that people's worldview shapes their consciousness and forms the theoretical framework within which knowledge is sought, understood or critiqued. African scholars such as Tanyaniwa and Chikwanha (2011), Nsamenang (2006) and Ntumngia (2009) submit that knowledge has cultural relevance and it must thus be examined within its particular cultural context. Understanding and attitudes towards the disabled are not always uniform within a region or even within a country. In Zambia, like any other country in Africa, communal narratives about disability, may also affect social behaviours and practices towards the disabled. Individuals tend to have different beliefs about the causes of disability (see chapter five to nine). At times individual beliefs vary from those held by wider society (Mung'omba, 2008). People with disabilities in Africa carry a double burden, firstly by virtue

of being disabled and by being neglected by society because they are often perceived as a curse by society (Tanyaniwa and Chikwanha, 2011). Owusu-Ansah and Mji (2013:2) argue that *'African knowledge has much to enrich existing Western knowledge and methodologies'* on disabilities. This African traditional, original and indigenous knowledge about disability has evolved over time. Proponents (Tanyaniwa and Chikwanha, 2011, Ntumngia, 2009) of this traditional knowledge state that within the indigenous knowledge of disability, there is now an emphasis to stop perceiving persons with disabilities as objects of pity, but as individuals who have potential to contribute not only to disability research but also to the socioeconomic development of society. Contemporary African scholars thus call for *'a participatory and emancipatory research paradigm, such as the Afrocentric method […] with the goal being to understand how the [oppression] of disabled people happens and discover ways to challenge it'* (Owusu-Ansah and Mji (2013:2). This understanding of disability within the contemporary indigenous knowledge of disability resonates with the Western perspectives of understanding disability and especially when drawing on the social model of disability. The importance of this dynamic interaction between the person and their environment is now emphasised and enshrined in the social model of disability. According to this theoretical framework, it is society that disables persons with impairments. Disability, thus results from an interaction of people with impairments and their social and physical environment and that this interaction hinders persons with disabilities from full participation in society on an equal basis with others.

2.3 Theorising Disability- The Significance of Social Model of Disability

Historically, disability is a contested concept that has different meanings in different societies (McNally and Mannan, 2013, Adnams, 2010, Dowling and Dolan, 2001). The term has been defined from sociological, political and medical perspectives, and these varied descriptions have had an impact on the eligibility of people for social support from governments, as well as social attitudes towards them (Thomas, 2004, Baird et al., 2000). From within the context of the Zambian legal framework (Disabilities Act No 6 of 2012), for

example, disability is conceived of as being a *'permanent physical, mental, intellectual or sensory impairment that alone, or in combination with social or environmental barriers, hinders the ability of a person to fully or effectively participate in society on an equal basis with others'* (Zambian Government, 2012: 72).

The United Nations' definition of disability includes *'those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation'* (Harpur 2012:3). The only difference between the two definitions is that the Zambian Disability Act Number 6 of 2012 states that disability is *permanent*, while the United Nations' definition states that it is *long-term*. Remaining mindful of the critiques of definitions of disability, this research adopted the definition of the United Nations because it is internationally recognised.

In addition, the study on which this thesis reports is explicitly located within a social model of disability. Within the sociology of disability, there are two main domains of understanding disability that have been developed in industrialised societies. These are disability studies and the sociology of chronic illness and disability. Whilst they share a common value base, they also each have a slightly different emphasis in relation to their theoretical stance. The core standpoint of disability studies is to assist in advocating on behalf of people with disabilities in fighting for equality and social inclusion (Cobigo et al., 2012, Bigby and Wiesel, 2011, Hall, 2010). Proponents of this perspective, such as Turner (2003) and Shakespeare (2006), argue and theorise evidence that it is society that disables people (adults and children) with impairments rather than disability being an inevitable consequence of impairment; hence, people with disabilities are seen as a group that is socially excluded and oppressed by the mainstream society, as well as facing barriers in the built environment. This approach has also constituted a social movement, and knowledge has been driven by the activism of people with disabilities (Goodley, 2017, Oliver, 2013, Thomas, 2004). A tenet of this approach, is that people with disabilities should be advocating for a change in societal attitudes and should have control over their

own lives (Hall, 2013, Barns and Mercer, 2005). As a result, there is a widely held view that definitions of disability should go beyond focusing on impairment, and should also consider the physical environment, and the socio-economic and attitudinal barriers that people with disabilities face (Simkiss et al., 2011, Barnes and Mercer, 2010). Disability is thus, seen as a consequence of social oppression and social barriers (Panitch, 2008, Finkelstein, 2001, Oliver, 1993). Rather than feeling pity for people with disabilities, there must be policy and legal frameworks to promote and protect their human rights (Harris and Enfield, 2003, Bickenbach et al., 1999).

The other model, *'associated with medical sociology, or specifically its sub-genre the sociology of chronic illness and disability', is informed by the idea that disability is caused by illness and impairment and entails suffering and some social disadvantage'* (Thomas, 2004:571). This perspective explores disability from the sociology of the body. Bury (2000) argues that disability is caused by impairment, and impairment can be a consequence of disease, active pathology, genetic disorders, accidents or trauma. Within this stride of understanding disability, activity restriction is perceived to be as a result of an illness or impairment and also by some social and cultural factors (Williams, 2001, Priestley, 2001). Sociology of illness and disability perspective thus acknowledges that disability is a consequence of both biological and social factors (Bickenback et al., 1999). This view gives rise to *'conceptualization of disability that focuses on the interaction between individuals and social location'* (Thomas, 2004:575). However, proponents of both models are committed to pursuing sociological scholarship that is aimed at informing policy-makers and professionals in the disability service arena (Thomas, 2012, 2004).

The social model of disability, with the two overlapping domains described above, emerged as a reaction and challenge to the prior dominance of a medical model (Morgan, 2012, Blackburn et al., 2010, Gabel and Peters, 2004). The medical model medicalised disability; it located disability within an individual and generally viewed it as a personal deficit or tragedy (Oliver, 2013, Shakespeare, 2006, Barnes and Mercer, 2005). The aetiology of disability is

seen within the context of biological, physiological or intellectual defects, deficits or dysfunctions within an individual; therefore, disability is approached and treated like a medical condition (Oliver, 1996; Thomas, 2004). This view is elucidated by Llewellyn and Hogan (2000:158) who submit that *'in the past the problems arising from the care of children with physical disabilities have been the province of medicine to be treated by professionals with medical training.'* Disability was seen as an individual's functional limitation and the solution in medical rehabilitation (Barnes et al., 2002, Braddock and Parish, 2001). According to the medical model, individuals need to be 'fixed', which promotes dependency, help and compassion (Oliver and Barnes, 2012, Thomas, 2012 Priestley, 1998). However, there were many perceived deficiencies in the medical model, and dissatisfactions with this on the part of people with disabilities led to different social movements in Britain and the United States (Slorach, 2014, Oliver and Barnes, 2012, Oliver, 1983), as indicated above. One result was that the British Council of Organisations of People with Disability, the Disability Alliance, and the Union for the Physically Impaired Against Segregation (UPIAS) started advocating for a social model of disability (Shakespeare, 2006, Oliver, 1990, Oliver and Zarb, 1989). During the 1970s, these social movements made up of individuals with disabilities began to mobilise themselves and started pressing for changes in the way that people with disabilities were perceived and treated (Finkelstein, 1981, Oliver, 1996, Shakespeare, 1993). This saw the birth of the social model of disability. These social movements stated that:

> In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society (UPIAS, 1976: pp.3-4).

Concomitantly, in industrialised countries, the institutionalisation of people with disabilities was still widespread in the 1970s, and they faced many physical and social barriers in society (Shakespeare, 2006, Barnes, 1992). People with disabilities were seen as second-class citizens in Britain, and they were marginalised and excluded from many social activities (Barnes and Mercer,

2005). Thus, social movements started to raise awareness of the need to change negative and discriminatory attitudes towards people with disabilities, and they also advocated for empowering disability models, and realised that they themselves could be empowered in the process, by being the agents of social change (Lewis, 2004, Barnes et al., 2002). Other scholars such as Shakespeare (2006:33) argue that the slogan *'disabled by society, not by our bodies,'* demonstrated the need to remove social and attitudinal barriers that perpetuated the discrimination and stigmatisation of people with disabilities. The social model of disability was, thus, crucially important to the social movements because they sought to dismantle social barriers, liberate people with disabilities from oppression and to promote social inclusion (Goodley, 2001, Finkelstein, 2001). Other scholars have argued that at the root of disability and disablement are sociocultural and political constructs. Hence, social movements used the social model of disability as a political platform and tool to advocate for the rights of people with disabilities (Oliver, 1990).

In Zambia, these debates have not been prominent in the way they have been in the United Kingdom, United States and other developed countries such as Canada, Australia and the Nordic countries. Importantly, it appears that Zambia is taking this trajectory (advocating for the rights of people with disabilities). The debates for the rights of people with disabilities are beginning to be championed by organisations for persons with disabilities such as the Zambia Federation of Disability Organisations (ZAFOD), a national umbrella organisation for disability organisations in Zambia that is working in the legal reform and human rights sector. With a membership of 12 organisations, ZAFOD aims to advocate for the promotion and protection of the rights of persons with disabilities (Chirwa, 2011, Mung'omba, 2008).

As a theory of disability with overlapping domains, the social model has been applied in research mostly to understand how society perceives people with disabilities (Goodley, 2017, Thomas, 2012). Thus, the model has evolved over time under the influence of disability studies. For example, the earlier version of the social model argued that capitalism was one of the main causes of the

social exclusion of people with disabilities (Harpur, 2012). This view is echoed by other early proponents (Oliver, 1993, Finkelstein, 1981) of the social model who advocated for altering the social environment rather than people with disabilities. As explained by Mitra (2006), within the social model, there are many strands which include: the oppressed minority model, the discrimination model, and the social constructionist version. However, despite the various versions, generally disability is seen as a social construct, that is created by social barriers. Some commentators (Shakespeare, 2006, Barnes et al., 2002, Goodley, 2000) argue that using a social model of disability in research provides the *'ontological and epistemological basis for research production'* (Barnes, 2002:234). Amongst academia, the model has inspired scholars to focus on the role of the social and cultural context in disabling people (Shakespeare and Watson, 2002, Goodley, 2003).

Proponents of the social model posit that as a theory of disability, the social model helps illustrate how the social arrangements disable people (Goodley, 2000), and that there is a need to focus on the socio-political strategies that will lead to removing social barriers. There is a need to mainstream disability in both policy and practice. Shakespeare (2006) emphasises the importance of using a social model in understanding people's attitudes, and that there is a need to work towards attitudinal change among the mass populace so that disability is not seen as a disadvantage, burden or hardship (Goodley, 2000). It has also provided the basis for a sense of identity among people with disabilities.

It is important that disability rights activists pay sufficient attention to the important role that families and caregivers play in the lives of children and adults with disabilities (Barnes et al., 2002, Thomas, 1999). The social model helps illustrate how people's perception of disability could have an impact on people with disabilities. For example, carers of children with disabilities, who in most cases are mothers, are known to suffer *'isolation, feelings of being undervalued, fear, resentment, anger, guilt, embarrassment, role reversals, a sense of loss, the effects of emotional stress, and strain on relationships'*

(Shakespeare 2006: 190). Sections of society, in some instances, blame mothers for the disability of their children without understanding the difficulties they go through. This model can also be useful in understanding the role that families (especially mothers in Zambia) play in the transition of their members from childhood through to adulthood. Carers of people with disabilities are often placed on the margins of society, this coupled with patriarchal societies in most developing countries, weakens their voices. Dowling and Dolan (2001) echo this view by arguing that the presence of a child with disabilities in a family disables especially the carer. They further state that carers experience a range of inequalities and restrictions in terms of opportunities in the labour market, health and education among others.

In this study, the social model of disability is helpful in understanding the lived experiences of mothers from a point of having a child with disabilities, and is used as a framework to understand the conceptions of and prejudices against mothers and their children with disabilities within the context of Zambia. Furthermore, this model can equally help in gleaning whether mothers' understanding of causes and impacts of disabilities reflect a social or medical model. As Gabe and Peter (2004) explain:

> The social model of disability has been used to explain ways in which disability is constructed by society and as a call to action against the oppression of the disabled. In contrast, the medical model, an objectivist account of disability within which theories operate has been used to explain, diagnose, treat, and cure disability as pathology (2004: 588).

As Lewis (2004) argues, disability shapes the experiences of carers, changing and reinforcing some barriers and adding others. For example, the demands of caregiving roles may hinder the chances of a carer getting a job.

However, the social model of disabilities has not been without criticism. It has been criticised for generalising the challenges that people with disabilities experience. These differ depending on the age, sexuality, class and race of people with disabilities (Barnes and Mercer, 2005). Criticisms of the social

model have also included that, in refuting a tragedy view of disability, it has not always recognised the emotional and psychological impact on parents and families of having a child with disabilities. Feminists criticise it for being too narrowly focused, as it does not incorporate issues of identities such as gender. The model is also silent on how different identities such as gender, disability and socio-economic status intersect to perpetuate and compound poverty, oppression and discrimination of people with disabilities and their carers. Another limitation of this model is that it underestimates the *'subjective experiences of the pain of both impairment and the disability'* (Barnes and Mercer, 2005:23). Despite these criticisms, the social model of disability remains a vital framework in understanding the lived experiences of people with disabilities and their carers, and arguably it has the capacity to recognise both the social and physical conditions which create disability and disablement and the impact of having a child with a disability on mothers, fathers and other family members.

2.3.1 Theory of Biographical Disruption

This study has also drawn on the theory of biographical disruption, and this has been incorporated in the social model of disability to explore and understand the impact of a child's disability on mothers. Biographical disruption was initially conceptualised by Bury (1982) to describe how an onset of a chronic illness is experienced as a biographical disruption in a person's everyday structures and relationships. In his study that involved thirty participants that had been diagnosed with rheumatic arthritis, Bury (1982) argued that there are three aspects of disruption. Firstly, the breaching of common-sense boundaries, this is followed by a second stage that involves significant disruption to a person's biography and self-concept. This phase is characterised by questions such as *'why me?'* The third stage involves a person responding to disruption by either changing the situation or mobilising resources that can help build resilience (Larsson and Grassman, 2012, Reeve et al., 2010, Wilson, 2007). According to Bury (1982: 169) a chronic illness is *'a major kind of disruptive experience […] where the structures of everyday life and forms of knowledge which underpin*

them are disrupted'. Recent proponents (Reeves et al., 2010, Wilson, 2007) of the theory of biographical disruption have argued that disruption of person's biography can have an impact on how their self-identity, how they think they are viewed by others and their assumption about the future. Cayless et al. (2010) sum it up by stating that biographical disruption '*can lead to social isolation and a sense of difference from contemporaries, culminating in a perceived failure to fit in or as 'disrupted feelings of fit'* (Cayless et al., 2010:12).

 The social model of disability and the theory of biographical disruption illuminate how a disability can be as disabling to the caregiver as the person with a disability. The long term disruptive effects can be such as uncertainty and loss of social identity which can be in the form of loss of social status (structural invisibility) or withdrawing from social activities (physical invisibility) (Morgan, 2012, Reid-Cunningham, 2009, Mahon-Daly and Andrews, 2002, Willet and Deegan, 2001). The concept of biographical disruption is closely connected to the concept of liminality.

Liminal describes the process of social change whereby a person is in a transitional form, that is neither in the old nor a new position within society. It is argued that in the liminal or suspended state, an individual cannot state their position exactly (Mahon-Daly and Andrews, 2002). For example, Ryan and Runswick-Cole (2008), illustrate the relevance of this and connect it to mothers of children with disabilities. They argue that:

> …within disability studies mothers of disabled children occupy a liminal position because they are often not disabled and yet they can experience forms of disablism. Their experiences can differ markedly from the experiences of mothers of non-disabled children and yet the consequences and outcomes of these experiences, such as developing a 'special competence' is largely overlooked. Mothers can work to effect change on behalf of their children and, in some cases, for disabled people more generally, however, this role of activist mother is largely undervalued (2008:199).

Using a combination of social model of disability and the theory of biographical disruption helps in exploring the impact of a child's disability on these carers.

Mothers often experience liminality due to the uncertainty and disruption of their daily structures caused by the need to provide lifelong care to a child with disabilities. This state of liminality can also be compounded by an interplay of different social categories as the next section will demonstrate.

2.4 Feminist Intersectionality Theory

The preceding section highlighted the relevance of using a social model of disability in understanding the connections between disability and being a mother of a child with disabilities. This is because the model is *'particularly helpful in focusing our attention on those aspects of disability that emphasise the commonality of disability and gender, rather than the medical condition or impairment that has relegated disability to the specialised and depoliticised, realm of medicine'* (Emmett, 2006:446).

This section develops discussion about the relevance of understanding overlapping forms of oppression by addressing the interface of different social categories such as gender and disability within the context of other inequalities, and how these can impact on people with disabilities and their carers. As a theory of knowledge, intersectionality elucidates and interprets multiple dimensions and intersecting systems of oppression, disadvantage and privilege (Tsouroufli et al., 2011, Davis, 2008, Yuval-Davis, 2006). A term introduced by Crenshaw (1991), intersectionality is considered as one of the most recent concepts in feminist theories (Carbin and Edenheim, 2013, Cho et al., 2013, Nash, 2008). It was introduced in order to understand how the intersection of social categories such as ethnicity, race, gender and class led to the exploitation, exclusion and oppression of black women from socioeconomic and political activities in the United States (Stoltz, 2014, Crenshaw, 1989). Crenshaw suggested that it was important to investigate the various identities that perpetuated the discrimination and marginalisation of black women. At that time, black women suffered what was referred to as a 'triple oppression', that is, 'as a black', 'as a woman', and 'as a working class person' (Crenshaw, 1991, 1989).

While early feminist intersectionality scholars (Crenshaw, 1989) focused on social categories relating to black women, contemporary feminists (Walby et al., 2012a, Lewis, 2009, Yuval-Davis, 2006) have constructed intersectionality in such a way that it is used to understand how different identities intersect, and result in some individuals (not only black women) being discriminated against, oppressed or disadvantaged. Further, Yuval-Davis (2006) asserts that social divisions are embedded within social structures such as the family, institutions, organisations and laws. These social structures have a bearing on power relations in society, and are subject to varied interpretation. In the light of this, it is important to consider historical and social contexts when investigating social oppression and divisions in society (Choo and Ferree, 2010).

Thus, intersectionality is a contested concept, many scholars tend to focus on gender, class and race (Walby et al., 2012b, Valentine, 2007), yet, there are some that have also included other aspects such as disability (Moodley and Graham, 2015, Shaw et al., 2012, Emmett, 2006). For example, Emmett illustrates a significant relationship between gender and disability. Significantly, particularly for a study undertaken in Zambia: Emmett's work:

> …locates disability within the context of other social inequalities and disadvantages such as poverty, race and family structure. The complex interconnection of issues such as these have implications not only for families or households in general, but also for women in particular. The role of disability and gender is then considered within the context of developing countries, where conditions such as pervasive poverty, lack of services, and limited recognition of women's rights have profound implications for both women and people with disabilities (Emmett, 2006:446).

There has been some diversity in theoretical development in feminist intersectionality that has resulted in varying analytical outcomes in academic research. For instance, scholars such as Yoshida and colleagues (2014) have provided another way of viewing and applying theories of intersectionality. They have submitted that categories such as gender, poverty and disability can be seen as *forms of oppression that can be conceptualised as simultaneously intersecting systems of relationships and meaning'* (Yoshida et al., 2014:2162).

People that are disadvantaged on the basis of gender, disability, and poverty are said to be experiencing a triple burden. Therefore, employing an intersectional approach is critical in assessing how disability and gender can intersect to produce poor outcomes for the marginalised. Yoshida and colleagues (2014) also support the view that an intersectional approach provides a lens through which a new insight into the lives of people with disabilities and their families can be gained. In this study, intersectionality helps to elucidate how gender, disability and inequalities intersect, and how this might result in poor outcomes for people with disabilities and their families.

From a feminist intersectionality perspective, different structural factors are intertwined, and these compound the impact of gender inequality in society. For example, gender, racism, disability and socio-economic status can intersect to result in more profound oppression and discrimination against an individual (Cho et al., 2013). Interestingly, Erevelles and Minear state that *'the omission of disability as a critical category in discussion of intersectionality has disastrous and sometimes deadly consequences'* (2010:28). Therefore, in applying an intersectionality approach to fully understand the experiences of the oppressed, it is important to focus on the impact of other factors such as their class and gender. Intersectionality should not therefore, be looked at in a singular dimension but on how different identities come into play in a complex intersectional way (Gillborn, 2015, Gopaldas, 2013, Shaw et al., 2012) to understand issues of discrimination and marginalisation from a more complex perspective without sacrificing the significance of gender inequalities.

As argued by some commentators, *'the intersection of multiple systems of oppression and domination shapes individual and collective experiences and struggles'* (Thiara et al., 2011: 759). In this study, ideas from feminist intersectionality theory help to explore and analyse how the intersection of multiple identities *inter alia* age, gender, class, disability, and educational background can put women in a vulnerable position, and perpetuate their oppression and poverty (Moodley and Graham, 2015, Pearson, 2010). It is therefore, critical to attend to various identities, as intersecting categories on

the basis that these are not merely cultural (Gillborn, 2015, Carbin and Edenheim, 2013, Carbado et al., 2013, Garland-Thomson, 2002). However, feminist intersectionality acknowledge that there are differences among women; hence, the oppression they experience differs depending on their social relations. Additionally, as a theory, researchers have used feminist intersectionality as a lens to gain greater insight into the personal experiences of people by looking at the various aspects that shape their identities and perpetuate their poverty (Tremain, 2013, Cole, 2009).

Furthermore, 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, and how these power dynamics impact on most marginalised members of society. Disability, gender and power can thus, be regarded as emergent and dynamic within the different social and cultural context in which people find themselves. As explained by Yoshida and colleagues (2014), an intersectional approach has the potential to *'create spaces for agency within the locations of oppression'* (2014: 2162). The argument is that women have to deal with multiple barriers such as oppression, patriarchal system and gender among others (MacKinnon, 2013, Yuval-Davis, 2006). Citing the Centre for Women's Global Leadership (2011), Yuval-Davis states that *'oppressed women and other multiply-burdened groups who are located at these sections by virtue of their specific identities must negotiate the traffic that flows from the intersections in order to obtain the resources for the normal activities of life'* (Yuval-Davis, 2006:197). Intersectionality is therefore, more broadly concerned with the importance of acknowledging and accounting for the various aspects of identity. It considers areas that are often neglected, but are very important to society, as these can and do perpetuate inequality. Intersectionality can help us to identify and address factors, policies and practices that discriminate against people on the basis of gender, disability and class (MacKinnon, 2013).

The concept of intersectionality has many benefits, but yet weaknesses have also been highlighted. One of its major flaws has been lack of clarity on how it

should be studied. As a result it is open to different meanings and interpretations. For example, Chang and Culp (2002) point out the difficulties of paying attention to points of intersection because there is no agreed number of intersections. Furthermore, different scholars point to different identities, (Crenshaw, 1991, Cole, 2009) mentions race, class and gender as the main identities while contemporary scholars (Cho et al., 2013; Yuval-Davis, 2006; Nash, 2008; Shields, 2008) include political, economic and social identities in their analysis of intersectionality. Despite the limitations that have been highlighted, intersectionality remains an important theory especially in feminist research. Within the context of my study, the theory of feminist intersectionality is significant in exploring the nuances of social identities through hearing mothers' voices and listening as they recount their lived experiences. Of particular interest is assessing whether they believe that they have been impoverished (or face discrimination) due to negative societal attitudes surrounding both women and disabilities. Furthermore, adopting an intersectionality approach to this study allows for an exploration of different variables that intersect with one another to determine the power dynamics at both family and societal levels, and how these power dynamics impact on mothers of children with disabilities. It is also useful in understanding the concept of motherhood. The theory of feminist intersectionality is also useful in analysing how laws, policies and programmes can be scaled-up in order to empower them.

2.4.1 Understanding Motherhood with the Context of Feminist Intersectionality

Authors have argued that a feminist intersectional approach is important in exploring *'the effects of race, class, marital status upon identity construction'* (Wilder et al., 2009:59) of motherhood. The concept of motherhood has evolved over time and, it is viewed and defined differently by scholars depending on their philosophical orientation and the context (Koyama, 2002, Walker, 1995). In defining mothering, Arendell (2000) states that it is a set of universal, socially constructed relationships and roles performed by women and that central to

this theorisation is the primary focus of mothers providing care and rearing children. The argument is that a good mother raises 'normal' children (Wilder et al., 2009). To this, Singh (2004) submits that mothers of children with disabilities construct themselves as good mothers by employing various strategies in order to overcome the challenges that are associated with parenting children with disabilities. The functions are performed *'in relation to particular children, in specific community circumstances and cultural milieus'* (Datta, 2011:39). It is also a transition that is characterised by multifaceted changes in a woman's life, that is, the biological, lifestyle, identity and social changes that accompany motherhood. These various and complex dimensions have led to divisions among scholars studying motherhood.

In patriarchal societies, the dominant ideology of mothering tends to link mothering to biological reproduction. This view is based on three widely held myths: all women desire to be mothers, women need children, and children need their biological mothers. These beliefs are perpetuated by existing socio-cultural factors (Oakley, 1992, 1981). Earlier in the 1920s and 1930s, proponents of psychoanalytic theory stated that motherhood was closely linked to femininity. Hence, the desire to have a child was seen as inherent in women. Later on in the 1960s, the assertion was that a child needed a caregiver, preferably their biological mother for the purposes of developing a sense of self and in order to be able to interact with others (Glenn et al., 1994). These assertions were however, labelled as false, and it was said that they were intended to oppress and keep women in positions of subordination to men (Oakley, 1992). However, from the 1970s onward *'gendered expectations that support the discourse of an inseparable relationship between women and child rearing began to be challenged and deconstructed'* (Shih, 2012:38).

In the recent past, a variety of sociological and practical literature has been written on how the family has become the focus of political and social discourse (Glenn, 1994). Of particular interest is how motherhood is contextualised. As feminist sociology argues, motherhood is a field of social activity that is critical to human reproduction. For example, Cowdery and Knudson-Martin (2005)

view motherhood as deeply rooted in feminism, and state that gender is central to theorising motherhood. Building on earlier feminist literature (Glenn et al., 1994) they submit that mothering is a social construct that involves various activities and relationships including nurturing and caring for people. Despite having diverse backgrounds, mothers are said to experience similar struggles, joys and desires with regard to their children (Miller, 2005).

Feminists argue that gender relations dominate in the domains of family, politics and, socioeconomics as well as identity. Based on the above, motherhood is seen as a social construct as opposed to a biological one (Smyth, 2012). Further, it is argued that feminist politics and scholarship shape the discussion on motherhood in all disciplines. Feminist theorists assert that it is important to focus on the wellbeing of mothers, their satisfaction and the distress they encounter in raising and caring for their children (Datta, 2011). From the feminist perspective, motherhood should be seen as a gendered division of labour, and something that hinders women's ability to develop their full potential in other spheres of life such as the labour market (Miller, 2005).

Other scholars (Arendell, 2000, Raskin, 2006) explain that mothering practices and experiences are influenced by various factors such as: socioeconomic status, political, and sociocultural contexts. The aforementioned factors have both direct and indirect impact on the way in which mothers nurture, socialise with and protect their children. Researchers (Kingston, 2007, Laney et al., 2013) see it as an empowering experience, especially for mothers of children with disabilities. With the challenges that come with having a child with a disability, seeing such children grow, and learning new parenting skills are significant achievements. Generally, the joy of seeing their children grow far outweighs the challenges and difficulties that mothers of children with disabilities face (Laney et al., 2013).

Kingston (2007) differentiates between the terms 'caring for' and 'caring about' with regard to mothering. 'Caring for' entails providing physical help to another person while 'caring about' has to do with providing emotional support. Mothers

are often expected to play both roles. Having a child with disability whose life is dependent on a mother, '*forces such mothers to extend her affection links indefinitely*' (Kingston, 2009:17). As a result, women in most cultures are considered as natural carers in both the personal and private spheres. Despite the important role that mothers play on behalf of their children, not much attention is given to their role in society (Maher, 2005). Maternal roles that mothers play often go unrecognised at home, and are neglected culturally and financially by many stakeholders including governments.

In most sub-Saharan African societies, morality is seen as an important aspect of motherhood (Kingston, 2007). Women are expected to set a good example to their children and society as role models. For example, Noyoo (2000) argues that mothers are expected to put the interests of their children ahead of their own. Women also have the responsibility of bringing up the next generation, and are thus responsible for the actions of the children who are under their care. Noyoo (2000) demonstrates the shift in the roles of mothers in Zambia with the introduction of neo-liberal policies that led to changes in family structures from extended to nuclear families. This was because of the high cost of living and poverty levels that did not allow families to take in extended family members. There was also a shift in family roles as more women enter the labour force to supplement the efforts of their husbands (Miller, 2005).

Some scholars have highlighted that motherhood is socially constructed as a barrier to mothers' quest to fulfil their full potential and ambitions. They argue that this explains why there are high poverty levels among women compared to men. This is because women spend time caring for their children while men are developing their abilities. Hence, gender is intertwined with issues of class and social position (Shih, 2012). Feminists have demonstrated how childrearing and motherhood hinder them from contributing effectively to society and this in turn affects their emotional wellbeing. They suggest that the state should remove all of the impediments and oppression that women experience in their daily lives (Arrow, 2016).

In conclusion, there are different interpretations of what constitutes good motherhood and how it has been conceived over time. However, motherhood is generally considered as socially constructed and is affected by many factors that include, political, socioeconomic, family and socio-cultural. Caregiving roles in many developing countries are seen as exclusively the responsibility of women (Wilson, 2011). Feminists have however, challenged the oppression that women and mothers go through and the gendered role of caregiving (Shih, 2012). Most mothers of children with disabilities are said to suffer poverty and are powerless. The next section explores the link between lack of social power and poverty.

2.5 Social Empowerment Model

The relevance of using Friedmann's social empowerment model is that it looks not only at income poverty, but also at how lack of access to other bases of social power hinders people's ability to engage in various social activities (Friedmann, 1992). In this study, it is important to keep in mind that both poverty and riches extend far beyond what can be bought and sold. Friedmann's model is a testament to that, and is appropriate for understanding the relationship between social power and poverty.

At the heart of Friedmann's theoretical approach is the concept of social power which is at the centre of every household economy. *'Poor households lack social power to improve the condition of their members' lives'* (1992:66). Poverty is thus, viewed as a lack of social power within a household. According to Friedmann there are eight inter-related bases of social power, and these bases can help illustrate how lack of access to social power can disadvantage individuals:

1) Financial resources - knowledge of and accessibility of formal and informal credit facilities including household income. Money is one empowerment outcome that helps individuals to gain greater control in their lives and community, or of the effects of interventions designed to empower participants

41

(Zimmerman and Warschausky, 1998). This model has been applied in research, mostly in exploring the situation of individuals by examining their ability and knowledge to access financial resources, credit facilities, and also their ability to be in employment.

2) Surplus time- that is, free time. Surplus time is defined as the *'time available to a household economy over and above the time necessary for gaining subsistence livelihood'* (Friedmann 1992: 68). The ease with which a family can obtain basic necessities for life such as food and water, and access to social services such as medical services, will determine its poverty level. Surplus time also encompasses the time needed for household chores and gendered division of labour. The model is therefore, useful in exploring how knowledge and accessibility to social services are dependent on household economy.

3) Human capital – the knowledge and skills of family members. Empowerment entails helping individuals to acquire skills and knowledge that can enable them to overcome challenges or obstacles that may hinder their full participation and integration in social activities in their communities (Luthans et al., 2004). This base of social power can be helpful in recognising that people's lives are heterogeneous (Connors and Stalker, 2007), and the way they juggle between different chores both in and out of the home depends on their skills.

4) Appropriate information - knowledge about the availability of public services, and wage - paying work and methods of household production. Appropriate knowledge also covers issues about knowledge of appropriate and available social services, childcare and acceptable health care practices (DuBois and Miley, 2014). Social *'power and knowledge are closely tied together, and serve to reinforce one another'* (Giddens, 2009:990). The extent, to which individuals have appropriate information to care for their families, and overcome the challenging situations they may find themselves in, depends on the extent of their access to bases of social power.

5) Social organisations - formal and informal groupings to which households belong, which can connect them to the broader society. These social groups can provide mutual assistance in meeting certain needs, help in overcoming common challenges or have the desire to bring about social change (Adams, 2008). As delineated by John Friedmann (1992), and elaborated by subsequent commentators (Staub-Bernasconi, 2010, Adams, 2008), empowerment stems both from socioeconomic resources, and from belonging to formal and informal organisations and groups that hold greater collective power. Individuals who lack social power can look up to such organisations to help them *pursue 'legitimate needs and goals'* (Staub-Bernasconi, 2010: 47). Power is vital as it affects the ability of individuals to be active participants in social activities, and to access resources. The core of empowerment at the individual level is to see how individuals view their participation and control of various activities, and their ability to understand the factors that can limit or enhance their participation in social activities (Adams, 2003). Thus, empowerment in this context would imply understanding the mothers' ability to take an active role in developing their lives within the context of their socio-cultural and political environment by belonging to support groups.

6) Social networks –family, friends and neighbours make up the bulk of one's significant others. Social networks with the world beyond an individual's neighbourhood are important as they provide information in relation to alternative work and income opportunities beyond their daily contacts. Social networks are also important in providing social support and problem-solving abilities beyond the individual or family unit (Giddens, 2013). Interestingly, Mann looks at social networks from a sociological perspective and states that societies are constituted of multiple overlapping and intersecting socio-spatial networks of power (Mann, 2012). The study of social networks in research has been conducted to understand the importance such networks with regard to providing social support and ability to be connected to the wider community. Further, using Friedmann's model, it could be understood how social networks could be a source of encouragement especially in times of adversity.

7) Instruments of work and livelihood – the importance of this, is related to how a households economy can be revitalised (Deshingkor and Farrington, 2009) and the tools available for household production such as physical strength and access to factors of production that can help reduce their poverty.

8) Defensible life space- physical space. This includes safe space for, among others things, cooking and sleeping. Defensible life space also includes intermediate space in the neighbourhood (Friedmann, 1992).

The degree of poverty in a household can thus be assessed by the extent to which families (and in the case of this research, mothers) have access to these eight bases of social power.

However, it must be acknowledged that, whilst a social empowerment model is important in helping to understand the lived experiences of mothers with regard to their poverty and its impacts, the model has shortcomings. For example, not all eight bases of power may apply to individuals. Furthermore, the definition of poverty is relative; it depends on how individuals perceive their situation. Hence, the definition and characteristics of poverty provided by Friedmann are not context specific. The model has also been criticised for not explicitly dealing with identities such as disability and gender that intersect to create oppression (Wilson, 2013). Other commentators (Mullender et al., 2013) state that there is lack of clarity on what constitutes empowerment. Definitions of the concept are mainly influenced by the ideological positions of people. Therefore, empowerment is interpreted differently depending on one's theoretical position. Adams states that *'the richness of theorists and activists in the contemporary field of empowerment is partly responsible for the lack of synthesis in the concept and its application to practice'* (2003:32). There is therefore, no consensus among the theorists on the concept of power.

Despite the highlighted shortcomings, the model is helpful in understanding the quality of life of mothers of children with disabilities. For example, caring for children with profound disabilities can often hinder such mothers from engaging

in income generating activities. This causes them to experience multiple dimensions of poverty, cause them to go deeper into poverty, and make it likely that they will never escape impoverished living. In addition, not only are mothers expected to be the primary caregivers for the child with a disability, they still have to fulfill their other roles that accompany being a wife and mother. Add to this is the fact that many women have to face the stigma; myths and stereotypes that accompany disability in many developing countries, and one can see that such women lead challenging lives indeed.

2.6 Summary of the theoretical framework

This chapter has set out the range of theoretical influences that helped shape the research process. This research adopted a framework using insights from different theoretical perspectives in order to better explore and understand the experiences and views of mothers of children with disabilities in Zambia: social disability model, feminist intersectionality theories and social empowerment model. This study was approached using social model of disability to understand the sociocultural factors that may be active in devaluing mothers of children with disabilities and excluding them from the rest of society. It was also used to explore how mothers view the disabilities of their children. Women in Zambia have the responsibility of clothing, feeding and educating their children; however, their disability or that of a dependent may limit their chances of getting a job and earning a living (Nyoni and Serpell, 2012). This, in turn, would greatly impact on their livelihood and various responsibilities (Emerson et al., 2006, Read and Harrison, 2002). Thus, economic, social and political factors all work together to influence whether an impairment is truly disabling or not. If those systems do not integrate those with disabilities or their carers (mothers in countries such as Zambia) as equal and contributing members of society, the result is poor health, isolation, loneliness and poverty for those with disabilities. The social model of disability was thus important in understanding the lives of mothers of children with disabilities.

The study also used feminist intersectionality approaches to elucidate the power dynamics between men and women, and how disability and motherhood combined impact upon these relations, at individual, household and societal levels. This approach also helped in appreciating how different social categories such as socioeconomic status, gender and disability intertwine to disadvantage mothers of children with disabilities. Another primary tool that was utilised and is consistent with feminist intersectionality theory was the social model of empowerment as postulated by John Friedmann (1992). This perspective focused on aspects of poverty experienced by mothers. It focused on how having a child with disabilities impacts on mothers' ability to among others find or remain in employment, form strong social networks and belong to social organisations. This framework was also relevant to different situations where disempowerment was an issue among mothers of children with disabilities in Zambia that have been neglected and have suffered poverty due to lack of power.

Of course, none of the theoretical perspectives that influenced the study is without some criticism. As well as seeking new empirical data about the lives and experiences of the mothers of children with disabilities in Zambia, critical reflection was also exercised. The data that emerged has also allowed an evaluation of the relevance of these theoretical perspectives which will be explored in the thesis after the chapters that present the study findings. Furthermore, the literature reviewed indicates a dearth of discourse on what it is means to mother children with disabilities especially in sub-Saharan Africa. Therefore, one way of understanding the meanings given to motherhood is through the lived experiences of mothers, especially those with children with disabilities. The next chapter focuses on just such empirical studies and draws heavily on literature from the United Kingdom and other countries within East and Southern Africa.

Chapter Three

Engaging with Literature on Parenting a Child with Disabilities

3.1 Introduction

Having set out theoretical positions in the previous chapter, this chapter reviews the extant literature on the experiences of parenting children with disabilities. Many of the studies in this area have been undertaken in the developed countries particularly the United Kingdom, United States, Canada, Australia and the Nordic countries. Few studies have also been undertaken in the sub-Saharan African countries such as South Africa and Kenya. In the theoretical discussion in chapter two, one of the things I highlighted was that sometimes parenting is approached in a gender-neutral way but in reality what we find is that parenting is unequal and gendered. Mothers are often the primary caregivers (Boyer and Spinney, 2016, Laney et al., 2013, Cowdery and Knudson-Martin, 2005). There is a general body of literature on parenting children with disabilities (Theule et al., 2013, Dabrowska and Pisula, 2010, Estes et al., 2009) and there is specific literature on mothering children with disabilities (Chirwa, 2016, Blum, 2015, Read, 2000).

In order to review this literature, the chapter is divided into six sections. The first section focuses on how literature was searched in the databases. The next five sections reflect the dominant themes that emerged from the literature. The first of these themes focuses on repositioning parents within the context of disability studies. This section focuses on literature on how parents navigate their daily lives following the disclosure of a diagnosis of their child's disability. This is followed by a section that discusses the belief system, attitude and perception about disability. The third section highlights research on the families with children with disabilities with regard to their quality of life with a focus on their financial wellbeing. The fourth section focuses on the social support systems available to such families. Finally, the fifth section discusses how parents of

children with disabilities cope with the challenges associated with raising a child with disabilities.

A diligent search of literature on mothering a child with disabilities in Zambia revealed that there is a dearth of literature in the area. The closest works to the present study include a phenomenological study on the challenges that parents (ten mothers and seven fathers) of autistic children experience in Lusaka (Nyoni and Serpell, 2012). Similarly, another study looked at how eleven mothers of children with physical disabilities utilised community based rehabilitation centres in Lusaka (Hansen et al., 2014). The above two qualitative studies focused on specific conditions of children. Another study was by Traini and Loeb (2012), who used data collected from surveys to compare the living conditions among people with disabilities in Afghanistan and Zambia. Mung'omba's (2008) study focused on people's perception of intellectual disabilities in Zambia. And even then, the aforementioned studies did not look at relevant issues from the mothers' perspective, as my study did. Other qualitative researches explored an intersection of HIV/AIDS and gender among people with disabilities in Lusaka (Parsons et al., 2015, Yoshida et al., 2014, Wickenden et al., 2013, Nixon et al., 2011). These studies did not differentiate males and females. My thesis sought diversity in terms of age and disabilities of children.

Despite the important role that mothers play on behalf of their children, not much attention has been given to their role in Zambia (UNICEF, 2008, Maher, 2005). This section focuses on empirical studies on motherhood and disability undertaken in various parts of the world, this thesis draws on studies undertaken in the West particularly in the United Kingdom. This is where a lot of research has been conducted. Zambia was governed by the United Kingdom until 1964, and as a result, the two countries have a shared political and economic history. Zambia adopted the British legal and education system (chapter one highlighted the connections between the two countries). This study also draws on the literature from East and Southern Africa. Zambia and the countries in the two regions have a shared social and cultural history; they

are all predominantly Bantu speaking people who share a lot of socio-cultural traits (Noyoo, 2000). Based on the above stated reasons, this thesis makes significant references to literature from the aforestated country and regions.

3.2 Literature Search Strategy
3.2.1 Data gathering techniques

Peer reviewed articles and eBooks were accessed from the University of Warwick library databases. These included: materials obtained from databases in the form of academic journals and articles, reports, e-books and documents published by international organisations. Many databases were utilised, among which included: Web of Science, Google Scholar, Encore, Science Direct, JSTOR, Sage, Elsevier, Springer and Wiley. Hardcopy books were also accessed from the University of Warwick. Zambian legal and policy documents were obtained from the Zambian Central Statistical Office, Ministry of Community Development, the University of Zambia and the Zambian Government Printers (CSO, 2011).

3.2.2 Search terms and Inclusion and exclusion criteria

Under this heading, books, conference papers, unpublished papers and meeting discussions were excluded. Peer reviewed, primary research articles were included concentrating on Zambia, sub-Saharan Africa, the United Kingdom and the United States. The rationale behind the utilisation of peer reviewed articles only, was because prior to any serious article publication, each article is critically reviewed. The purpose of this process is to filter the articles to ensure that only works of sufficient quality were sought. A combination of words were used during the searching for materials for the study. Search terms such as mothers, parents, disabled children, disability, care, and family were used. Both qualitative and quantitative studies were included in the search and this process lasted throughout my PhD study period (2013 to 2017). Grant and Booth (2009: 92) state that conducting literature review involves excluding literature that is not directly related to the topic of

research but that it entails *'summarizing the best of what remains.'* I also thoroughly went through all the articles to ensure that they were of appropriate quality, and I further searched all the journals' websites to ensure that the articles were from peer- reviewed journals.

3.3 Repositioning Mothers within the Context of Disability Studies

Within the context of disability studies, mothers parenting children with disabilities are said to *'occupy a liminal position because they are often not disabled and yet they can experience forms of disablism'* (Ryan and Rumswick-Cole, 2009:199). It is therefore, important to understand how mothers navigate as well as approach their daily lives within the context of patriarchal society and disabling environments. Research (Ryan and Cole, 2009, Landsman, 2008, Blum, 2007) indicates that most mothers of children with disabilities report not having experienced disability before having a child with a disability. This has raised the importance of mothers knowing the diagnosis of their disabled child's condition to enable them to navigate and prepare for a long journey of caregiving. For example, scholars (Avdi et al., 2000) note that the importance of a diagnosis is that it enables parents to be involved in decision-making regarding the available support services and other services such as their child's education and other treatment options available. The above assertions are allied with the views of other commentators. For example, it has been stated that communicating a diagnosis to parents about the condition of a child with a disability can be distressful to both professionals and parents (Feniger-Schaal and Oppenheim, 2013, Baird et al., 2000) especially if the child's condition is severe and irreversible, and that the child would experience general limited functioning. In such situations, professionals need to exercise good judgement on how they disclose the condition of the child to parents (Schuengel et al., 2009, Graungaard and Skov, 2007, Mansell and Morris, 2004, Marvin and Pianta, 1996).

Another reason for the importance of disclosing a disabled child's condition to parents is that when parents are informed of the diagnosis, it puts them in a better position to advocate for the removal of social barriers that they and their child with disabilities may face (Barak-Levy and Atzaba-Poria, 2013, Abbott and McConkey, 2006). Literature further, indicates that there has been an increasing number of research on the support services to children with disabilities. In their qualitative study in West Midlands in the United Kingdom on how the three sets of parents of children with disabilities constructed expert knowledge, Avdi et al. (2000) found that parents were appreciative of the advice they received from professionals. The parents further reported feeling appreciated, valued and engaged in decision-making regarding the support services available to their children with disabilities. They described professionals as committed to empowering them (parents) and that they valued the parents' opinion. They concluded that the *'parents in this study constructed their experience […] as very helpful and made frequent references to feeling supported, valued, listened to, respected and consulted.'* (Avdi et al., 2000:335). Interestingly, findings from a cross-sectional study in Northern Ireland and the Republic of Ireland by Keenan et al. (2010) found that diagnostic and planning process were distressful to many parents of children with disabilities. Ninety-two participants of which 92 percent were females and 8 percent were males complained of the long time that statutory diagnostic took. Other studies such as a mixed methods research involving seven mothers and two fathers of children with autism in the United Kingdom by Dale et al. (2006) found that these parents were uncertain of their child's future following the diagnosis. They also complained that diagnosis process took too long.

This disclosure of the diagnosis often results in changes to everyday routines in order to accommodate the demands of caring for the needs of the child with disabilities. Feniger-Schaal and Oppenheim (2013) submit that parents' reaction to diagnosis progresses through three stages. The initial reaction involves denying the diagnosis, expressing shock while others may resolve to search for a reason behind their child's condition. This phase is followed by emotional disorientation that is characterised by feelings of guilt. The third stage

of reaction occurs later in life and mainly involves parents adapting and coming to terms with their child's disabilities. In this regard, Aldersey's (2012) qualitative study in Tanzania with thirteen participants on their perception of intellectual disability revealed that families experienced a crisis after noticing that there was something wrong with their child. The researcher further found that following a diagnosis, a number of families attributed the child's condition to illnesses such as seizures and cerebral malaria. However, this study did not differentiate the gender of the participants. Aldersey and colleagues (2014) conducted another qualitative study on the beliefs and understanding of intellectual and development disabilities in the Democratic Republic of Congo. Their participants included nineteen adults with intellectual and developmental disabilities, twenty-four family members of people with intellectual disabilities and sixty members of the community. Their findings revealed that family members attributed their child's condition to inaccurate and lack of early diagnosis and treatment. The majority of the participants rejected the diagnosis altogether. The parents initial reaction to diagnosis is often said to be similar to news related to bereavement, and this is usually followed by parents going into denial or seeking second opinion or believing that the physicians were inaccurate in their diagnosis (Heiman, 2002). The parents in Aldersey's (2012) and Aldersey et al.'s (2014) studies, sought the opinion of traditional healers and spiritual healers. The findings revealed the importance to parents of traditional healers in the management of many conditions in Tanzania and the Democratic Republic of Congo.

The World Health Organisation in 1978 at its conference on Primary Health Care (PHC) in Alma Ata recognised traditional healing as a form of healthcare system apart from conventional medicine. Traditional medicine is defined as '*a junction of beliefs, practices and stories of ancestral origin adhered to by large groups within populations in different countries in the world*' (Stekelenburg et al., 2005:68). Traditional healers are thus said to play a critical role in the healthcare system especially in developing countries (Chinsembu et al., 2016, Semenya and Potgieter, 2014, Baskind and Birbeck, 2005, Kale, 1995). Literature indicates that as much as 80 percent of the people in sub-Saharan

Africa seek the services of the traditional healers in relation to a range of health issues (Stekelenburg et al., 2005, Kale, 1995).

A number of studies have examined the role of traditional healers in the healthcare system. In Zambia, the role of traditional healers has been highlighted. In a qualitative study involving a focus group discussion with traditional healers, community health workers and tribal headmen on epilepsy care in Zambia, Baskind and Birbeck (2005) identified various reasons why many carers seek the opinion of traditional healers. Among the reasons stated include: inability to access modern healthcare facilities especially in rural areas because of distance to the facilities, delays in being attended to by the medical personnel, and medical user fees make it difficult for most people to seek modern healthcare services. The authors further noted *that 'not only are traditional healers accessible to patients, but they also offer greater cultural and conceptual familiarity […] and offer explanations of disease causality in an ecologically valid fashion'* (Baskind and Birbeck, 2005:1121). The researchers did not state the number of people who took part in a focus group discussion. Interestingly, an earlier qualitative study in rural Zambia (Ndubani and Höjer, 1999) on the role of traditional healers found that the people in Chiawa were more inclined to seeking the help of the traditional healers than modern medicine. The participants in the study perceived traditional medicine as part of their culture.

Aldersey's (2012) study in Tanzania found that the level of education of the thirteen parents of children with disabilities who took part in the study, determined the type of healthcare service they sought for their child with disabilities. Family members with higher level of education were more inclined to seek conventional medicine while the less educated turned to traditional healers because most of them believed that their child's condition was caused by witchcraft and they, therefore, felt that traditional healers could cure the condition. McKenzie and colleagues (2013) undertook a review of literature to understand key issues that affect persons with intellectual disabilities in Africa. Findings of their study showed that a greater number of the parents of children

with intellectual disabilities in Africa sought the opinion of traditional healers in the diagnosis and management of disabilities. Based on the above studies, it is important to take into account the role of the traditional healers in the diagnosis and management of conditions. McConkey and colleagues' (2016) study on the role of family in overcoming stigma revealed that in Zimbabwe, the traditional healers *'attributed the cause of disability to the evil spirits that possessed the child because of the mother's misdeeds or breaking taboos and used traditional rituals to cast out these spiritual'* (McConkey et al., 2016:184). Similarly, Kromberg et al.'s (2008) quantitative study on childhood disability in Bushbuckridge in South Africa found that traditional healers were consulted by parents of children with disabilities in the diagnosis of disabilities and that parents hardly referred children to hospitals. Findings from the above studies revealed that traditional healers in sub-Saharan Africa continue to play a significant role in the management of various conditions.

A cross-sectional study was conducted by Masasa and colleagues' (2005) involving sixty participants who included children and their caregivers attending the physiotherapy at the Tygerberg and Red Cross Children's Hospitals in South Africa. Findings revealed that besides seeking medical treatment and traditional healers, participants in their study stated that it was also important to seek God's intervention. Elsewhere, the importance of spiritual healing has been explored. For example, in Zimbabwe, many people with disabilities turn to the prophets and other members of clergy for healing. The church leaders are believed *to 'heal by divine command and aspire to biblical standards of treatment and cure'* (Mpofu and Harley, 2002:29). The belief that evil spirits cause illnesses and disabilities has made some parents to turn to spiritual healing. The clergy are believed to possess power to diagnose and cure illnesses and disability through divination. They mediate between the people and their gods (Stekelenburg et al., 2005). Another qualitative research undertaken in Tanzania by Mushi et al. (2012) found that faith healing was a significant part of treatment for families with a member with disabilities. An interesting research was conducted by Mwale and Chita (2016) that focused on Pentecostalism and disability in Zambia using six video recordings from three

Pentecostal churches. Their study revealed that disability was depicted as curable though prayers. There was a strong belief among congregants that it was God's will to heal people with disabilities through the clergy. However, the research did not state the type of impairments that were healed through prayers.

The literature above particularly from sub-Saharan Africa shows that some parents were not satisfied with the clinical disclosure hence, they decided to move from one type of healthcare provider to the other in search of a second opinion about the child's condition. For example, they moved from conventional to traditional healers and eventually to spiritual healing. It could be argued that this is similar to parents in affluent countries who seek second opinion from a different medical doctor.

3.3.1 Beliefs, Attitudes and Perceptions

Literature from many sub-Saharan African countries such as South Africa, Kenya, Uganda and Tanzania (Russell and Norwich, 2012, Barak-Levy and Atzaba-Poria, 2013, Baird et al., 2000) indicates that a revelation of a diagnosis can be a grieving process for most families with children with disabilities, involving mothers, fathers and siblings. As already alluded to, parents go through a process of adjusting to the news that a child had a disabling condition. In most cases, studies from across developed and developing countries have revealed that mothers in particular experience their child's disability as disabling them as well. Their significant others, too, react differently to the news of a disabled child (Shakespeare et al., 2017, Schuengel et al., 2009, Graungaard and Skov, 2007, Mansell and Morris, 2004). For example, in most developing countries disability is perceived as a consequence of religious and sociocultural misfortunes which in most cases is directed at a mother (Banda-Chalwe et al., 2012, Jackson and Mannix, 2004, Singh, 2004). Specific literature on the perspectives and experiences of mothers of children with disability in Zambia is nearly non-existent (Chirwa, 2011).

The majority of studies have been undertaken in the Western countries, Adnams' (2010) review of literature in South Africa found paucity of published literature on disabilities. Few have focused on mothers' experiences in developing countries, particularly within the African context such as Tanzania (McNally and Mannen 2013), and Swaziland (Thwala et al., 2015). Recent studies in Zimbabwe (Van der Mark and Verrest 2014) and Namibia (Grobler, 2012) have revealed how religious and traditional beliefs have perpetuated the difficulties that families, especially mothers, of children with disabilities face in their daily lives. These beliefs, coupled with the patriarchal family systems in most developing countries, and especially in sub-Saharan Africa, have made the lives of most mothers of children with disabilities very hard. Beliefs have influenced the way society perceives people with disabilities and families with a member with disabilities (Shefer et al., 2013, Sakala et al., 2012, Durà-Vilà et al., 2010, Danseco, 1997). Patriarchal systems endanger the dignity and freedom of women as their voices and views are hardly taken into consideration, especially in decision-making. Mother-blame is a persistent feature in many developing countries. Added to the principal responsibilities of women in a patriarchal system, mothers of children with disabilities have the daunting task of carrying out their expected domestic roles while juggling the care of a child with disabilities (Singh, 2008, Jackson, 2004, Strega, 2004). This leaves them with little chance to engage in other activities such as those within the labour market and in leisure activities. Women are thus more likely to suffer poverty (Emerson et al., 2009, Lukemeyer et al., 2000), as the subsequent sections will show.

Researchers focusing on dominant societal attitudes towards families with a member with disabilities have pointed to many significant challenges that families, especially mothers and their children with disabilities experience. These include their inability to access support services that would enhance their lives (Davis and Gavidia-Payne, 2009, French, 1994). In Zambia, Mung'omba's (2008) study focused on the status of intellectual disabilities in the country. The study revealed that persons with disabilities and their families were perceived as cursed by God. In some instances, mothers were divorced and forced out of

their villages, together with their children with disabilities, by the village headmen and chiefs. There were also strong beliefs that some conditions such as intellectual disabilities were inherited, and this made many people avoid marrying into such families. Mung'omba's (2008) study further showed that poverty was prevalent in most families of people with disabilities. Recent research in Zambia has also validated Mung'omba's earlier findings that families with a child with severe disabilities may experience marital problems. For example, Nyoni and Serpell (2012) conducted a phenomenological study that examined the impact of having an autistic child on the family relationships in Lusaka. The researchers found that the challenges associated with parenting a severely autistic child had strong impact on the marital relationships. Participants reported experiencing marital discord while others stated that they had been divorced by their partners.

In other Southern African countries, reviewed literature shows that there are some studies (Kelly et al., 2012, Masasa et al., 2005) that have been undertaken on religious and traditional beliefs regarding disabilities. Masasa et al. (2005) carried out a qualitative study in South Africa with sixty caregivers that was aimed at investigating knowledge of beliefs and attitudes around disability in three different groups: black, bi-racial and white. The study brought out intriguing findings: the black community believed that disability was due to witchcraft, while the bi-racial and white groups of caregivers believed that disability was a result of human error, such as not immunising children against childhood diseases like polio and measles. However, all the groups stated that disabilities were a result of God's will, and that it was important to pray to God. On treatment, all the groups agreed that mothers should be involved in the treatment process of a child with a disability. Beliefs about disability affected the way people with disabilities and their carers were viewed by society. However, mothers still accepted the disabilities of their children. Similarly, Kelly et al's. (2012) qualitative study in Northern Malawi revealed that the birth of a child with disabilities in Malawi is considered a tragedy and the mother receives the blame. Participants included ten parents (mothers and fathers), three staff and four local village leaders. In rural areas, mothers are even isolated for

having a child with disabilities – especially those with intellectual disabilities. Their findings revealed that mothers were often excluded from social activities in their communities, and this led to some mothers developing negative attitudes towards their own children. These negative attitudes were strongly embedded in the local culture and society's stereotyped views. Mothers felt that their children with disabilities pushed them into poverty, as they had to spend more time caring for their children at the expense of doing other productive work. The studies did not differentiate the experiences of mothers from fathers.

In East Africa, a study by Hartley et al. (2005) involving fifty-two participants in three districts of Uganda showed strong beliefs that disabilities were a result of mothers grieving the spirits, or witchcraft. Other participants believed that disability was a result of God's will – something that was destined to happen. Mothers, therefore, accepted the disability of their children and the challenges that came with raising such a child. Findings from a study undertaken in Tanzania by Mushi et al. (2012) concur with the findings of Hartley et al. (2005). Mushi et al.'s (2012) phenomenological study on the carers of epileptic children, focusing on mothers' perceptions, social lives, treatment and education gaps in rural Tanzania, found that there were high levels of stigmatisation against such children and their mothers. Both studies (Hartley et al., 2005, Mushi et al., 2012) found that people associated disabilities with shame, and consequently such children were seen as an embarrassment to their family – especially their mother – and they were not supposed to be seen in public. This reflected dominant understanding of disability by society within the context of a medical model. However, negative attitudes were also common in families where children were staying with their grandparents. Despite the negative attitudes, mothers still accepted the disabilities of their children.

Similarly, Aldersey's (2012) study in Tanzania found that stigma was rife in families with a child with intellectual disability. This was manifested in situations where a husband abandoned his wife and the child with disabilities. Most divorced mothers became destitute. Other scholars have however, argued that families can either fight or perpetuate stigma. This mainly depends on how the

family reacts to the diagnosis of disabled child's condition. Reviewed literature indicates a general feeling by the significant others that conditions such as intellectual disability can *'bring shame on families'* (McConkey et al., 2016:183). It is therefore, not uncommon that some families prefer not to expose their child with disabilities in pubic because of fear of being stigmatised and discriminated against (McConkey et al., 2016, Parsons et al., 2015).

However, some scholars have disputed the notion that the presence of a child with disabilities has a negative impact on the marital relationship. For example, Havens (2005) argues that marital challenges can also be because of the stress associated with parenting a child with disabilities while other couples may have had challenges prior to the diagnosis of a child's disability. Havens (2005) further explains that some marital relations improve when the child is diagnosed with an impairment as the couple work together to overcome their challenges of raising a disabled child, and they become emotionally closer.

3.3.2 Quality of Life of Families with Children with Disabilities

This section focuses on the quality of life for the family as opposed to an individual. Society expects its members to have a stable and fulfilling quality of life with a place to live in and a stable income at the minimum (Beadle-Brown et al., 2015, Brown and Schormans, 2014, Brown et al., 2013). Some of the domains of quality of life include satisfaction, health, competence and productivity, empowerment and independence, and social belonging and community integration (Totsika et al., 2017, Schippers et al., 2015, Zuna et al., 2014, Park et al., 2002). However, there is a vicious cycle that connects poverty and disability across different countries. Scholars have buttressed this argument by stating that families with a child with disabilities tend to fare badly in terms of quality of life relative to families without a disabled member (Brown and Schormans, 2014, Brown et al., 2013, Zuna et al., 2014, Schippers et al., 2015, Totsika et al., 2017). For example, Simkiss et al. (2011: 4) contend that "*poverty is both a cause and consequence of disability*". The poor are more at

risk of experiencing poor health than the better-off. These poor health conditions may increase the likelihood of having – among other problems – low birth weight, living in unsanitary conditions, and injuries. These in turn increase the likelihood that people in such conditions may become disabled (Geok et al., 2013, Odom, 2007). Disability, on the other hand, may prevent people with disabilities and their carers from participating in the labour market because of the demand and burden of caring for people with disabilities. This may lead to reduced income at household level (Groce et al., 2011, Beyer and Kaehne, 2008). This argument that those families with a member with disabilities are more likely to experience poverty was supported by a comparative survey carried out by Traini and Loeb (2012) in Afghanistan and Zambia, whose aim was to investigate the relationship between poverty and disability. The study discovered that the relationship was complex, but that people with disabilities had lower access to social services such as healthcare and education, and to the labour market. This created a vicious circle in which people with disabilities were poor and this in turn affected their families, especially their mothers who were in most cases carers.

Closely related to the above argument of a link between poverty and disability is the Capabilities Approach as postulated by Amartya Sen. This perspective was developed to analyse *inter alia* poverty, quality of life and wellbeing (Sen, 2005). The framework focuses on the quality of life of people and their capability to achieve (Mitra, 2006) their potential. The argument is that the poverty of disadvantaged individuals such as those with disabilities and their carers is a consequence of social disempowerment and social exclusion from mainstream society (Knight, 2012, Mitra, 2006, Totsika et al., 2011). This theoretical underpinning therefore, offers some insight into how disability and development are interlinked. The approach is also compatible with the social model of disability and the International Classification of Functioning, Disability and Health (WHO-WB, 2011).

Within the field of disability studies, researchers have laid out various challenges that families of the disabled face. Studies (McCabe, 2010, Shearn

and Todd, 2000) have shown that one of the key determinants of family quality of life is financial stability. Employment is one of the key sources of income. Researchers (Brown et al., 2013, Emerson, 2007) have argued that having a child with disabilities usually impacts on the mothers' ability to remain in employment. Brown and colleagues' (2013) study across fourteen countries found that mothers often gave up work when they had a child with severe disabilities who required constant care. This impacted negatively on the family's income. Caregiving roles added to financial pressure to the stress that mothers experience. The worries of finding money took a toll on these women's health; physical and mental.

Hatton and Emerson (2009) examined the socioeconomic status of a sample of 136 south Asian parents raising a child with severe disabilities in the north of England. The study found that the severity of a child's condition had a negative impact on the health and wellbeing of their carers. The research further showed that mothers were more distressed than fathers, and suffered greater socioeconomic deprivation. The main reason for such challenges faced by mothers, was that the majority of them were not working. They, therefore, depended on their spouse's support. They also suffered isolation, insecurity and social anxiety as they hardly participated in community activities. They spent most of their time looking after their children with disabilities. Findings further revealed that the inability by mothers to work affected their financial independence. One of the strengths of this study was that the researchers undertook an independent back-to-back translation from Urdu, Gujarati, Bengali and Hindi into English in order to attain accuracy in the translated transcripts. However, the study only focused on parents whose children were in school; the socioeconomic status of parents whose children were not in school was not investigated.

Totsika and colleagues (2017) reviewed data from 2009/10 from the United Kingdom's Department of Health and Work and Pension on survey of carers to understand the quality of life of the carers in the UK. They found that the majority of the carers were female, single, uneducated, unemployed and they

suffered economic hardships. The study further discovered that the burden of care had an impact on the carers' health and personal life. Eighty percent of the carers had poor health outcomes. Elsewhere in the United Kingdom, other studies have confirmed that mothers of children with disabilities suffer disproportionate levels of poverty.

Emerson et al. (2006) assert that the poor socioeconomic position of mothers has a direct bearing on a wide range of adverse outcomes for their children, and these include barriers to accessing social services and provide basic necessities for their children. Emerson et al. (2006) carried out a study that used data from the 1999 National Statistics Survey of Mental Health of children and adolescents. This was a quantitative study that applied multivariate analysis to twenty-two health indicators. The results showed that the poor health status of children with disabilities was closely related to maternal education and occupational status, revealing the close association of mothers and their children with disabilities. The findings are related to the above (Hatton and Emerson, 2009). They concluded that the condition of children with disabilities had negative effects on the health and socioeconomic status of their mothers. However, the findings of Emerson et al. (2006) raise some methodological concerns: the study was based on data collected by another agency, therefore the way Emerson and colleagues' (2006) categorised data may not have reflected or provided in-depth information about the participants' own perspectives. Data was collected in 1999; so many aspects of the mothers' situations could have changed between the time of data collection and analysis as could social conditions. Importantly, one advantage of the research was that it was based on a National Survey; therefore, it is highly likely that the data addressed a broad spectrum of mothers' opinions and policy initiative services. Both studies (Totsika et al., 2017, Emerson et al., 2006) provided some understanding about the interconnectedness of economic hardship and the health of the family.

Findings of Emerson and colleagues' (2006) study are similar to those of Blackburn and colleagues (2010). The latter study used data from the Family

Resource Survey, and was aimed at investigating the prevalence rates of child disability in the United Kingdom. They reported that the number of single-headed households was greater for families with a child with disabilities than those without. Their survey further revealed that families with a child with disabilities were poorer than those without a child with disabilities. The above thesis is supported by Read and Harrison's (2002) assertion that *'higher costs of disabled living, combined with the more restricted earning opportunities for adults in the households with disabled children, leaves many susceptible to living in poverty'* (Read and Harrison, 2002: 216).

Findings of studies undertaken in the United Kingdom are similar to those conducted in other countries. For example, a systematic review by Parish and Cloud (2006) in the United States showed that families' financial wellbeing was affected by the high cost of caring for children with severe disabilities. The research revealed that the out-of-pocket expenses associated with raising a child with disabilities were twice as much as raising a child without disabilities. Carers, who in most cases were mothers, found it difficult to meet the expenses of caring for a child with special needs. Parental employment was thus important in avoiding poverty, given the costs associated with caring for a child with disabilities.

The inability to juggle between the competing responsibilities of looking after a child with disabilities and working usually leaves many mothers with little time to find enough resources. Other researchers (McCabe, 2010, Parish et al., 2008, Shearn and Todd, 2000) have shed light on how this impinges on families of the disabled. The time needed to care for children with disabilities affects their (parents) employment, with some parents having to resign from their jobs while others reduce their working hours. This results in reduced income and savings for the family. The increased financial burden leads to high poverty levels among mothers and their families (Grut and Ingstad, 2010, Park et al., 2002). The severity of the disability determines whether mothers stop working altogether or reduce their working hours. In the case of Parish and colleagues (2008), their study found that increased treatment costs, specialised day care,

and making the home environment safe for children with disabilities increased the financial burden on mothers. Overall, their findings revealed that the presence of a child with disabilities in the family impinged on the family's socioeconomic opportunities and resources.

Similarly, commentators such as Karst and van Hecke (2012) argue that material deprivation is often common among such parents of children with autism in the United States. Autistic children needed increased investment in their healthcare and education among other costs. Caring for autistic children reduces the chances of the mothers gaining full-time employment. This often leads to reduced finances at home, which results in high poverty levels among most families with autistic children.

In Kenya, Gona and colleagues (2011) carried out research into the experiences of mothers of children with disabilities. This was a qualitative research that involved interviewing twenty carers, ten community members and five teachers. The study participants stated that providing care to a child with severe disabilities was extremely demanding. They hardly had time to do other household chores or to engage in income-generating activities. This often resulted in exhaustion and financial challenges. The studies cited above (Parish and Cloud 2006, Parish et al., 2008, Gona et al., 2011) bring out interesting points on the different challenges faced by mothers of children with disabilities; juggling the competing responsibilities of looking after a child with disabilities and maintaining their employment, so as to have the financial resources needed for supporting their children and the families at large. However, the studies did not bring out the voices of mothers on what should be done to help them face these challenges and the poverty that they suffer. In Cape Town, South Africa, researchers (McKenzie and McConkey, 2015) exploring the views of families caring for an adult with intellectual disability found that these families were generally poor and in most cases, they suffered poor health outcomes. The carers who in some cases were grandparents often expressed their commitment to care for their disabled family members. These carers in most cases needed social support.

3.3.3 Social Support to Families with Children with Disabilities

Having a child with disabilities can increase stress experienced by families. Social Support has been defined in both qualitative and quantitative terms (Sipal and Sayin, 2013, McLaughlin et al., 2012). In qualitative terms, social support refers to the degree to which social networks provide emotional, material and moral support. Quantitatively, it is defined as *'social relationships or the structure of a person's social relationships'* (Sipal and Sayin, 2013:1104). Stress can limit mothers' capacity for positive interaction with their children as well as with other family members and society at large. Feher-Prout (1996) argues that a recurring theme in literature is that mothers whose child with disabilities has lower levels of communicative skills experience high levels of stress and depression than mothers whose child with disabilities has higher levels of communicative skills. Feher-Prout (1996) cites an example of mothers of autistic children as being more stressed than mothers of children with other disabilities such as Down's syndrome. Despite the aforementioned challenges (stress, poor social relationships), the family is supposed to be the first source of support to the mother of a child with disabilities (Aunos et al., 2008, Heiman and Berger, 2008, Bromley et al., 2004). It is also said that mothers of children with disabilities experience various challenges. Their significant others such as family and friends may not be in a position to help, hence, some could decide to withdraw resulting in mothers experiencing loneliness (Warner et al., 2011, Heiman and Berger, 2008).

To that effect, theoretical models of social support applied to families with children with disabilities have a number of similar components. Among the models that have been used are the stress and coping models. These models *'identify that psychological and emotional outcomes for parents of disabled children may be affected by the availability of resources to them'* (White and Hastings, 2004:181). The stress-strength model posits that individuals experience stress when the support resource base available to them is inadequate or not helpful (Domma and Giordano, 2012). Similarly, the social model of disability states that families experience stress due to various

socioeconomic and environmental factors (Blackburn et al., 2010, Benson and Karlof, 2009, Estes et al., 2009). These can be as a result of poverty, negative societal attitudes to families with children with disabilities, inadequate social support and, hostile and inaccessible physical environments. Most of the restricting and damaging situations faced by mothers of children with disabilities are socially constructed (Theule et al., 2013, Freedman et al., 2012, Meadan et al., 2010, Read, 2000). Other scholars have identified different types of resources available to families that are stressed due to having a child with disabilities. These include: personal resources of each family member (financial, physical and emotional wellbeing), internal resources of the family system (cohesion, adaptability, communication, mutual support) and external social support (Harper et al., 2013, Woodman, 2014).

Social networks are also one of the key sources of support to families with a disabled member (Barker et al., 2011, White and Hastings, 2004). Studies have revealed that social networks act as a buffer when a mother finds herself in the challenging situation of providing lifelong care to a child with disabilities. Woodman (2014) conducted a longitudinal study with 108 parents of children with developmental disabilities in Massachusetts. The researcher found that family cohesion was a mediating factor of stress levels among families with children with disabilities. Stronger social support from the significant others was key to parents' ability to cope with their child's condition. Earlier research found similar findings. Ryan and Cole (2009) conducted a qualitative study in the United Kingdom aimed at understanding advocacy and activism among mothers. The study had a sample size of thirty-six mothers of children with Attention Deficit Hyperactivity Disorder (ADHA). It was discovered that the mothers viewed social networks with their colleagues who also had children with disabilities as important. They formed peer support groups that helped them cope with the stress of looking after a child with ADHA. It was through such groupings that mothers shared their experiences, and through interactions they were able to develop a sense of value of themselves and of their children. This shows that they understood their children's condition within the context of a social model of disability. The importance of peer support groups has also

been buttressed by other scholars (Shilling et al., 2013, Kingsnorth et al., 2011) who argue that these groups are cardinal in providing information and emotional needs of the members which are significant in enabling parents to cope with the stress associated with caregiving. The assertion by Kingsnorth and colleagues (2011) and Shilling and colleagues (2013) allied with the wider literature. For example, some peer support groups are actively involved in advocacy and challenging stereotyping that the members and people with disabilities experience (Hall, 2013, McCabe, 2007, Goodley, 2000).

Other scholars have sought to understand the significant role that peer support groups play in the lives of families with children with disabilities. For example, Aldersey et al. (2016), Read et al. (2010), and Ryan and Runswick-Cole (2008) all highlight the benefits of peer support groups on parents' health, wellbeing and impact on family. Other researchers have argued that peer-to-peer support helps in enhancing social identity among members (Hartley et al., 2005). Through these groups, parents learn from the experiences of others; personal growth and they support each other. Peer support groups promote emotional, social and practical support such as coping and problem solving skills (McCabe, 2010, Nyoni and Serpell, 2012). Peer support groups are also said to facilitate the feelings of social companionship, belonging and community with other parents, reducing feelings of loneliness and enabling sharing of ideas and strategies to advocate and protect the rights of their children with disabilities (Kingsnorth et al., 2011, Mueller et al., 2009).

Similarly, McConkey et al. (2013:10) submit that peer support groups are important networks *'based on strong social ties between similar people which maintains a strong group loyalty and reinforces specific identities.'* McConkey and colleagues' (2013) argument is confirmed by a systematic review study (Shilling et al., 2013) on peer support for parents of children with disabilities that identified four themes. Findings demonstrated that parents who belonged to peer support groups had a shared identity and there were benefits to members because they were learning from each other's experience. The study further found that members described the support they received as invigorating and

promoted personal growth. Social identity among group members was cardinal in helping them develop a sense of belonging and this was significant in moderating feelings of isolation that many had before they joined peer support groups, and some members described it as empowering. Other studies have found that social support from peers leads to lower stress levels, and members develop positive attitudes towards their disabled child's condition (Aunos et al., 2008, Boyd, 2002). In sum, the research findings suggests that peer support groups are important in providing psychosocial support to the members which in some cases has fostered their coping mechanisms. These groups have also been key in advocating for the rights of people with disabilities.

The role of social support is emphasised further by Boyd (2002) who states that increased burden of disability on families is often related to fewer social capital which exacerbate stress among families. Other studies have highlighted how mothers perceive social support they received from their significant others. For example, Read (2000) conducted a qualitative study in England with twelve participants. The researcher found that mothers acknowledged the importance of help rendered to them by other household members in caring for family members with disabilities. The focus was on understanding how mothers viewed themselves and how they were adapting to their new role of caring for a child with disabilities. Support was in the form of psychosocial, practical, morale-boosting, and financial aid. Another study involving thirty-three participants of adolescent children undertaken in England, by White and Hastings (2004), on social and professional support given to mothers of children with moderate-profound intellectual disabilities, discovered that there were positive correlations between social support and the wellbeing of mothers. The findings further revealed that informal support resulted in higher parental wellbeing than formal support.

Elsewhere in England, Shih's (2012) research examined perceptions of becoming and being the mother of a child with disabilities. It involved interviewing sixteen participants, all based in Newcastle. Three theoretical perspectives underpinned this qualitative study: the social model of disability,

feminism and postmodernism. Some of the findings showed mothers admitting to having difficulties in raising their children with disabilities. They responded that the existing support system, including their families, often failed them. *'Several mothers reported a grief when losing their intimacy with existing social networks because of their child's impairments'* (Shih 2012:93). Mothers experienced isolation from close friends and relatives, and some even felt that they had lost their social life and position in society. This limited their ability to engage in income-generating activities, as people did not want to be associated with such mothers. Shih's findings validate the notion that mothers of children with disabilities are often banished from mainstream society, suffering isolation and marginalisation.

McConkey et al., (2013) undertook studies in Scotland and Wales. Their aim was to find out how families, particularly mothers, perceived the family support services provided to their children with severe disabilities (up to the age of 19 years). The support took the form of *'overnight breaks in a small residential home for two-seven days at a time. A complimentary service is also provided in which staff will come to the family home and accompany the young person at activities with the local community while providing advice and training to the family in managing behaviours'* (McConkey et al., 2013: 272). The results indicated that service staff, who included social workers, provided valuable support to families. Support was in the form of providing them with relevant information and guidance on how to care for their children. The mothers interviewed acknowledged valuable support rendered to them, also stating that they experienced reduced stress levels and feelings of disempowerment, especially due to the training they received. The above findings are in line with the stress-strength model, which emphasises the importance of social support to individuals (Domma and Giordano, 2012).

Related to McConkey et al.'s (2013) study, was Welch et al.'s (2012) research focusing on the use of direct payments to fund short breaks for families with a child with disabilities in England. The study was quantitative in nature and involved 348 families. Short breaks are support services offered to carers of

children with disabilities, which enable them to take time off from their responsibility of caring for such a child. Direct payment is the money given to eligible carers to use in payments for short break services. Findings showed that both direct payments and short breaks were of great help to the carers as they enabled them to undertake other activities. Male carers were less keen on using the services compared to their female counterparts. Meanwhile, it was found that carers who had attained *'higher levels of education were more likely to use direct payments'* (Welch et al., 2012: 906). This was attributed to the fact that they were well informed about the services and had confidence in them. The study also revealed that it was not easy to access the services because information about them was complicated and unclear. Socioeconomic status also influenced the perception and accessibility of the services.

Existing literature in the developed countries has thus shown that social support is multidimensional, it can be formal or informal, and can come from different sources such as a spouse, extended families, social institutions, or statutory and voluntary services (White and Hastings, 2004, Read, 2000). There seems to be a general agreement on the importance of social support to mothers of children with disabilities (for example McConkey et al., 2013, Ryan and Cole, 2009, Read, 2000). However, Shih (2012) has a different view of social networks. Her findings revealed that often social networks are not supportive to mothers. Further, these studies (Doutre et al., 2013, Shih, 2012, Read, 2000) have some strengths in that they did not specify the disabilities of children, thus, they helped to capture a broader picture of the impact of disabilities on mothers. The main value of all the above-cited studies was that information was elicited from the parents using semi-structured interviews; they (parents) therefore, had opportunity to express their personal experiences.

Leiter et al. (2004) conducted a study using data drawn from a 1998-1999 survey involving 100 families with disabled children aged below 18 years in twenty states in the United States. Eighty-eight percent of those who participated in the study were mothers; 7 percent fathers and 5 percent were grandmothers. However, only data from mothers was included in the analysis

because mothers were the primary caregivers. The aim was to investigate the effects of mothering a child with disabilities. The findings revealed that mothers viewed the task of parenting a child with disabilities as difficult: they highlighted bathing, feeding and caretaking as some of the most challenging tasks. Mothers of children with severe disabilities were under greater burdens in providing care to their children. The results further showed that caregiving roles took a greater toll on mothers both financially and emotionally. However, mothers valued the support they received from their friends and families. Much as the study brought out interesting findings, Leiter et al.'s (2004) study has some limitations in that the data used in the analysis could have been outdated considering that it was collected in 1998-1999 while the researchers analysed and drew conclusions from it five years later.

In the developing world, the weakening social fabric in terms of social ties has resulted in less social support for parents of children with disabilities. Most societies in sub-Saharan Africa were mainly modelled along the lines of mutual aid were families where closely knit (Metz and Gaie, 2010). The family and society was the source of support to people with disabilities and their carers. The lack of social support has had ramifications on carers (Mathambo and Gibbs, 2009, Richter et al., 2009) Scholars have identified stigma, social isolation and poor mental health among most carers in sub-Saharan Africa as some of the consequences of the weakening of social fabric (Campbell et al., 2008). Studies have examined the impact of lack of social support on carers. In Kenya, Geere et al. (2013) undertook a study whose objective was to explore the physical effects on carers of children with moderate to severe motor impairment. They used a mixed methods approach, and it was informed by the framework of the International Classification of Functioning, Disability and Health in defining disability (ICF). The researchers used purposive sampling to recruit twenty mothers of children aged between five and sixteen years. The study formed part of a larger action research project aimed at designing effective programmes and services to integrate persons with disabilities and their carers into the community. The carers were segmented according to their *'sex, age, care/child relationship and distance between carers' home and*

therapy centre' (Geere et al., 2013: 383). Interviews were conducted in the preferred language of the participants. They were audio-recorded, then transcribed and translated into English. The results showed that mothers suffered stress, exhaustion and tiredness. The participants asserted that they needed help, especially with suitable equipment such as wheelchairs for their children.

Grut and Ingstad's (2005) study in Kenya also brought out some useful findings on the experiences of parents of children with disabilities – especially those with profound or severe disabilities such as autism. Mothers faced severe challenges even from within their households, as fathers often demanded that mothers hide a child with disabilities from the public, and in some instances women were divorced for having a child with severe disabilities, while others were not financially supported by their spouses. This resulted in increased poverty levels among some mothers. Such cases (Grut and Ingstad, 2005) are not isolated, but are common in most developing countries where children with severe disabilities and their mothers are banished by society (Geere et al., 2013). Commentators such as Mung'omba (2008) attribute such negative attitudes to ignorance, and strongly entrenched traditional and social norms that are prevalent in some developing countries. Azar and Badr (2010) argue that the kind of support parents receive has a direct bearing on family cohesion, acceptance of the disability, and their ability to develop problem-solving skills. The above studies further revealed that most households in sub-Saharan Africa have a hierarchy and division of labour mediated by gender and kinship. Mothers play a major role in caring and providing for their children with disabilities (John, 2012, Azar and Badr, 2010, Chang and Hsu, 2007), while fathers in some cases reject and deny their wives for having a child with a disability.

Much as the above studies bring out interesting findings regarding the importance of social networks and highlighting some of the challenges and support mothers encounter, there are methodological issues that arise especially from the Greere et al.'s (2013) study, which make any generalisation

of their findings somewhat unreliable. Their study focused on a particular age group of children (five-sixteen years), and generalising their findings to mothers whose children are above sixteen or below five years is difficult. However, one of the positives about Geere et al's. (2013) study was that the participants were segmented into different categories. This helped to capture the views of parents with diverse characteristics (such as age, gender and carer/child relationship). Thus, my study focused on mothers raising children with disabilities up to the age of eighteen years – the official definition of a child (UNICEF 2008).

3.3.4 Coping Mechanisms and Resilience

Having a child with severe disabilities can be challenging to families. It can impact on all family members, and can affect both internal and external family relationships. McConnell (2014) and colleagues posit that all families of people with disabilities *'face the same enduring adaptive challenge: to create and maintain a sufficiently predicable daily routine, or way of life, that is congruent with their values and aspirations, and the needs, interests and competences of individual family members'* (McConnell et al., 2014:3). Parents often have to balance their needs, those of their child with disabilities and the needs of the family given their circumstances. Despite the difficulties they encounter, many parents adapt and adjust to the demands of parenting a child with disabilities. However, the coping strategies that families adopt are not homogeneous, they differ from family to family and from individual to individual. The coping mechanisms that they adopt are usually influenced by their culture (Lyons et al., 2010, Graungaard and Skov, 2007, Taanila et al., 2002). Research findings have validated the view that parental coping strategies are grounded in cultural factors. John's (2012) study found that culturally prescribed gender roles influenced the types of coping mechanisms that carers adopted.

There are different strategies that families employ to overcome stressful events such as parenting a child with disabilities. Scholars (Dabrowska and Pisula, 2010, Evans, 2010 Salmela et al., 2010) identify a problem-oriented coping strategy. This involves dealing with the source of a distressful situation. Another strategy is referred to as an emotional regulating coping strategy, this involves adopting efforts that reduce stress and help to maintain an inner feeling of satisfaction (Aldao et al., 2010, Evans, 2010). Sloper (1998) on the other hand suggests two different models that parents can use to cope with or adapt to the birth of a child with disabilities: the collectivist and individualistic models. Families who use the collectivist model depend on their significant others to adapt to the birth of a child with a disability. Help in this model is informal, and this is more common in developing countries. Families in developed countries are more likely to adopt the individualistic model (Taamila et al., 2002); seeking professional help to a greater extent in helping them cope with the birth of a child with a disability (Chavira et al., 2000, Read, 2000). On the other hand, Dardas and Ahmad (2015) identify various coping mechanisms that families adopt. These include: confrontive coping which involves suppressing the situation before it escalates; seeking physical, moral and emotional support, and *'detaching oneself from a stressful situation and minimise its significance […] some parents of the disabled children use 'cognitive coping strategies such as positive appraisal, reframing, acceptance and planning'* (Grant et al., 2013:283), these strategies are said to increase maternal wellbeing.

Sloper (1999) argues that the cognitive model of stress and coping is a model that views people as capable of interpreting and responding to stressful situations that may arise when caring for a child with disabilities. However, the actions people take to cope with stress depend on the availability of resources that include financial, material, physical, psychological and social factors. Hence, the support to families with children with disabilities should be centered on such resources. Park and colleagues (2002) state that a *'safe and comfortable house is a basic condition for any family life'* (Park et al., 2002:156). Poor families are therefore, more likely to face difficulties in coping with a disability since this is also likely to affect the quality of housing available to

them. The socioeconomic status of a family is thus one of the most powerful variables in coping with a child's disability (Chirwa, 2016, Salmela et al., 2010, Heiman, 2002). Families that have strong interpersonal relationships and adjusted their socioeconomic life are more likely to cope with condition of the child with disabilities (Pasana, 2011, Smith et al., 2011). Other authors (Lyons et al., 2010) have stated that families of children with disabilities are more likely to overcome the challenges associated with caregiving if they have strong social relationships. Research that have been carried out on the coping strategies of families have focused on models of social support. For instance, Hastings and colleagues (2005) sought to explore the coping strategies mothers and fathers of the disabled adopt. This study was conducted in the United Kingdom. These researchers found that *'positive coping was associated with lower levels of depression in mothers and fathers of children with autism'* (Hastings et al., 2005:386).

The above arguments are congruent with studies (Kelly et al, 2012, Gona et al., 2010) undertaken in Africa. Gona et al.,'s (2010) study in Kenya identified family cohesion and togetherness as one of the most important coping strategies for most mothers. Gona and colleagues (2016) conducted another study in Kenya that explored the coping mechanisms of families with children with disabilities. The researchers reported that parents used problem and emotion-focused coping strategies that involved respite care where an autistic child was taken to a boarding school. Beliefs that the child was a gift from God, and that they were special parents chosen by God helped most parents overcome the grief of having a severely autistic child. In Malawi, according to Kelly et al's. (2012) study, mothers were able to cope with the disability of their children by working with community health volunteers. However, they faced challenges, since while they always spent their money on other family members, men often used any surplus income to secure a second wife especially if the first wife had a child with severe disabilities.

However, as much as resilience among mothers is enhanced by social cohesion and togetherness, the strength of African social ties is weakening

owing to the collapse of traditional support systems coupled with social inequality, high prevalence of HIV/AIDS and increasing poverty levels, especially among rural dwellers (Nooyo, 2000). Despite weakening of family support, other researchers have shown that families can build resilience in their child with disabilities by offering positive experience and support (Greeff et al., 2010, Heiman, 2002, Goodley, 2000). This is especially true in the developing world where there is usually a shortage of professional support. Families can play an active role of challenging commonly held societal views and attitudes towards people with disabilities and their carers, and by advocating for the rights of their children with disabilities (McConkey et al., 2016). For example, a study in Northern Ireland revealed that knowledge and competence on the part of those who were marginalised was key to greater inclusion (Abbott and McConkey, 2006). Writing as both researchers and parents of a child with disabilities, Turnbull and Turnbull (2015) affirm the view that parents have a role to play in advocating for the rights of their children with disabilities.

3.4. Summary of Literature Review and Formulation of Research Questions

The literature review in both developed and developing countries indicates that there are a range of studies that considers the implications for family members of having a child with disabilities. A number of studies show the numerous and varied challenges that mothers specifically experience in raising their children with disabilities. Research shows that having a child with disabilities has an effect on the socio-economic status of the carers, who in most cases are mothers. A review of literature has revealed that the main reasons for this- are the high costs associated with accessing treatment, and the reduced capacity of carers to engage in formal employment due to the demands of looking after children with disabilities. These factors make it difficult for mothers and their children with disabilities to escape from impoverished living circumstances (McFerson, 2010, Park et al., 2002). Disability and poverty have a complex and interdependent relationship. An intersection of poverty and other individual characteristics such as gender, age and the environment such as

76

socioeconomic and cultural can perpetuate poverty among families of the disabled. In addition, negative societal attitudes, especially in sub-Saharan African countries, towards people with disabilities and their carers' increases stress among parents (Woodman, 2014, Harper et al., 2013, Azar and Badr, 2010, Boy, 2002). This can in turn affect the wellbeing of parents. However, on one hand, studies reviewed provide some valuable insight into how the United Kingdom has successfully developed and implemented programmes and strategies aimed at helping mothers overcome some of the challenges. On the other hand, it is evident that there are still some significant research gaps when it comes to experiences of mothers in sub-Saharan Africa and Zambia in particular. To highlight local issues and strategies, there is need to provide empirical evidence through research that can aid these countries in coming up with ways of helping carers.

There is, therefore, a need for interventions that will empower as well as enable mothers. To this end, it was important that their views, opinions and experiences were sought, so that interventions can be tailored towards the areas of their greatest need. However, as already alluded to, a diligent search of literature on mothering a child with disabilities in Zambia revealed that there is a dearth in literature on the uniqueness and barriers to provide insight into their lives. This is despite Zambia's enactment of legal and policy frameworks on gender and disability (CSO, 2012a). Raising a child is enormous and challenging to parents but this is more challenging to those raising a child with a disability. The literature, further, shows that women and people with disabilities in Zambia rank among the poorest of the poor. Further, part III of the Persons with Disabilities Act of 2012 prohibits discrimination and stigmatisation of people with disabilities, their parents, and guardians and custodians of children with disabilities (CSO, 2012a, CSO, 2010). In order to improve the circumstances of parents, we must understand what their experiences are. Some studies that have been undertaken in Zambia include Mung'omba's policy brief on the status of people with intellectual disabilities; Nyoni and Serpell's (2012) study explored the experiences of families with children with autism; Traini and Loeb (2012) used survey data to investigate the relationship

between poverty and disability in Afghanistan and Zambia. Other studies have focused on the intersection of HIV/AIDS, gender and disability (Parsons et al., 2015, Yoshida et al., 2014, Wickenden et al., 2013, Nixon et al., 2011). All the above mentioned studies did not differentiate the experiences of mothers from fathers. This chapter together with the previous chapter provide the rationale for my research questions, which are: the overarching research question was: What are experiences of mothers in respect to parenting a child with disabilities in Zambia? This study also sought to answer the following:

1. How do mothers view their children's disabilities and the causes of them? And what are their reactions to the child's diagnosis?
2. How does having a child with disabilities affect the mothers' in relation to power dynamics at the family and society level?
3. What are the mothers' present concerns and sources of support, and what are their future expectations?

Chapter Four

Methodology and Methods

4.1 Introduction

Previous chapters have set the stage and established the rationale for the study. Chapter one focused on the context in which the research was conducted and explored the living experiences of mothers parenting children with disabilities. Chapter two discussed the theoretical frameworks that informed the study. Chapter three discussed the literature on parents of children with disabilities across both developed and developing countries. It was shown that parenting is not a gender-neutral activity and that it is both a gendered and unequal experience (Blum, 2015). In this chapter, therefore, I discuss the link between the theoretical underpinnings that informed this research project and the methodology and methods employed in addressing and exploring the research questions. The chapter will start by elucidating the crosscutting theory of methodology concepts that informed and provided a framework for this research design. An overarching research aim of my study was to explore and make sense of the experiences and desires of mothers parenting a child with disabilities in Zambia from their own perspectives. The study was conducted as a small scale qualitative inquiry undertaken in two geographical areas of Zambia with a diverse sample of mothers of children with disabilities using predominantly biographical methods and incorporating some participatory elements. Thereafter, in this chapter, I will show how the theoretical assumptions were employed and translated into the entire process of empirical research in order to adequately address the research questions.

The theoretical assumptions and research questions adopted in this research necessitated the development of a methodology within a qualitative paradigm. The rationale for this was to design a methodology that would give a voice to mothers to express themselves about their lived experiences. In addition to individual interviews, this study also involved mothers in earlier stages of the

research process through focus groups, in order to add a participatory dimension to the study. The mothers therefore, were positioned as participants, but also some mothers were consultants at the outset since I relied on their knowledge on the research setting which informed subsequent stages of the study. Some members of the parent support groups were also involved in shaping the interview guide and they provided guidance about the dos and don'ts when out in the field. Consistent with this approach was the central significance of social constructionist grounded theory approach to generate new knowledge from the mothers' own accounts. The nature and sensitivity of the enquiry required a high level of reflexivity not least because of the power dynamics involved of, a male researcher interviews women.

This chapter is divided into seven sections with the first part addressing the range of philosophical assumptions that informed the study. The second section discusses the methodological approach adopted for this research which is derived from these philosophical assumptions. The third section addresses aspects of the pre-fieldwork activities that helped provide an orientation to the fieldwork. The fourth focuses on activities undertaken during fieldwork such as study sites, gatekeepers, criteria used to select participants, the demographic characteristics of the participants and the methods used to obtain data. The fifth section looks at participants primarily in relation to ethical issues. The sixth part deals with issues related to positionality and reflexivity and how a critical stance was maintained throughout the whole process of fieldwork. Finally, the seventh section describes how data was managed, analysed, and interpreted and its integrity maintained.

4.2 Philosophical Underpinnings

The methodological theory on which my study is based draws on a range of ideas from interpretivism, grounded theory and feminist approaches, with a view to according pre-eminence to the knowledge elicited from the participating mothers. The philosophical assumptions presented in this methodology chapter are congruent with the theoretical perspectives outlined previously in chapter

two. For example, it integrates ideas from a feminist standpoint which argues for giving a voice to the marginalised to be heard, and it also explored the impact of different social conditions on mothers (Morrow et al., 2015, Beckman, 2014, Mullender and Hague, 2005). The philosophical and theoretical frameworks that informed this study further helped shape the methods and the interpretation of research findings. Scholars (Peta et al., 2015, Thill, 2015) have argued that an epistemological framework which operates within or draws from these key paradigms is essential to the development of a research model which takes into account mothers' position as a marginalised group in society, as well as engaging with them in order to research their views on what it means to parent a child with disabilities. The philosophical perspectives that informed this study are outlined below.

4.2.1 Interpretivism Paradigm

This view emerged as a response to the positivist paradigm's view of social reality. Proponents of positivism advocated for the use of natural sciences methodologies, and assumed the possibility of objectivity in the social sciences (Hasan, 2016, Aliyu et al., 2014, Crotty, 1998). However, interpretivism focuses on understanding social reality from the standpoint of those experiencing it (Gimbel, 2016, Thanh and Thanh, 2015). In the worldview of interpretivism, people attach varied and multiple meanings to social reality; this has led to researchers seeking to obtain diverse views on social phenomenon (Packard, 2017, Creswell, 2007). The focus of interpretivism on seeking people's accounts from their own perspectives, is often called an inside or emic perspective (Bryman, 2012, Hennink et al., 2011, Bryman, 2004, Gabel and Peters, 2004).

Using an interpretivist perspective as a framework enables mothers to construct their lived experience of parenting children with disabilities. It also allows them to construct their social worlds in different ways. For example, scholars (Kashima, 2014, Rubin and Rubin, 1995) have argued that people attach subjective meanings to their social world and that these meanings are shaped

by their knowledge, experience and their socio-cultural and historical factors. Thus, my research explored individual narratives and experiences, but at the same time situated these mothers within the context of the prevailing Zambian sociocultural, historical, political and economic milieu, not to mention their personal contexts that enabled me to gain an understanding of their needs, views and opinions.

This epistemological approach to research is consistent with the overarching theoretical imperatives stated in the research questions of the study. The main question is: what are experiences of mothers in respect to parenting a child with disabilities? The other questions are:

1. How do mothers view their children's disabilities and the causes of them? And what are their reactions to the child's diagnosis?
2. How does having a child with disabilities affect the mothers' in relation to power dynamics at the family and society level?
3. What are the mothers' present concerns and sources of support, and what are their future expectations?

4.2.2 Grounded Theory

Grounded theory was used because it is consistent with interpretivist perspective since it emphasises generating a theory from data from the perspectives of people experiencing a phenomenon (Baker et al*.,* 1992, Mills et al., 2006). The first proponents of grounded theory, Glaser and Strauss (1967), stated that theory could be discovered from data. However, much as they advocated for a grounded theory approach, the two proponents had different epistemological orientations. Glaser was inclined towards a positivist approach while Strauss was an interpretivist, with an emphasis on symbolic interactionism, (Goulding, 2005, Pandit, 1996, Punch, 1999).

The original formulation of grounded theory by Glaser and Strauss (1967) drew upon objectivist assumptions founded in positivism. This version of grounded

theory focuses on answering the question 'why' (Charmaz, 2008). According to Charmaz (2005:4) 'Glaser's (Glaser, 1978; 1992) strong foundation in mid-twentieth century positivism gave grounded theory its original objectivist cast with its emphases in logic, analytic procedures, comparative methods, and conceptual development and assumptions of an external, but discernible world, unbiased observer, and discovered theory.' Like Glaser, Strauss and Corbin also advocated for positivistic procedures in grounded theory, albeit different ones. Their version was rooted in pragmatism and symbolic interactionism with an emphasis on meaning, action, and process (Strauss and Corbin, 1990, 1998). As much as Strauss and Corbin stressed the importance of meaning and action, they introduced new technical procedures and made verification an explicit goal and, thus, brought grounded theory closer to positivist ideals. In divergent ways, the earlier versions of grounded theory by Strauss and Corbin as well as Glaser's discourses were underpinned by objectivist assumptions that were grounded in positivism.

An objectivist grounded theory has been criticised for remaining within a positivist paradigm. Charmaz (2008:401) eschews objectivist grounded theory by stating that *'grounded theory strategies are just that-strategies for creating and interrogating our data, not routes to knowing an objective external reality…through value free.'* Charmaz developed a social constructivist grounded theory method that aligns with the interpretivist paradigm, and a social constructionist theoretical position. A social constructivist grounded theory, according to Charmaz (2006, 2008), adopts grounded theory guidelines as tools but does not subscribe to the objectivist, positivist assumptions. The approach emphasises the studied phenomenon rather than the methods of studying it. Scholars who draw on this perspective take a reflexive stance on modes of knowing and representing studied life. That means giving close attention to empirical realities and our collected renderings of them—and locating oneself in these realities. This means that social constructivist grounded theorists are cognisant of the subjectivity of a researcher such as their prior interpretative frames, biographies, and their interests. Researchers are also influenced by prevailing social conditions as well as their relationship

with the participants, research context and concrete field experiences among others. However, all variations have similar methodological strategies, use of theoretical sampling and are closely connected to an interpretive perspective (Charmaz et al., 2011b). My study's methodology drew on Charmaz' social constructivist approach to grounded theory because this was a biographical study, and biographical studies involve social construction of reality (Charmaz et al., 2011a, Merrill and West, 2009, Roberts, 2002). This research project encouraged the participants' own interpretations and meanings to emerge with minimum predisposition by the researcher.

However, it must be noted that all variations have similar methodological strategies, use of theoretical sampling and are closely connected to an interpretive perspective (Charmaz et al., 2011b).

4.2.3 Feminist Intersectionality

My research drew on the feminist epistemological insights because the lived experiences of women were central to the whole project. Gender is significant in feminist research, and the focus is to elicit meanings women give to their social world (Cuomo and Massaro, 2016, Hesse-Biber, 2013). The use of feminist perspectives in my study meant that the voices of mothers of children with disabilities were prioritised because they are less privileged and less powerful members of society in Zambia (O'Reilly and Gordon, 1995). However, the debates amongst feminist researchers about intersectionality have reflected various views such as perceiving intersectionality as a discipline, rather than a theoretical and methodological concept. These different views are influenced by people's ontological and epistemological orientations (Cho et al., 2013, Gopaldas, 2013, Lewis, 2009).

One approach to intersectionality focuses on the *'discursive debates about the scope and content of intersectionality as a theoretical and methodological paradigm'* (Cho et al., 2013: 785). As a theory of methodology, it illustrates the relationship between theory and practice. The rationale is that practice ought to

inform theory, and that in turn theory should influence best practices. Indeed, intersectionality has been adopted and used both as a theory and a methodology particularly by feminist researchers (Beckman, 2014, Yuval-Davis, 2006), because issues of difference and identity are essential to feminist researchers (MacKinnon, 2013, Crenshaw, 1991).

Feminist intersectionality provided a new methodology to this study as it aided in capturing different facets of oppression and challenges that mothers experience in Zambia (Yoshida et al., 2014, Carbin and Edenheim, 2013, Wickenden et al., 2013, Nixon, et al., 2011). As a theory of methodology, this perspective drew on the vantage points of the research participants (Chapman, 2011, McCall, 2005, Nash, 2008). In light of this, intersectionality helped in uncovering various identities that perpetuate the discrimination and stigmatisation of the mothers on the basis of the condition of their children. In short, my research project contributed to the development of feminist research on mothering a child with disabilities.

4.3 Biographical Methods

Biographical studies in qualitative research can be traced back to as early as the 1920s when the Chicago School of Sociology carried out life story research with immigrants (Lal, 1986). It also has roots in oral history (Suarez-Ortega, 2013). A biographical method *'denotes research which utilises individual stories or other personal documents to understand lives within a social, psychological and/or historical frame'* (Merrill and West, 2009:10). These approaches are underpinned by interpretivist perspectives that emphasise that in the telling of stories, individuals give meaning to their lived experiences albeit in specific contexts (Findlay et al., 2016, Pool et al., 2015). Biographical studies have thus, become significant as a form of qualitative research because they provide the means through which people's accounts about their life transitions and changes can be obtained directly through their narratives (Corbally, 2015, Cederberg, 2014, Howatson-Jones, 2011). These perspectives draw on symbolic interactionism, phenomenology, narrative analysis and grounded theory among

others (Merrill, 2015, Goodson, 2012, Roberts, 2002, Chamberlyne et al., 2000). As delineated by Merrill and West (2009) and elucidated by Fillis (2006), personal or life documents are often used to discover and understand cultural meanings and to identify changes that occur in individual or group experiences over time.

There is, however, a debate within research studying people's life histories. One view supports the idea of realism, that is, reality can be objectively studied based on the stories that reflect a lived experience (Roberts 2002, Rustin, 2000). For other scholars (Barabasch and Merrill, 2014, Spector-Mersel, 2010, Plummer, 2001) biographical methods eschew the idea of objectivity and scientific approach in understanding life experiences. They further, argue that identities such as class, ethnicity and gender have to be taken into account when getting information from participants.

Feminist perspectives and biographical methods are congruent. For example, biographical methods enable voices that remain marginalised to be heard through telling their story about their personal lives (Merrill, 2015, 2003, O'Neill, 2014, Alheit, 2007). Feminists such as Reinharz (1992) and Oakley (1981) remind us that feminist research focuses on the lives of women by giving them a voice. Feminists in biographical studies are concerned with theorising and exploring the different ways through which women's experience is gendered by different processes of life, such as symbolic discursive processes and material conditions (Goodley et al., 2004, Wengraf, 2001). Biographical and feminist approaches in the present study complemented each other in making voices of mothers of children with disabilities central to the research process (Roberts, 2002). This thesis furthermore, relied on the epistemological standpoints of feminist research by understanding the social world of mothers of children with disabilities from their life accounts.

Biographical methods were therefore, appropriate for the current study because they enabled me to fully understand the experiences of mothers within their socioeconomic and cultural context as they narrated their stories, constantly

linking their lives before they had a child with disabilities, their present situation and how they perceived their future and that of the child with disabilities. This view has also been buttressed by Merrill (2012:25) who argues that biographical methods *'highlight the dynamics of structure and agency, the self and society, and macro and micro by placing the individual within a historical, cultural and social context.'* In telling their stories, the participating mothers were also constructing their identity and as Giddens (1991) opines, this reflected that identity and biography are intrinsically linked.

Table 1: Stages in the Research Process

Setting / Activities	Lusaka	Kaoma
Pre-defined fieldwork		
Ethical Approval	Fourth week of February 2015	
Pilot study	First week of April 2015	
Meeting gatekeepers	First week of May 2015	First week of September 2015
Meeting government/NGO's officials	Second and third week of May 2015	Second and third week of September 2015
Focus group discussions	First week of June 2015	Third week of September 2015
Fieldwork phases		
Biographical interview with mothers	June to August 2015	October to December 2015
Transcribing	June to December 2015	
Data analysis	June 2015 to February 2016	
Exit meeting	Last week of June 2015	Last week of December 2015

4.4 Pre-Fieldwork Phase

4.4.1 Developing the Proposal

In the pre-fieldwork stage, research objectives were tailored in a way that reflected a process of investigation and inquiry that would elicit knowledge relating to caregiving roles of mothers. From a detailed review of literature and theoretical framework, research questions were developed that focused on the mothers understanding of disability and how they navigate through their daily lives with their children with disabilities. I also prepared all the necessary supporting documents and submitted the proposal for ethical scrutiny and approval by the Humanities and Social Sciences Research Ethics Committee (HSSREC) of the University of Warwick (see Appendix A), my letter of introduction written by my supervisor (see Appendix B), information sheets for the participants (Appendix E), interview guide (see Appendix D) and consent forms for the participants (Appendix D). I also inquired from the University of Zambia if I needed to obtain ethical clearance from their ethics committee before commencement of fieldwork. I was however informed that it was not necessary if I produced evidence that the study had ethical approval in the United Kingdom. A draft interview schedule was also prepared on the basis of the literature review and with the intention of amending this subsequently through the involvement of mothers of children with disabilities in Zambia (see section 4.8 below).

4.4.2. Making and Maintaining Contact with Potential Gatekeepers

Throughout my study period prior to data collection, I kept in touch with the Kaoma District Forum and Cooperative Society of the Disabled, and the Zambia Federation of the Disability Organisation, an umbrella organisation for all Disabled People's Organisations in Zambia. I kept updating them on how the study was to be undertaken and the inclusion criteria of the participants, among others (the role of gatekeepers within the research is discussed in much greater detail in section 4.7.1).

4.5 Pilot Study

Before embarking on the main study, I piloted the draft interview guide with mothers likely to have similar characteristics as the potential interviewees (Keen et al., 2007, Stevens et al., 2016, Strydom and Delport, 2011). The first pilot study was undertaken in the United Kingdom with a mother of a child with disabilities. The purpose of this study was to test the data collection instruments to gain the view of a potential participants, and to review them with my supervisors before I went to the field. The other two pilot studies were undertaken in an urban and rural areas of Lusaka Province after preliminary meetings with the gatekeepers. Pre-testing of data collection instruments helped highlight whether the participants easily understood the questions, and if the interview guide was good enough to generate data that was relevant to answer the research questions (Mackey et al., 2017, Bryman, 2004). It also shed light on the prevailing conditions in the field and allowed for adjustment in the data collection instruments. The pilot study further, helped me gain interviewing experience prior to embarking on the actual study.

4.6 Fieldwork Phase

I arrived in Lusaka, Zambia in the second week of April 2015 to start data collection and lived in Lusaka until the end of August when I moved to the second study site, Kaoma. I was in Kaoma from September until the end of December 2015 (See Table 3).

4.7 Study Sites

The study was conducted in two sites, Lusaka and Kaoma. The former is the capital city and the economic hub of Zambia, while the latter is in the Western province and is one of the poorest rural towns in Zambia (CSO, 2010). The two towns thus provided contrasting situations, enabling me to gain an in-depth understanding of the experiences of mothers in both settings that gave me a diverse holistic picture of their situation.

Kafue National Park

Kaoma
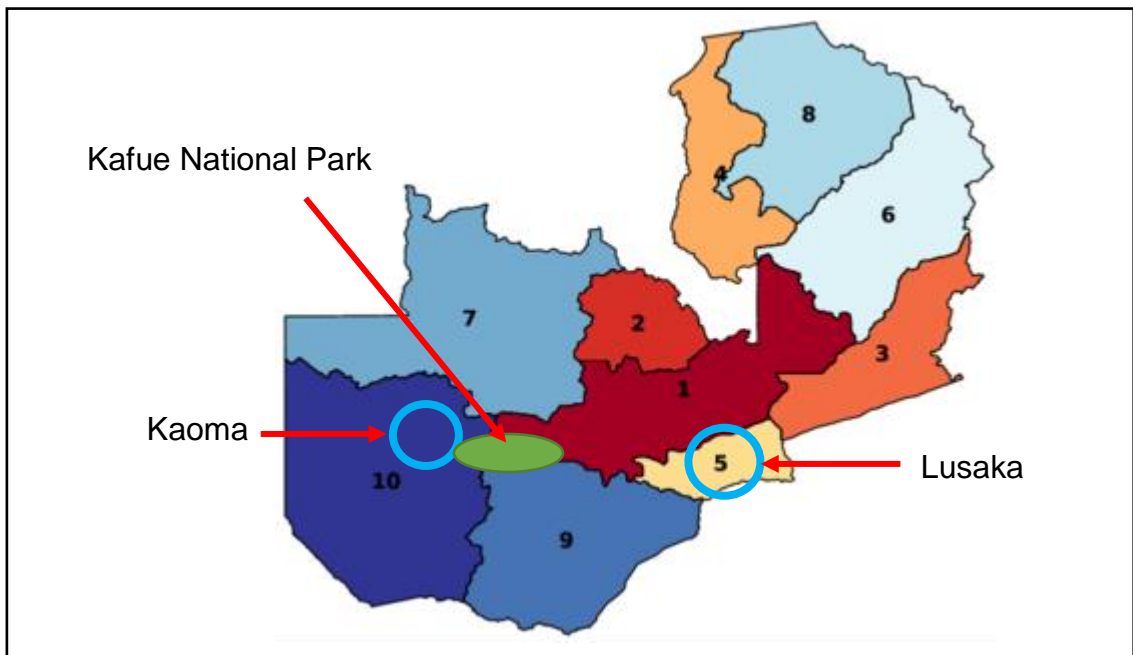
Lusaka

Figure 2: Map of Zambia

Figure 3: Lusaka

Lusaka, with an ethnically mixed population of approximately 2.2 million (CSO, 2012a), was chosen because of its high levels of economic activities, inhabitants with diverse backgrounds resulting in a multicultural population. Consequently, research participants were drawn from diverse sociocultural, economic, and ethnic backgrounds. Lusaka is a familiar place to me, I grew up and received all my education up to undergraduate level there. Thus, it was not a problem for me to situate myself and get the work done. Language was also not a problem as the language spoken is Nyanja, which I speak fluently.

Figure 4: Kaoma

Kaoma lies about 300Km (186miles) from Lusaka and is the first entry point to the Western province from Lusaka. It is populated by mainly rural and some peri-urban settlements. It has a population of approximately 200,000 and is predominately populated by the Lozi and Mbunda speaking people (CSO, 2012c). It was also chosen because it is one of the towns with the highest numbers of persons with disabilities (CSO, 2012a). The Western province as a whole has the highest percentage of people with disabilities in Zambia, standing at about 15 percent. The province also has the highest incidence of poverty, at about 64 percent (CSO, 2012b). Kaoma was also an appropriate site for the research project because I had already established contact with the Kaoma

District Forum and Cooperative Society of the Disabled (one of the gatekeepers), with whom I had previously undertaken research. This made it easier to establish rapport with the organisation, as they already knew me.

4.7.1 Gatekeepers and Negotiating Access to the Participants

In the initial stages of fieldwork, I drew on the knowledge and skills of the gatekeepers in navigating in the field in both research sites (Bengry-Howell and Griffin, 2012, Cole, 2009). They enabled me to gain formal access to the fieldwork sites quickly, to establish close and supportive working relationships, and build trust and confidence with the participants. This played a significant role in gathering rich and detailed data (Reeves, 2010, Johl and Renganathan, 2010, Caine et al., 2009). A detailed discussion of the gatekeepers is in section 4.7.3.

4.7.2 Meetings with Government and NGOs Officials

I also had meetings with heads of government departments and NGO officials. I was alerting them that I was undertaking a study because I knew that I would go back to them at a later stage when I have the findings as they are significant in the dissemination of findings and securing impact. I further wanted to understand what is being done in policy terms in relation to people with disabilities and support services available to vulnerable people so that if need arose; I was in a better position to refer participants to appropriate resource agencies. I met with officials from Ministry of Community Development and Social Welfare, ZAFOD, Archie Hinchcliffe, Beit Cure Hospital, Leonard Cheshire International, ZAPCD and Special Hope Foundation.

4.7.3 Gatekeepers in Lusaka
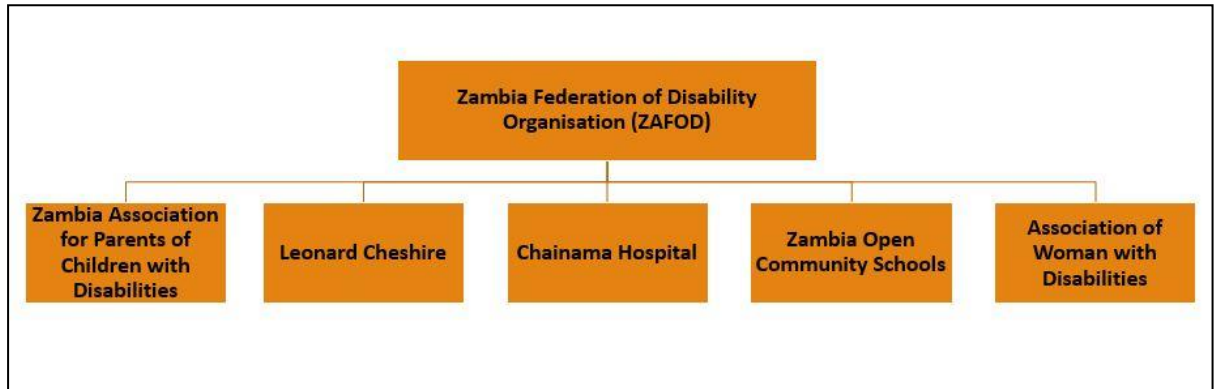
Figure 5: Disabled People's Organisation in Lusaka

During the second week of my stay in Lusaka, the first organisation I visited was the Zambia Federation of Disability Organisations (ZAFOD). This is an umbrella body of all disabled people's organisations (DPOs). I had been in touch with the organisation even when I was developing the proposal; hence, they had an idea of what my study was about. They provided me with a list of organisations they thought were relevant to my study and they also gave me the details of the contact persons in these DPOs.

I contacted the Zambia Association for Parents of Children with Disabilities (ZAPCD) and we had a meeting on May 11, 2015. ZAPCD works with other partner organisations, such as such as Archie Hinchcliffe, and together they offer physiotherapy at the University Teaching Hospital and at six (6) health centres in Lusaka namely: Matero, Chilenje, Chawama, Kanyama, Chelstone and Chipata.
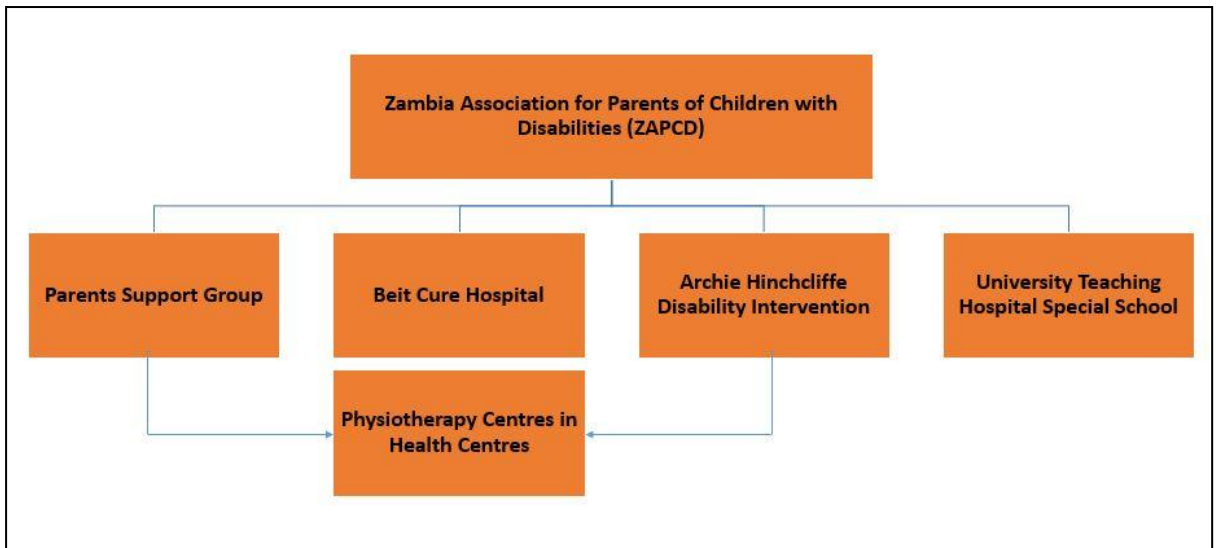
Figure 6: Organisations that ZAPCD work with

ZAPCD introduced me to the parents support groups and Archie Hinchcliffe. On my own, I further searched for more organisations that could link me to potential participants. I managed to get in touch with an organisation called Special Hope Network; it is an organisation that focuses on children with intellectual disabilities by providing them with physiotherapy services and food.

4.7.5 Gatekeepers in Kaoma

Gaining access in Kaoma was relatively easy because the gatekeepers, Kaoma District Forum and Cooperative Society of the Disabled made arrangements for me in advance to meet parent support groups. Being a predominantly a rural area, the gatekeepers liaised with the village headmen (despite not being a gender-neutral term, it is used to refer to traditional leaders in a village, so it can refer to men and women). When I went there, all was in place; they had even identified potential participants from a parent support group. However, since one of my interests was diversity, I explained to the members of the forum during the first meeting I had with them that I needed to apply both purposive and snowball sampling in recruiting participants. And this was the approach we adopted.

Gaining access to villages in Kaoma was not without challenges. For example, one day, we were on our way to do an interview with a mother of a child with disabilities who lived in an area called TBZ on the outskirts of Zambia's biggest National Game Park, Kafue. As the park can be dangerous, my travelling companions were a couple who had a child with disabilities. In the heat of the day, elephants tend to rest in the middle of the road, as they love the heat from the tarmac, and this was the case on that day. As we approached, our vehicle stopped and my companions told me to switch off the engine, and to remain perfectly still and quiet inside the vehicle, as the elephants can charge if they feel threatened. I felt panicky inside, but they were relaxed and said this happens fairly often. We waited for over an hour before the elephants left the tarmac. However, it was a reminder that researchers can face danger, especially when heading out to gather data from rural areas that border national game parks. It is quite a risk. When we told the locals what we had gone through, they told us it was common for animals to stray, and that animal-human conflict was high in the area (that is, elephants destroying homes and crops, lions killing domestic animals, among others).

4.8 Methods

As earlier alluded to, this study involved me, a male researcher, with no direct experience of parenting a child with disabilities, interviewing mothers of children with disabilities. One focus group discussion comprising of ten mothers was held in both research sites with the mothers who were members of parent-support groups. One of the reasons for this was to develop strategies of undertaking fieldwork. It was also a way of making the whole process participatory. This participatory element, although modest, was important in order to take on board the unique strengths of the local knowledge in the research process (Chatrakul Na Ayudhya et al., 2014, Halcomb et al., 2007, Morgan, 1997). In as much as I am familiar with the local culture, I still thought that it was important to get the views of mothers on socio-cultural norms before starting data collection (Bergold and Thomas, 2012, Horowitz et al., 2009, Cargo and Mercer, 2008, Lambert and Loiselle, 2008). These focus group

discussions in both study sites ensured that the interview questions were clearly stated, easy for participants to understand and that they were relevant to the lives of the participating mothers.

In Lusaka, I had a focus group discussion with ten mothers drawn from various communities and of diverse backgrounds. These were members of the parent support groups. A week prior to the focus group discussion, I met individually those who agreed to take part in the meeting and provided them with the interview guide. These discussions were not recorded but I wrote the main points in the field diary. Mothers who took part in the meeting made some suggestions some of which I incorporated in my research:

1. That the interviews take place in the homes of the participants and not at the health centres. They said that the implications of meeting at the health centre was that it would raise ethical issues as I would be required to be cleared by the Ministry of Health to use their facilities.

2. They proposed that I change my other research site from Kaoma to Mongu, a provincial capital and much bigger town. They gave the reason that mothers come from all the towns in the province to meet for a day once a month. I would, therefore, have a large pool of mothers, and they suggested that I do focus group meetings. I did not go with this suggestion because it would have been challenging to conduct over 10 interviews within a single day.

3. The mothers also proposed that we have an exit meeting once I was done with data collection. And this was done with the members of ZAPCD.

4. On the interview guide, they recommended that I include questions on self-blame and where mothers seek medical help for their children. This was done.

5. They expressed willingness to interview them as individuals in an event that I did not have enough or had difficulties recruiting participants.

I also held a focus group meeting with ten members of the parent support group in Kaoma. Just like in Lusaka, the discussions did not ask details about their lives. I was not as familiar with Kaoma as I was with Lusaka, hence, I needed to know, as a male researcher, what I needed to keep in mind when interviewing women especially as I did not know their culture too well. This addressed the issues of reflexivity and positionality. The participants made the following suggestions:

1. Just like in Lusaka, they recommended that interviews be conducted in the research participants' villages.

2. They indicated that the starting point in every village was to see the headman who would in turn introduce me to his or her subjects. Only after that would I be able to conduct interviews with the prospective research participants

3. On the issue of written consent, they advised that most people in the villages were illiterate; hence, verbal consent in the presence of a third person would be most appropriate.

Both focus group meetings were insightful and valuable in making suggestions to the whole research process. They all stated that the interview guide was clear and appropriate. This approach of first seeking the views of the local people, accorded mothers an opportunity to describe their lives from their own perspectives by letting them review the data collection instruments. This participatory element, much as it could not completely remove the power balance (hierarchical relationship) between me (male) and the mothers, to some extent it helped in addressing it. This was in tandem with most feminist researchers who challenge the traditional hierarchy between especially a male

researcher and the researched (Denzin and Lincoln, 2008, Hesse-Biber et al., 2004, Reinharz and Davidman, 1992).

4.8.1 Establishment of Inclusion Criteria for Participants

During the focus group meetings, we also talked about the criteria for those who were to be invited to take part in the project. These were to be mothers of children with disabilities, whose children have had impairment for one year or more, serious enough to warrant service provision. As elaborated by Shih 2012, the rationale for having a criterion of having had impairment for one year or more is that *'it can take over a year for families to settle into a pattern of adaptation to disability'* (Shih 2012:78). Participants were all residents of either Lusaka or Kaoma. However, I did not specify the types of impairments for this research, as I aimed to uncover a broader picture of the impact on mothers. Furthermore, restricting to a particular form of impairment would have made it difficult to find potential participants owing to the small population. For example, according to the population census of 2010, Kaoma has a population of approximately 200,000 (CSO, 2012c).

4.9 Recruiting Participants, Sample Size and Sampling

Data collection in every research project is of critical importance because *'it is meant to contribute to a better understanding of a theoretical framework'* (Etikan et al., 2016:2). The primary sample for this study consisted of mothers whose children with disabilities were eighteen years and below [official age of a child in Zambia, (CSO, 2010)]. Overall, thirty mothers (fifteen from each study site, Kaoma and Lusaka) participated in the study. This number was sufficient enough that allowed me to do an in-depth investigation of their experiences. Researchers (Malterud, et al., 2016, Marshall et al., 2013, Adler et al., 2011) support the notion of having small sample sizes in qualitative studies, especially when studying hard-to-reach participants. This sample size was also justified because this was a biographical study that involved a detailed analysis rather than generating a large amount of data. Literature that I reviewed also showed

that, thus far, this was an initial and exploratory study in Zambia. Overall, regardless of the size, a sample must be able to provide enough insight into any given phenomenon under investigation (Robinson, 2014, Marshall et al., 2013). Additionally, mothers of diverse range (segmented according to age, and diverse in terms of the age of their children, and the nature of disability) were recruited with the aim of capturing a variety of experiences. Depending on their age or that of their children, mothers shared different experiences.

The goal of this study was not to recruit a representative sample, but rather to focus on participants who possessed certain attributes that were relevant to this study (Bryman, 2008, Cohen, 2007, Taylor, 2013). I therefore, employed a combination of purposive and snowball sampling in recruiting the participants. Cohen (2011) submits that purposive sampling involves choosing participants who have certain qualities or experience that would be essential for the research. I used purposive sampling to establish part of my sample. In addition to purposive sampling, I also employed snowball sampling. *'The snowball sampling outreach strategy finds individuals […] who have the desired characteristics, and uses that person's social networks to recruit similar subjects, in a multi-stage process. After the initial source helps to recruit respondents, the respondents then recruit others themselves'* (Sadler et al., 2010: 2-3). This nonprobability sampling technique involved the use of existing study participants already initially recruited through purposive sampling to recruit future participants from among their acquaintances (Mehl, 2012, Guthrie, 2010). The mothers that I interviewed were asked to link me to other mothers. Then, after I interviewed the referred persons, I would ask them whether they also knew other women in the community who also met the study criteria (Cohen et al., 2011, Miller, 2003, Grinnell, 1998). This process proved to be successful and continued until I could not find any variation in data (Urquhart, 2013, Carey, 2012, Lapan, 2012, Oktay, 2012, Birks, 2011, Corbin, 2008). In summary, I was identifying themes that were emerging from the interviews which I was exploring further in subsequent interviews.

Snowball sampling has the advantage of reducing time and cost associated with recruiting participants of sufficient diversity (Bryman, 2012, Sadler et al., 2010). This sampling strategy was effective because someone familiar to the potential participants and whom they could trust linked them to the study. This helped in alleviating any concerns potential participants may have had, and it resulted in a high response rate. Although I employed snowballing, I placed much emphasis on diversity in terms of age, socioeconomic status, number of children a mother had, and their marital status so that I could have nuanced understanding of their lived experiences.

I was aware of some of the limitations of snowball sampling such being biased towards highly connected respondents meaning that potential participants who are not part of social networks may not be included. And also, the possibility of participants easily recognising other participants (Hennink et al., 2012, Sadler et al., 2010), which may inhibit their participation and generate fears about confidentiality. I compensated for the above weaknesses by initially recruiting participants that were as diverse as possible, and the use of gatekeepers helped to array the fears about confidentiality.

4.9.1 Demographic Characteristics of Participants

I interviewed thirty mothers whose child had a disability significant enough to qualify for intervention services. The participants' children had a wide range of disabilities at the time. These included; cerebral palsy, spinal bifida, scoliosis, osteogenesis imperfecta, muscular dystrophy, autism and Down's syndrome. Fourteen of the participants were single or divorced at the time whilst four were widowed. Three where in polygamous marriages and nine were still married at the time of the interview. The study participants ranged in age from 22 to 59-years. Levels of education varied as well; twelve never attended school, while seven went as far as grade nine which is considered as basic education in Zambia. Six of the women had completed high school while one was still studying. Two of the mothers had undergraduate degrees. In the rural area

(Kaoma) nine of the participants had no formal education, with the remainder having basic education, although they still could not read or write.

The table below outlines the demographic characteristics of the participating mothers.

Table 1: Demographic Characteristics of the Participants

No	Name	Age	Marital Status	No of Children	Position of Disabled Child	Age of Disabled Child	Type of Impairment	Education level of Participant	Research Site
1	Mwila	35	Divorced	1	1	8	Cerebral Palsy	Grade 12	Lusaka
2	Gertrude	49	Widow	3	2	18	Scoliosis	Grade 9	Lusaka
3	Chilinda	54	Married	5	Last born	18	Osteogenesis Imperfecta	University Degree	Lusaka
4	Astridah	40	Widow	4	2	15	Hearing Impairment	Grade 12	Lusaka
5	Zion	31	Single	1	1	10	Cerebral Palsy	Grade 12	Lusaka
6	Emma	22	Single	3	1	6	Cerebral palsy	Still studying-	Lusaka
7	Violet		Married	5	4	12	Hydrocephalus	No education	Lusaka
8	Dorcas		Married	3	3	4	Hydrocephalus	No education	Lusaka
9	Sophia	23	Single	1	1	5	Cerebral Palsy	Grade 9	Lusaka
10	Amake Fortune	28	Divorced	3	2	8	Autism	Grade 9	Lusaka
11	Susan	27	Divorced	1	1	3	Cerebral Palsy	Grade 12	Lusaka
12	Tandiwe	46	Married	5	5	5	Cerebral Palsy	University Degree	Lusaka
13	Faggy	47	Divorced	5	2 disabled children	18 and 14	Muscular dystrophy	Grade 9	Lusaka
14	Esther	29	Divorced	1	1	1	Cerebral Palsy	Grade 12	Lusaka
15	Hilda	59	Widow	9	9	18	Cerebral Palsy	No education	Lusaka

No	Name	Age	Marital Status	No of Children	Position of Disabled Child	Age of Disabled Child	Type of Impairment	Education level of Participant	Research Site
16	Cleopatra	30	Married	4	3	12	Cerebral Palsy	Grade 9	Kaoma
17	Amake Gideon	27	Married	3	3	3	Hydrocephalus	Grade 9	Kaoma
18	Amake Esther	24	Widow	2	1	7	Sclerosis	Grade 7	Kaoma
19	Chikombe	31	Polygamous Marriage	1	1	4	Cerebral Palsy	Grade 12	Kaoma
20	Boma Angela	38	Divorced	5	5	11	Hydrocephalus	Grade 9	Kaoma
21	Boma Kanjengu	34	Married	3	3	9	Cerebral Palsy	No education	Kaoma
22	Boma Kanyanga	40	Married	6	2 disabled children	15 and 12	Sclerosis	No education	Kaoma
23	Boma Musuwa	30	Divorced	4	4	8	Cerebral Palsy	Grade 10	Kaoma
24	Shenda	Over 40	Polygamous Marriage	3	3	18	Down's syndrome	No education	Kaoma
25	Boma Kasweka	28	Divorced	4	4	6	Cerebral Palsy	No education	Kaoma
26	Boma Anne	51	Polygamous Marriage	6	6	15	Cerebral Palsy	No education	Kaoma
27	Boma Mwila	33	Divorced	4	4	3	Muscular dystrophy	No education	Kaoma
28	Kaimbu	26	Divorced	2	2	2	Cerebral Palsy	No education	Kaoma
29	Boma Barbara	40	Divorced	2	1	9	Cerebral Palsy	No education	Kaoma
30	Namutondo	39	Married	5	1	14	Muscular dystrophy	No education	Kaoma

4.10 Data Sources

4.10.1 Biographical Interviews

Biographical interviews focus on the researched telling a life story usually over an extended period of time (Roberts, 2002, Chamberlyne et al., 2000). The nature of the interview, therefore, requires a researcher to establish a rapport and create a good environment for the interviewee to tell their life story (Cederberg, 2014, Howatson-Jones, 2011, Rosenthal, 1993). Kazmierska (2004:181) sums up the core of these interviews by stating that *'in this type of interview, people are stimulated to tell the stories of experiences they have lived through.'* Biographical interview emphasises on giving control and ownership of the narrative to the interviewee (Goodley et al., 2004, Schutze, 2008). The emphasis on giving much weight to the voice of the researched, a focus on life experience and giving control of the story to the researched are what make biographical interviews distinct from other interviews (Roberts, 2002, Wengraf, 2001, Miller, 2000). In the case of my study, biographical interviews were conducted with thirty mothers. The rationale for using biographical interviews over other forms of interviews was; firstly, little was known about mothers' experiences; secondly, such interviews (biographical) gave control to the mothers to look at their present situation in relation to their past, thus allowing them to tell their story within the context of their lived experiences under their own control. The interviews also focused on how the participants envisioned their future and that of their children with disabilities. This study therefore, drew on a feminist approach to interviewing (Brugar, 2013, Riessman, 2008). Details about information given to potential participants is in Appendix C.

All mothers had been provided with an information sheet prior to the interview (see Appendix C) and the interviews were audio recorded with the permission of the participants which was included within the informed consent form (see Appendix D). They were assured that I would be the only one who would listen to the recordings because I needed to transcribe them

for the purposes of analysing. All the participants in both study sites agreed to audio record the discussions. This study adopted an interactive technique, where a range of topics covered was shared with the women at the outset of the interviews. This type of interviewing allowed for exploration of further issues or lines of thought not previously considered that emerged from the discussions (Cohen et al., 2011, Roberts, 2002).

Thus, the interviews were preceded by reminding the mothers of the purpose of the research including issues of confidentiality and their right to withdraw at any time without giving reasons. Prior to the discussion I made sure that I established rapport with the participants. I prepared an interview guide that was refined with the help of the members of parent support groups. This had topics but the interview schedule was flexible so I let the conversation flow naturally depending on the story of a mother. The themes for questions mainly focused on three levels; their first reaction and that of their significant others to the disability of a child. Secondly, I discussed with them how they are navigating through their daily lives now, and thirdly how they foresee their future and that of their children. Thus, these interviews did not strictly adhere to the guide. I tried as much as I could to create a relaxed, informal atmosphere where the participants were able to freely share with me their personal stories.

Reflections: my reflections on conducting biographical interviews was that since this type of interview entails a participant sharing their life history which in some cases can be very sensitive, it was important for me to handle the rapport I built with the participants cautiously. In this regard, I remained and listened attentively as the mothers narrated their stories. I never tried at any time to interrupt any of the participating mothers. I also learnt the importance of transcribing at the earliest convenient time after the interview when the story was still fresh in my mind. In doing this, I always remained attentive to my research questions. However, what I noticed was that despite generating rich information from biographical interviews, I also experienced challenges. For example, I found the interviews to be long and

time consuming, therefore, there is a need for diligent planning when choosing this method of interviewing.

Interviews were mainly conducted in local languages; Lozi in Kaoma, and Nyanja and English in Lusaka. At the close of the discussion, I thanked the participants for their time and asked them if they had any questions, concerns or clarification. I also reminded them that they were free to contact me if they wanted us to talk about other issues concerning the interview. Throughout the process of conducting interviews, all the participants were willing to share their stories. I scheduled all the interviews at the time and place convenient to the mothers. There were moments where mothers could stop talking, and I paraphrased what they had been saying. In some instances, we changed the topic to help them regain their composure. I also listen attentively, I sought clarification where I was not clear and I probed where necessary.

I also tried to break down the power hierarchy between myself as a male researcher and the participating mothers (Oakley, 1981). In doing this, the interviews took the form of a conversation. I tried as much as I could to bring myself into play by focusing on the similarities we had. For example, when I was interviewing participants from rural Kaoma, I spoke about a few times that I had been to the village and the things I liked about my visits to the village. I noticed that each time I spoke about such, the mothers appeared to be more relaxed and they asked me personal questions. As for the participating mothers of Lusaka, it was easy to talk about events that were happening in Lusaka. Overall, biographical interviews provided unique insights into the lives of mothers, the information which would otherwise have proved difficult to gather using other interviewing techniques.

Zambian languages have gender neutral phrases, there were instances where I did not capture the gender of the child because some names apply to both males and females. In such cases, I went back to verify the child's

gender. This was one thing I could have done better by clarifying during the interviews.

4.11   Ethical Considerations

The notion of researching vulnerable and marginalised subjects in qualitative research has been well documented (Dickson-Swift et al., 2008, Sampson et al., 2008, Watts, 2008). Researching such individuals requires skill in engaging participants in a discussion, and at the same time awareness of the potential impact of the study on both the researcher and the participants. Scholars such as Dickson-Swift et al. (2009:62) argue that sensitive research '*has the potential to impact on all of the people who are involved in it.*' Dickson-Swift and colleagues' (2009) assertion is relevant to the current study. Exploring the life history of the participating mothers in the present study was quite sensitive. I was aware that the discussions I had with them had the potential to evoke emotional pain associated with discrimination and stigmatisation that they were experiencing in society. For example, it was possible that mothers were worried about being blamed or judged harshly by society. Furthermore, it was possible that merely discussing the experience of taking care of a child with disability was potentially distressful and emotional; thus, I took care not to coerce participants into talking about issues that they were not comfortable with. Watts (2008:7) supports the above approach by stating that '*researcher sensitivity to issues on a number of different levels is a feature of feminist inquiry.*' Because of the many issues associated with my study, the research proposal was subjected to scrutiny by the Humanities and Social Sciences Research Ethics Committee (HSSREC) at the University of Warwick. Based on the approval granted by the University of Warwick, the University of Zambia also gave a go ahead for the study upon proof of ethical approval from the former.

4.12   Maintaining Confidentiality

I adhered to the Data Protection Act 1998 and the data security guidelines of the University.

https://www2.warwick.ac.uk/services/vco/exec/registrar/legalservices/data protection

Data was kept in a secure place which was password protected. I put in place measures to ensure that data was well secured and anonymised by removing all the identifiers from the transcripts before being seen by anyone else other than myself. However, I encountered some unique issues related to confidentiality in Kaoma where some participants preferred to be interviewed in the presence of some family members. A case in point was when I went to interview a mother of a child with cerebral palsy in Kaoma. We had visited her a few days prior to the interview at which she revealed that her husband had left her a few years ago to live with another woman who had six children of her own. When we arrived to have the interview on the date we had agreed, we noticed a group of people sitting in the shade under a mango tree. It was the wife (and her family), and the estranged husband (and his family). Apparently, the husband had been racked with guilt and remorse over the past few years, and had come in the hopes of reconciling with his wife. When I saw the scene in front of me, I suggested that we postpone the interview, but the wife insisted that we carry on. She said that before any talks on reconciliation happened, she wanted her husband to hear about all she had gone through over the past few years without him. All parties agreed and the interview began. It must be noted that the presence of the husband (and both their families) may have resulted in her emphasising certain stories over others, or adding certain emphases for emotional impact. Still, I felt it was important to respect her wishes and empower her to say what was on her heart and mind.

Another case was when I went to have an interview in one of the villages in Kaoma. It was going to be a private interview, however, the mother insisted that all of her village should sit-in on the interview and offer their contributions. She explained that in their small village, everyone was aware of the hardships she was facing daily, and so she wanted their involvement. So she went and called people and over thirty people gathered, both young and old. In essence, it became more like a focus group discussion. Elders in the group who had known her a long time began adding stories about her upbringing. Others added comments here and there reiterating what she was saying but my focus was on what she was saying.

4.12.1 Informed Consent

Great care was taken to ensure that mothers were willing to participate in the study. All the participants were provided with information in writing concerning the nature and basis for carrying out the research, and this was meant to allay any concerns they may have had (see Appendix D). I explained to potential participants the purposes of the study and how I was going to use the data that I was collecting. I endeavoured to treat all participants equally and to let them decide if they wanted to take part in the project. This approach is echoed by other scholars (Krumholz, 2010, McCullough and Chervenak, 2007, Wiles et al., 2005) who assert that participants in a research project ought to make their own informed decisions with regards to taking part in a study.

Ongoing Consent: participants were reminded throughout the research project of their right to withdraw from the interview at any time and without giving any reason (Heath et al., 2007, Guillemin and Gillam, 2004). However, as I was aware of my culture (Zambian) that it is seen as impolite to terminate a conversation without giving reasons, I paid attention to both verbal and non-verbal cues, as can be seen from the excerpt below:

Bo ma Mwila: we have been talking for over one and half hours

Masauso: oh yes, it's over one and half hours now. Do you
            have another commitment or are tired?
Bo ma Mwila: yes, I do.
Masauso: thank you very much for your time. Unless you
            have something to share with me, otherwise, we
            can end the discussion now.

Compensating Participants: There is no agreed upon principle when it comes to compensating research participants (Ripley et al., 2010, Ndebele et al., 2008). I found modest but practical and locally acceptable ways of reciprocating their good gesture of finding time to discuss with me their lived experiences. At the end of each interview (which lasted between 50 minutes-3.30 hours), in agreement with the mothers, I was giving them equivalent of £5.00 (K50.00 Zambian currency). All of them liked the idea while others also requested for further assistance with accessing social services such as schools for their children. I was referring such mothers to appropriate resource agencies that I identified in the research sites prior to commencement of data collection (when I had discussions with the policy makers and staff from NGOs).

4.13   Positionality and Reflexivity

Reflexivity is the process of self-evaluation by researcher on their own social backgrounds, values, actions, and beliefs, and how these factors can influence the research process (Berger, 2015, Probst, 2015, Jootun et al., 2009, Watt, 2007). Positionality, according to Hennink et al. (2011) refers to power and social relations between a researcher and the participants. As interviewers interact with their research participants, both sides bring their personal values and identities such as masculinity and ethnicity to the research process and, in so doing, this shapes the data that results (Perez-Milans, 2016, McCabe and Holmes, 2009). Researchers can either be insiders or outsiders in any given research project. They can thus consciously or unconsciously contribute towards the construction of the interpretation (Enosh and Ben-Ari, 2016, Stronach et al., 2007). Indeed, I was aware that my personal values, beliefs and opinion could influence the

way I was collecting data, analysing and interpreting it. Being aware of this reflexive relationship that could exist with the study participants was critical in the whole research process (Berger, 2015, Gentles et al., 2014).

My study placed me both as an insider and an outsider. Firstly, the research was done in Zambia; I was therefore an insider because I am Zambian and familiar with the socio-cultural context of the research place, especially Lusaka where I grew up. In Lusaka, as an insider and able to speak the local language, I could understand the interviewees' perspectives both literally, as I could understand the language, and with respect to their body language. Spending time at the physiotherapy centres enabled me to listen to the stories that mothers were sharing amongst themselves, I also observed how they interacted and made sense of their lives. This gave me insight of how power dynamics change at home when they have a child with disabilities. It became clear that gender, disability and class intersect. Scholars have also highlighted the advantages of being an insider. For example, Greene (2014:3) states that *'insider researchers are free from the effects of culture shock: they are able to blend into situations without disturbing social settings.'* I constantly reflected on my position as an insider because I realised that there was a risk of losing objectivity. Concomitantly, I was an outsider in Lusaka because I have not had similar experiences to these mothers, nor am I a woman. I was also an outsider because I am a researcher and studying abroad.

In Kaoma, I was more of an outsider when I went there. I belong to a different ethnic grouping, hence, that made me an outsider. It was easy for people to know my ethnicity based on my name. I was also an outsider because I studied abroad, and have never lived in the area. To overcome this challenge, I learnt the local language (Lozi). This helped a lot in being viewed as an insider because I could communicate with them in their own language. I also spent time interacting with the locals, and attended some social gatherings. This also helped me to be accepted as an insider.

Zambia is generally a patriarchal society especially in the rural areas (Phiri, 2016, Amoyaw et al., 2015). Being male, meant women generally respected me especially those in Kaoma. My PhD student status and being based in the United Kingdom placed me in a different social class. Thus, in both study sites, I had to position myself in terms of hierarchical power. I tried to share with participants some of my experiences about being a father but still that could not match what these mothers were going through. As the study was done in both urban and rural areas, I tried to conform to the local cultural norms and values by seeking guidance from the gatekeepers and participants in focus group discussions on matters pertaining to appropriate conduct towards the opposite sex, my personal appearance and appropriate dress. In summary, I endeavoured to follow the suggested protocol, and was also continuously reflecting on my own actions, values and perceptions, and how these had the potential to impact on the research process.

Despite all these efforts, I felt that to some extent the power hierarchy still existed between the study participants and myself owing to me being a man (Karnieli-Miller et al., 2009, Ely and Padavic, 2007). This view is echoed by Reinharz's (1997) assertion that researchers bring and create self (their own values and norms) in the field. I also thought that to some extent, I controlled the interview process. This could be attributed to the fact that education is highly valued in Zambia, and those with higher education are seen to have high status in society. Overall, despite being male, I felt that this did not have a negative impact on the research process because I was working with the people they know and trust the gatekeepers. This was evident because many mothers expressed happiness at being given an opportunity to share their lived experiences of raising a child with disabilities.

4.14   Quality of Research- Reliability and Validity

Throughout this study, I maintained rigour by having my work peer reviewed (Levin, 2012, Oliver, 2011) by my supervisors. I used to communicate regularly through emails with my supervisors when I was in the field

collecting data. They facilitated my consideration of methodological activities and provided feedback concerning the accuracy and completeness of my data collection and data analysis procedures. The goal was to enhance the credibility of the whole data analysis process. Peer reviewing provided valuable —second opinion on the meaning of data, proposed categories, and the emerging theory. I sent them (my supervisors) some transcripts that I anonymised for them to provide feedback. We also met in person when I came back to the United Kingdom to discuss the research, focusing on among others the coding process.

Some interviews were undertaken in local languages, this meant that I had to transcribe in the local Zambian language and then I translated them into English. The researchers at the Department of Literature and Language at University of Zambia verified the quality of my anonymised translation. This helped in ensuring that the translation was as accurate as possible. This approach is supported by some scholars (Alkass et al., 1998, Chiovitti and Piran, 2003, Emden and Sandelowski, 1998) who contend that investigator triangulation by experts is not only effective but can potentially improve the credibility of the study findings by highlighting both the flaws and strengths, and suggesting areas that require improvement. I also used member-checking process whereby some transcripts were sent back to the participants in order for them to determine accuracy. This is one of the most important techniques used to establish credibility (Rolfe 2006, Tobin and Begley, 2004). Ten participating mothers agreed to check the transcripts after I finished transcribing. The participants had the right to either agree or disagree that the transcript reflected their views, feelings, and experiences. All the participating mothers who reviewed their transcripts affirmed them as accurate and complete. This enhanced credibility of the study.

4.15   Data Management and Analysis

The starting point was data preparation. This involved transcribing interviews into text verbatim, using the original language (Nikander, 2008,

113

Squires, 2008 Carlile, 2004). The interviews that were done in Zambian local languages were transcribed in the original language and then translated into English. In cases where the concepts were not universal, I endeavoured to produce meaning based translation as opposed to word-for-word. This view is buttressed by Esposito (2001:571) who argues that *'the translator's goal is to develop transcripts that are accurate, clear, sound and as natural as possible.'* The translated copies together with original copies were then sent to researchers at the University of Zambia to verify the quality of translation.

To maintain participants' anonymity, all interview schedules and researcher notes were separated from research agreements as soon as possible after interview. Identifiers such as their names and locations that could lead to identification were removed, and all interviews subsequently identified alpha-numerically. All copies of transcripts were kept on the computer and password protected. Auto recordings were similarly identified and carefully separated and labelled immediately after interviews. Identifiers were attached to pseudonyms. In short, I conformed to University of Warwick guidance on data security.

After each interview, I immersed myself in the data by reading and re-reading, and listening to the recording several times in order to maintain familiarity with the recordings before transcribing. This helped me to develop a coherent story from it (Miles et al., 2014, Harper, 2013, Mills, 2006).

In order to produce an interpretation of the findings which made sense to the participants, and was therefore authentic and credible – criteria for validity – I remained close to the data throughout the analysis and aimed for a sense of immersion in the topic and in the participants' worlds (Charmaz 2006; Creswell 2007). I therefore, analysed data manually (see figure 4). Another reason was that at there was intermittent supply of power especially in Kaoma, it would have been challenging to collect and analyse data simultaneously using a software on the laptop.

The next stage was to develop codes. As Charmaz (2014) and Grix (2010) submit, data coding is the building block of analysis. Sarantakos (1998: 203) defines coding as, *'asking questions about the categories and their relationships'*. A code can be an issue, opinion or a topic in the data. It is a vital link in grounded theory, because it acts as a link between data collection and developing a theory (Corbin and Strauss, 2008, Charmaz, 2006). Coding aided in identifying concepts, categories and sub-categories that were further broken down. In summary, just as scholars such as Denzin (1989), Grbich (2009) and Scott (2004) have stated, I was trying to conceptualise what was happening in the data. I was also constantly comparing data to data (see Appendix F). This was meant to *'identify which codes to explore as tentative categories'* (Charmaz, 2014:115). Open and axial coding was completed. Open coding involved reading the texts 'word-by-word', 'line-by-line', and repeatedly to identify phrases that interviewees were using to describe things and issues. Sarantakos (1998) explicates this by stating that this entails questioning data in order to have a clear understanding of an issue, and to see how it connects with other issues, and to determine whether underlying or overarching themes can be drawn from the data.

The coded data was then categorised (grouped) according to different characteristics in order to better understand the data (Bryman, 2012, Strauss and Corbin, 1998). If, for instance, if an interviewee raised an issue such as '*shame of having a child with a disability'*, I coded this under '*perceptions of disability'*. So then, every time a participant described aspects of perception of disability, I grouped the words together so that I could have an in-depth understanding of their perceptions (see Appendix G). Equally, a mother might have talked about the impact of disability on her relationship. Whilst this might relate to aspects of social networks, it may also relate to challenges of being a mother of a child with a disability; I coded this, for example, under *'motherhood'*. I thus focused my analysis on these specific issues that were identified in the data (Charmaz, 2006, Corbin and Strauss, 1998). A list of all the codes that were relevant to this study were

kept in a codebook. I used the codebook to take note of any changes that I was making to the codes, since these can change as the study progresses (Harper, 2012, Hennink et al., 2011, Annells, 1996).

Axial coding was then employed to develop connections between the concepts. As pointed out by Charmaz (2006: 60), *'axial coding relates categories to subcategories, specifies the properties and dimensions of a category, and reassembles the data you have fractured during initial coding to give coherence to the emerging analysis'*. This coding process was not a linear one. Axial coding enabled the development of categories and subcategories, and an understanding of *'the properties and dimensions of a category'* (Charmaz, 2006:60). For instance, the experience of uncertainty began to emerge as significant, and I was able to explore how especially first-time mothers of children with cerebral palsy experienced the category biographical disruption across multiple spheres of their lives, and to identify how this was related to the condition of the child (see Chapter Six and Eight). During this process of comparing data to data, codes to codes, and developing categories to sub-categories, I discovered that relationship between categories began to emerge, and this gave a picture of the experiences of mothers. For instance, the relationship between future uncertainty and the everyday caregiving responsibilities emerged from the analysis of data.

Selective coding was then employed to figure out any core category around which other categories could be integrated to generate a theory. Creswell (2007) is of the opinion that selective coding entails that a researcher develops a story from interrelated categories; this results in the generation a theory. Adopting a constructionist grounded theory approach in this research was thus to be critical in developing an interpretation of the experiences of mothers raising children with disability which was grounded in the data.

This study also employed theoretical sampling. Glaser (1978) highlights strategies related to theoretical sampling, these include: following up on the patterns recurring in participant data, changing research sites, and changing the interview guide to include themes emerging from previous interviews. Draucker et al. (2007:1138) buttress this view by stating that theoretical sampling involves *'contacts with participants, observations of participants, and the literature.'* I employed theoretical sampling in my study by conducting follow up interviews with some selected participants to obtain more information on emerging categories that seemed significant to the developing theory especially in relation to biographical theory. I also had to refocus some interview questions in order to gain more and concise information about the emerging themes.

4.16   Conclusion

This study on which this thesis is based was conducted within an interpretivist qualitative framework. It also drew on insights from feminist theories and grounded theory in order to construct a methodology and value based appropriate to addressing the research questions of the study. Utilising biographical methods, this study brought to the fore the voices of a diverse sample of thirty mothers from the two research sites on what they experience, and have experienced, in raising children with disabilities within the current sociocultural, political and economic context of both rural and urban Zambia. The methodology incorporated some modest participatory elements by taking into account the views of mothers who participated in the focus group meetings, and applying their insights within subsequent stages of the research, particularly in relation to the design of the interview guide. Throughout this chapter, reflexivity and positionality have been addressed not least because of the power dynamics that can be reflected in research relations including those related to a male researcher interviewing women. It has also discussed how the whole research was operationalised by reviewing the pre-fieldwork and fieldwork aspects and how data were analysed. Throughout the research process, a number of

strategies have been adopted (Bryman, 2012, 2004, Cohen et al., 2011) to promote the validity and reliability of the research and to maintain the integrity of the data about the difficulties, struggles and joys that participating mothers described, and which form the basis of the findings set out in the next three chapters of the thesis.

Chapter Five

Becoming a Mother of a Child with a Disability

5.1 Introduction

Chapters five, six and seven present an analysis of the experience of parenting a child with a disability based on the accounts of the mothers in this study. These women narrate the challenges, the joys, and the happiness they derive from parenting children with disabilities. The chapters also highlight how mothers navigate the health and social services that may be available to them. In accordance with the theoretical perspectives presented in chapters two and three, all three of the findings chapters are grounded in the importance of giving voice to a marginalised group of women through their own accounts. This approach is in line with the epistemological standpoint of feminist researchers and biographical methods of understanding the social world based on the life accounts of research participants (Spector-Mersel, 2010, Goodley, 2004; Oakley, 1988).

This chapter, and the next two findings chapters outline the variations in the experiences amongst the mothers across time. Subsequent chapters will also demonstrate how their relationships with the social service providers developed over time. In this study, the social structures and beliefs that constitute the institution of motherhood are of particular interest. The perspectives of mothers are therefore, important in providing insight into participants' experiences, with regard to mothering a child with a disability.

In this chapter, I will present four main themes that emerged from the data on what it means to become a mother of a child with disabilities. The first theme relates to how they recognised and responded to the child's condition, and the complex range of emotions this arose. The second theme discusses the concept of decision-making in relation to choosing a type of

healthcare for their children and how their decisions were influenced by different social factors. The third theme focuses on the mothers' encounter with professionals. I will conclude by looking at the reactions of the mothers, and their significant others. The insights from this chapter will provide a context for the subsequent chapters.

It is important to acknowledge, however, that there are a myriad of differences between mothers of children with disabilities and this of course applies to those who took part in this research:

> Zion [L]: much as we have disabled children, the way we respond to their needs, the way we look at them and the way we raise them is different.

Thus, in sharing their experiences, these mothers presented diverse responses in the way they reacted to their child's condition. I will discuss this and other issues throughout this chapter.

5.2 Growing Awareness and Responding to the Needs of the Child

The initial and the growing recognition in the family that a child has a disability or is different has the potential to create challenges such as stress, denial, depression and conflict among others (Panitch, 2008, Blum, 2007, Read, 2000). To a larger extent, these emotions are reflective of the social attitudes and historical realities of wider society (Kingston, 2007, Ferguson, 2002). Close contact with healthcare providers are important in helping parents become aware of the condition of their child. One example of this, is the use of essential services such as maternal care and the use of antenatal care clinics (Ensor et al., 2013, Kyei et al., 2012).

My study findings revealed that eighteen (thirteen from Lusaka and five from Kaoma) out of the thirty mothers reported attending antenatal care services at their local health centres during the pregnancy of their child with disabilities. Participating mothers provided varied accounts of their attitudes

towards attending antenatal clinics prior to having their child. For example, Bo ma Kanyanga remarked:

> Bo ma Kanyanga [K]: when the people from the health centre came to the village for an outreach programme. They told me to be going for antenatal. So, I went whenever I had time.

Similarly, Bo ma Angela [K] explained that the distance to the health facility and the time it took to be attended made it difficult for her to regularly attend. Another mother stated:

> Bo ma Kasweka [K]: ahhh…the health centre is very far. It's quite difficult to get there unless you start off very early in the morning before it gets hot but again we live very close to the game park so there is a risk of meeting dangerous animals that stray from the game park.

Bo ma Chikombe [K] travelled for about 4 hours to get to the nearest antenatal care services. However, when the pregnancy was in the third trimester, she stopped going there.

These comments especially voiced by mothers from Kaoma, suggested that there were many factors that impended the participants' ability to access antenatal care services regularly. Most rural mothers lived far away from facilities providing antenatal service. Much as the value of these services was appreciated, the practicality of getting there was overwhelming. My findings on distance to a health facility expand on previous studies, in particular with the findings in Zambia by Kyei et al. (2012) and Phiri et al. (2016) which reveals that distance to health facilities in rural Zambia affects the utilisation of services such as maternal and child health care. Kyei et al. (2012) argue that 9 percent of rural women have access to antenatal care services with an optimum level of provision within the distance of 15Km radius. More recent research by Phiri et al. (2016) revealed that few mothers in rural areas access maternal-child health (MCH) facilities. They stated that 73 percent of the women have unmet needs for their antenatal and postnatal

services in rural areas. These findings indicate that few rural mothers have geographical access to such services.

While Kyei and colleagues (2012) used the 2005 Zambia National Health Facility Census data to arrive at their findings, and Phiri and colleagues (2016) conducted focus group discussions with attendees at a health facility, my study expanded to a different area by obtaining the perspectives of mothers of children with disabilities in both urban and rural settings through biographical interviews, and demonstrated the challenges participating mothers experienced in accessing antenatal care services. My findings, further, demonstrated that mothers had other responsibilities that were equally important. Furthermore, as the pregnancy advanced, it became more difficult for mothers to attend antenatal care clinics especially in the rural Kaoma where distance to the facilities was a challenge.

Despite expressions like the ones described by mothers of Kaoma, most of the mothers in Lusaka did access antenatal services:

> Tandiwe [L] I used to go to the health centre every month for screening.

Another mother remarked:

> Violet [L] I used to regularly attend antenatal screening at Ng'ombe health centre.

It was evident that a significant number (thirteen) out of fifteen mothers from Lusaka attended antenatal clinic regularly. This adds to the Zambia Demographic Health Survey report (CSO, 2010) that states that the proportion of women in urban areas who attend antenatal services stands impressively high at 94 percent.

Although some (thirteen) mothers, especially those in Lusaka, accessed antenatal facilities; none of them reported that the child's condition was detected before the infant was born:

Sophia [L]: they told me that the baby in my womb was okay.

Gertrude [L]: they couldn't detect any condition in the baby during ante natal care.

While most developed countries such as the United Kingdom and Ireland are able to identify certain conditions in the foetus, for the mothers participating in my study, it appeared that healthcare facilities had no capacity to detect abnormal conditions. For example, studies by Budd et al. (2015) and Smith et al.'s (2011) in the United Kingdom indicate that the National Health Services carries out routine screening of pregnant mothers for conditions such as Down's syndrome, lethal skeletal dysplasia and spinal bifida amongst others.

Twenty-six (thirteen from each site) out of the thirty participants in both research sites reported that their babies were delivered in the health facility for example:

Faggy [L] I used to go to Kanyama health centre for antenatal and that is where I delivered from.

Similar cases were reported by Zion [L] a mother of a child with cerebral palsy and Fortunate [L] a mother of child with autism. Most of the mothers in Kaoma also said that they delivered from the hospital. Bo ma Kasweka [K] whose child had cerebral palsy said that she delivered from the local health centre. Similarly, Shenda [K] a mother of a child with Down's syndrome delivered at a local health centre.

In contrast, four (two from each site) out of thirty participants delivered at home. One mother explained:

> Dorcas [L]: I delivered in the night at home alone and I was preparing to go to the hospital […] in the morning I bathed and went to Kanyama health centre with the baby.

On the other hand, Bo ma Mwila [K] delivered at home but was assisted by a traditional birth attendant who lived in the same village. When asked why she did not go to the health facility, she said she preferred the traditional birth attendant because this was someone she knew very well, someone who was respectful, friendly and readily available. Kruske and Barclay (2004) cite the World Health Organisation in their definition of traditional birth attendants:

> …a person who assists the mother during childbirth and who initially acquired skills by delivering babies herself through apprenticeship to other traditional birth attendants […] a member of the community, chosen by that community to assist women in childbirth (Kruske and Barclay, 2004:306).

The narrative of Bo ma Mwila [L] adds to the findings of Sialubanje et al.'s (2015) study that focused on identifying factors contributing to low utilisation of maternal healthcare in Kalomo, Zambia. They argued that *'socio-cultural norms regarding childbirth, negative attitude towards the quality of services provided at the clinic, made most women deliver at home'* (Sialubanje et al. 2015:1). On the other hand, my findings indicated that the majority of participants both in rural and urban sites, delivered at a health facility despite some of them not regularly attending antenatal care clinics.

Sixteen (eight from each research site) out of the thirty mothers said that they did not realise early enough that their child had a disabling condition. Nineteen out of the thirty women reported that they had difficulties, either during pregnancy or when delivering, which they subsequently related to their child's developmental difficulties when they recognised them. Two (one from each research site) of the mothers reported that they were in labour for over 10 hours:

> Susan [L]: I had prolonged labour of over 10 hours then it was forced labour. I think that might have had an impact on my daughter.

> Bo ma Kaimbu [K]: I will just say the time I was pregnant; my pregnancy went up to 11 months, 2 weeks.

In both research sites, findings demonstrated that mothers aged 30 years and below at the time of the interview, reflected similar challenges in terms of noticing developmental delays. Most of this group of mothers were first-time mothers. Esther [L], aged 29 years-old and Bo ma Kasweka [K], aged 28 years-old both of whom had children with cerebral palsy, did not become aware that their child was not developing normally until their relatives noticed:

> Esther [L]: my sister was the one who came and told me that at this age, the child should be crawling. So, this child has a problem and needs to be examined.

> Bo ma Kasweka [L]: my auntie came to visit and she noticed that there was something wrong with the baby.

The above accounts from participating mothers reflected attempts to make sense of what was happening to their children and their growing awareness over time with the intervention of relatives. This situation was marked for first-time mothers, who were seemingly unaware of the developmental stages that a child would go through. However, the situation was different in both research sites for the mothers who already had a child, prior to having a child with disabilities. Eleven (seven in Lusaka and four in Kaoma) out of nineteen of these women reported that they were able to notice developmental delays in their children at an early stage. These more experienced mothers realised that their child was different very quickly. For example, Bo ma Anne [K], a mother of six children reported noticing that her daughter was paralysed in the early days after the child's birth. The situation was similar for Hilda [L], a mother of nine, who recounted:

Hilda [L]: I knew he must have had some form of disability when he did not cry when he was born. My other children were born without any complications.

In keeping with the findings of the assertions from other scholars (Maskey et al., 2013), these contrasting accounts from the mothers in my study suggested that experience of parenting was key in identifying conditions in their children. My findings revealed that the ability to respond to the needs of the child also varied according to the educational levels of the participants. All the seven mothers from Lusaka who had a secondary school education and above and had other children were able to read more about what was expected of a child at every stage of their life. This was not the case with mothers who were not educated to the level of high school. Two of the participants both of whom had professional jobs and were from Lusaka, reported that they had undertaken research when they suspected that their child had a condition. Chilinda [L] reported researching on her own to find out what was wrong with her daughter. Another mother commented:

Tandiwe [L]: there was a complication at birth, he didn't cry. When I left the hospital, I went on the Internet, and read and researched about the causes and consequences of a child not crying at birth and I discovered that there was brain damage because of a lack of oxygen to the brain.

It was evident from their accounts that the mothers' education had a positive impact on their knowledge of the child's condition. Depending on their level of understanding the child's condition, mothers reacted differently to the developmental delay of their child. This aspect is explored in greater detail in the next theme.

5.3 Mothers' Reactions to Developmental Delays

With regard to my study, the responses of the mothers to the developmental delays of their children varied across the two study sites. To some extent, their responses were shaped by their beliefs and their knowledge about

parenting (Aldersey et al., 2016, Sakala et al., 2012). When discussing their growing awareness that their child may have a disability, the participants shared their initial reactions, beliefs, thoughts and experiences about the condition of their child with others. Their attitude varied from suspecting the involvement of witchcraft, attributing it to a medical condition or believing that it was the will of God.

Six first-time mothers (five from Lusaka and one from Kaoma) reported that their initial reaction to having a child with development delays was one of the turning points in their life trajectory. They gave varying responses to the questions about their initial reactions to the child's condition. These ranged from pain to shock, disillusionment and feelings of depression:

> Zion [L]: I will never forget the pain of knowing that there must have been something wrong with her.

They described the joy of having a child changing to sorrow upon suspecting that the child had a problem. For example, two first-time mothers and whose child had cerebral palsy, described their experiences when they first discovered that their child had a developmental delay:

> Esther [L]: at first, I couldn't accept it because, I mean, I didn't just accept it. I literally cried […] I was disturbed because in my family there has been no case of anyone being born like this.

> Mwila [L]: I can remember that day like it was just yesterday. I couldn't stop crying […] there were days when I would lock myself in a room and cry and cry and cry. It was really hard to understand and accept that my child had a problem.

The accounts above were similar to that of the ten (four from Lusaka and six from Kaoma) out of the fifteen mothers who responded to the question on initial reactions in both sites who were not first-time mothers. They expressed sadness at their child's developmental delay. For example, Bo

ma Angela [K], a mother of three children described how she reacted when she first noticed the troubles of her daughter:

> Bo ma Angela [K]: her condition unsettled me. When she was born, she was fine but I started noticing that there was something wrong […] I have two other children besides her and I have never experienced such a condition.

Similarly, Bo ma Namutondo [K], a mother of five, stated that her reaction was one of surprise and shock; she had not experienced such a condition since her other three children were able-bodied. Bo ma Barbara [K] explained that she felt like her life had come to a standstill: hoping to deliver a 'normal' baby who would look after her in future, but discovering that child had a problem. One mother stated:

> Sophia [L]: it felt like I was dreaming. What would I do for my future and the rest of my life? I was grieved because my dreams were shattered. I was hoping that she would look after me in my old age.

These findings suggested that there are strong expectations in Zambian society that children will provide for their parents in their old age and that this is incorporated into parents' views of their future lives. This could explain why most mothers in both research sites were devastated when discovering their child had a developmental delay, not only in relation to their current role in caring for their child and their child's future, but they also saw their own future as bleak. One mother stated:

> Mwila [L]: I was quite devastated, I didn't know what had hit me. It was hard to imagine that she had a condition that was going to affect her development.

Many scholars in sub-Saharan Africa have highlighted the importance of the concept of reciprocity between parents and their children. For example, Noyoo's (2000) earlier work highlights the social living of Zambian society that is characterised by a general sense of reciprocity where children have

an obligation to look after their parents in their old age. Mapoma and Masaiti's (2012:109) study with young adults show that '*children in Zambia were expected to keep their old parents.*' This is attributed to a larger extent to the non-existence of formal support for the elderly by the state. While it is true that studies have been undertaken (Mapoma and Masaiti, 2012, Noyoo, 2000) that focused on reciprocity between parents and children, none of such studies focused on the perspectives of mothers of children with disabilities in this regard. Hence, my study findings added to the body of knowledge by expanding in a different area- centralising the voices of women about caregiving. Following the discovery that there was something wrong with the child, mothers had to make decisions regarding healthcare services to seek. The next section focuses on how these decisions were arrived at.

5.4 Decision-making Regarding Healthcare

My interviews with the participants, especially those from Lusaka, revealed that most of them (ten out of fifteen participants) felt that it was important to seek conventional medical treatment for the condition of their child. Others sought the intervention of traditional healers and some consulted both medical professionals and traditional healers (this is explained in the subsequent sections).

In making decisions regarding the type of help they sought, nearly all of the participants in each research site reported that they had to consult someone on the appropriate healthcare for their children. Eleven out of twelve (four in Lusaka and Seven in Kaoma) married mothers at the time of the interview, explained that they had to consult their spouses about what form of services were suited to their child. Mothers narrated:

> Bo ma Gideon [K]: my husband told me to take him to the hospital. So that's how we took him to Kheyema Rural Health Centre.

> Dorcas [L]: when we discovered the problem, my husband said we needed to seek medical attention. That is how I went to Kanyama Health Centre.

As is evident from the above accounts, most of the women consulted their husbands regarding the type of help their child needed. A mother recounted how she respected her husband's decision:

> Violet [L]**:** my husband said that we needed to seek the help of a traditional healer, I wasn't in favour of it but in the end, I followed what he said since he is the head of the family.

Similarly, a mother recounted on how they arrived at the decision of taking the child to the hospital:

> Bo ma Namutondo [K]: when it was time to decide, he told me to take the child to the health centre […] he didn't consult me, he made the decision.

The above accounts suggested that husbands were ultimately responsible for making decisions regarding social services. This reflected the power that husbands had over their wives. Just as men asserting their views is evidence of patriarchal power, what happens at the micro (individual) level reflects bigger tensions: the constraints on women to make autonomous decisions. This view of the micro reflecting what occurred at the macro level was consistent with Sialubanje et al.'s (2015) study in Kalomo, Zambia, which demonstrated that the husband makes decisions regarding seeking the services of traditional birth attendants and where a woman should go to deliver. These studies reflected a general attitude that elevates the position of men in the family. While the previous study (Sialubanje et al., 2015) focused on reproductive health in the rural Kalomo only, it was apparent from my study findings that decision-making regarding healthcare services in both urban Lusaka and rural Kaoma were made by the husbands.

Five mothers from Lusaka who were below the age of thirty, sought advice from their parents as in the case of Susan [L], whose relatives advised her to seek help from a traditional healer. Similarly, Sophia [L], stated:

> Sophia [L]: my partner wasn't interested in the child. I went to consult his (partner's) grandmother; she is the one who suggested that we take the child to the hospital. My family too advised me to be taking the child to the hospital.

Another mother remarked:

> Emma [L]: my mother told me to take the child to Chongwe District Hospital and for prayers where they used to give me anointing oil. I combined prayers and physiotherapy.

The situation for first-time single mothers was the same in both Lusaka and Kaoma. For example, Bo ma Kasweka [K], a single mother from Kaoma explained the factors that led to her choice of healthcare for her daughter:

> Kasweka [K]: the family told me to take her to the hospital. They also advised me to take her for prayers.

The interviews revealed that there were many social factors that influenced the mothers' decision-making regarding the type of healthcare facility to access. Moyer et al. (2014) identify these social factors as social norms and social values. In the case of young single mothers, their parents made most of the decisions regarding the type of healthcare service to seek. In all these cases, my findings revealed that mothers usually sought permission from their families before deciding on the type of healthcare service. Previous research such as that by Wickenden et al. (2013) in Zambia also shows that women are often viewed as passive and helpless in decision-making. However, their study explored an intersection of HIV, disability and gender. In the case of my study, the focus was on the perspectives and experiences of mothers of children with disabilities.

5.5 Encounters with Professionals

Regarding professionals, mothers expressed mixed responses to the information and suggestions provided by medical professionals that they saw. Many of those I interviewed who sought help in the early stages of their child's condition reported that most professionals emphasised the biological deficits of the child's condition, reflecting the dominance of a medical model (Goodley, 2017, Shakespeare et al., 2017, Bourke et al., 2010, Hall, 2010, Smith et al., 2004). Some mothers expressed feelings of hopelessness and discouragement at the beginning of their journey of parenting a child with disabilities especially after visiting medical professionals. Sixteen (nine from Lusaka and seven from Kaoma) of the twenty mothers who went to hospital were not initially told the diagnosis of the child's condition:

> Gertrude [L]: the first time I took Gilbert to the health centre, they didn't say what the diagnosis was. All they told me was that my child would not grow and that he would just be a 'cabbage' and they said that he had a small heart, and I was troubling myself going to the health centre. It was very depressing to hear that from the doctors.

> Faggy [L]: the doctors were very unhelpful and uncaring. I remember one of them told me that they were not allowed to reveal the diagnosis. It was very frustrating. It wasn't easy to understand what was going on, why they weren't saying what was wrong with my son.

Other participants like Emma [L] and Fortunate [L] who went to small health centres, they were told that there was no specialist to attend to them. While mothers such as Violet [L] and Susan [L] recalled that the medical professionals initially told them that they could not reveal the diagnosis and prognosis of the condition. One mother described her encounter with a physiotherapist:

132

Mwila [L]: he told me that he wasn't allowed to tell me the name of my daughter's condition. I didn't know what to do when he said that. I was left confused and I left.

When probed further as to why they thought they were not told about the diagnosis and prognosis of their child, some mothers reported:

Zion [L]: the nurse told me that they were not allowed to reveal because they feared that mothers would be depressed.

Scholars such as Russell and Norwich (2012) have previously argued that carers of the disabled often have the desire to have their children diagnosed, but they often face obstacles from medical and health professionals. This lack of disclosure by health care professionals caused anxiety among the mothers:

Bo ma Cleopatra [K]: I really didn't know what to do because they doctors weren't telling me what was exactly wrong with my daughter. I was left confused.

Those mothers that had higher educational qualifications insisted on getting information from healthcare professionals on their first visit to the hospital. Five of the fifteen participants, from Lusaka explained that they demanded an explanation and more information about the condition of their child. For instance, Chilinda [L] reported:

Chilinda [L]: when I took her to Kasama Hospital they said it was a fracture but they never told me how it came about. But I wanted to have more details […] I came to the University Teaching Hospital in Lusaka. I asked a nurse but she refused to tell me then I went to ask the Professor who was treating her […] So that's when we were told that she had a brittle bone disease, they call it osteogenesis imperfecta.

Other participating mothers, such as Gertrude [L] and Astridah [L] with time, they confronted the healthcare professionals and demanded to be told the name of their child's condition. Tandiwe [L] also reported pursuing the professionals in order to get a diagnosis. Hilda further illustrate this:

> Hilda [L]: I tried to ask what causes a child to be like this. The physiotherapist was hesitant to tell me. Then I asked a doctor, and he asked how I used to feel when I was carrying the pregnancy […] so the doctor said that because he didn't cry it caused the condition.

Only two participating mothers from Kaoma pursued the professionals when they were not told their child's diagnosis. One mother stated:

> Bo ma Mwila [K]: I asked the hospital staff but they told me that the child would be okay with time.

Many of the mothers who fought to know the nature of their child's condition said it was not their nature to be forceful, but they had to do so in order to stand up for the rights of their child. My findings are in congruent with Nyoni and Serpell's (2012) study that revealed that all the participants in their study had challenges in securing a diagnosis at the University Teaching Hospital in Lusaka. They described the process as arduous and time-consuming, and that hospital life was a rough experience. However, findings from my study differ significantly from previously studies undertaken in Western countries. For example, Kingston's (2007) study in Ireland found that professionals are quick at diagnosing conditions and linking the parents to support services. Similarly, Read's (2000) study in West Midlands in the United Kingdom show that mothers had no challenges in securing a diagnosis of their child.

In the case of my study, the often poor relationship that existed between healthcare professionals and mothers exacerbated the difficulties that mothers experienced. Bo ma Kaimbu [K] provides a good example of this struggle:

134

> Bo ma Kaimbu [K]: I insisted that I wanted to know the condition
> of the child. The doctor refused, then I followed him to his car.
> He just got into the car and said that what I was saying was
> foolish, and that is how he drove off.

Similarly, Zion [L] was embarrassed in the presence of other patients. She said that when she took her daughter to the hospital the doctor told her that he could only attend to her daughter after seeing other patients because Zion's daughter was 'disabled'. She explained:

> Zion [L]: he told me to wait so he could finish attending to
> 'normal' children before attending to Naku. I refused him to
> attend to me when eventually he called me because I didn't
> like the way he addressed my daughter.

These findings indicated that mothers were dismissed as lay people and not expected to question a medical expert or seek further guidance. These findings revealed that there was a great power imbalance between mothers and the healthcare professionals. Their voices were hardly heard (Oakley, 1992). As can be seen from my study, mothers who tried to ask for more information or help felt threatened. Nevertheless, there were also a few cases were mothers were assured that the child would get better. For example Bo ma Shenda [K] remarked:

> Shenda [K]: I constantly went to the health centre and eventually
> the doctors assured me that my daughter would get better.

As was evident from my findings, mothers experienced both fear and hope in obtaining a diagnosis from their medical professionals as one mother stated:

> Bo ma Kanjengu [K]: I wasn't sure of what to expect from the
> healthcare professionals. Those people can be rough at times.

Mothers were not provided with enough information by professionals so as to understand their child's condition. For example, from the mothers'

narratives, none of them were provided with treatment options. The accounts of mothers in my study are in stark contrast with the accounts of participants in an earlier study in the United Kingdom by Mansell and Morris (2004) that found that parents of disabled children were provided with various sources of information on the condition of their child.

As Faggy [L] stated:

> Faggy [L] a diagnosis is important in preparing mothers for what to expect with regard to the child and the mother's future.

The above comments by the mother resonates with Landsman's (2008) assertion that carers' knowledge of diagnosis and prognosis of impairments is vital. This is view is also supported by scholars such as Avdi et al. (2000) who assert that a diagnosis is significant because it enables parents to be involved in decision making regarding the available treatment options and support services.

Consequently, with time and persistence, most participants were given a diagnosis. Mothers reacted differently to learning about the condition of the child. Nine (six from Lusaka and three from Kaoma) out of sixteen mothers whose child had cerebral palsy reported being told that their children would not be productive in life and they would require lifelong care:

> Zion [L]: I was told that she wouldn't be able to do anything. I will have to do everything for her. You can see up to now she is unable to walk and cannot talk yet she is 10 years now.

One mother described the news of her son's diagnosis in the following words:

> Emma [L]: it was like a bereavement. I have never been this sad ever in my life […] I had this deep sadness. I didn't know what was going on in my life. It took a while for it to sink.

Similarly, Bo ma Anne [K] narrated:

> Bo ma Anne [K]: it was bad, my world was small and I just looked
> at the doctor, or was it a nurse. I never said anything because
> I was devastated, it was difficult to accept. I felt cold,
> something blocking and choking my throat.

Sophia [L], a 23 year-old first-time mother of a child with cerebral palsy stated candidly:

> Sophia [L]: I was grieving, my dreams were shattered upon when I
> knew that she needed to be cared for the rest of her life.

Like the parents in Aldersey et al.'s (2012) study in Tanzania on families' reaction to diagnosis of intellectual disabilities, mothers in my study experienced a crisis following a diagnosis. Most first-time mothers experienced what Bury (1982) calls 'biographical disruptions' in their life trajectories. Not only were their future plans irrevocably altered, but also the idea of parenting a child with disabilities affected the self-image of most of the participants. As one mother put it:

> Susan [L]: I had plans for her but everything is up in the air […]
> blown by the wind. I really don't know what to do now. I'm
> disturbed.

Feniger-Schaal and Oppenheim (2013) reinforce this view by stating that news about a diagnosis of a condition of a disabled child can be distressful to parents especially if the child's condition is permanent. Mothers in my study experienced biographical disruption through the disabling conditions of their child, as mothers commented:

> Bo ma Barbara [K] my life came to a standstill: hoping to deliver
> a normal baby who would look after me in future, but
> discovering she was disabled.

137

In the case of Emma [L] she immediately began contemplating having another child:

> Emma [L]: When I was told that the child had cerebral palsy and that he wouldn't get better, I started thinking of having another child. I knew that the disabled child was not going to look after me when I grow old.

Some mothers however, disputed the diagnosis. Two of the mothers I interviewed showed inconsistences in their reaction to the diagnosis. In the first interview, Esther [L] stated that she was not affected when the doctor said that the child would require lifelong care; however, in the second interview the mother explained that the news about her daughter's condition affected her negatively. One mother stated:

> Mwila [L]: I thought that it was nothing serious. You know, I doubted him when he said I would need to care for her for the rest of her life. They are just humans, they can also misdiagnose.

The above accounts illuminated emotional disorientation mothers experienced following news about the disclosure of a diagnosis. For example, Mwila's denial of a diagnosis revealed that parents were keen at having their child diagnosed by healthcare professionals, while at the same time disputing the diagnosis. Some mothers sought second opinion as the next section will show.

5.6 The Search for Diagnosis from Traditional Healers

My research revealed that while healthcare professionals eventually helped some mothers, at times the information about the diagnosis was confusing because different healthcare professionals saw them at different times. This meant that every time they had an appointment at the hospital, they had to provide information to different staff. It was like beginning the process anew every time they went to hospital. After receiving suggestions from various

138

professionals, some of mothers eventually gave up seeking conventional treatment and tried traditional medicine where they were at least assured of the consistency of always seeing the same person. As one mother explained:

> Bo ma Kanyanga [K]: we were seen by different doctors at the hospital and they were saying different things about my child. It was quite confusing, that's how I stopped going to the hospital.

Another mother stated:

> Emma [L]: I was frustrated because nothing much was happening. I didn't see any improvement in his condition that is why I decided to try the traditional healer. They kept telling me different things.

The accounts above revealed that lack of consistence in providing information caused some mothers to seek a second opinion. In most cases they turned to traditional healers because mothers believed that traditional healers were able to reveal the causes of the condition, and seemed capable of curing it. One mother explained what motivated her to seek the services of a traditional healer:

> Bo ma Namutondo [K]: I wanted to go to the traditional healer because at the hospital they can't tell us where the disease came from but the traditional healer is able to tell us who is behind the condition of my child [...] traditional healers are able to point and they know exactly the person who bewitched the child. At least I can revenge.

Bo ma Kanjengu [K] also stated that traditional healers were able to know exactly the person who bewitched her child:

> Bo ma Kanjengu [K]: he didn't say, he gave me signs of the person who bewitched him […] I really wanted to hit back at whoever did it to my child.

From the above narratives, it appeared that the belief in the ability of the traditional healers to identify exactly who was behind the child's condition resonated well with some of the participants. The mothers seemed to have great faith in and to have appreciated the services rendered by traditional healers. Furthermore, the desire to find a cure somewhere for their child's condition made some mothers move from one traditional healer to another, as the case was with Emma [L] who visited three different traditional healers:

> Emma [L]: I have been to three traditional healers, the first one we went to, told us that this child is about to be used for business rituals, some people want to use him for debt recovery. He said that there are two people who are fighting for him […] when one of them takes him that will be the end of him, he will die. The second one said that his grandfather from his dad's side was the one who had bewitched him. I believed him. The third was from Malawi […] he told us that this child has been put in something, which he (the traditional healer) needed to cut to remove Albert from there […] he gave us a porcupine's quill, it was white and black in colour.

The World Health Organisation (WHO) acknowledges the services of traditional healers. They state that traditional healers are key in attending to among others, stigmatised patients who often avoid public providers or are neglected by the healthcare system (WHO, 2002). The World Health Organisation further, defines traditional healing as:

> …the knowledge, skills and practices based on the theories, beliefs and experiences indigenous to different cultures, whether explicable or not, used in the maintenance of health, as well as in the prevention, diagnosis, improvement or treatment of physical and mental illnesses (WHO, 2002:1).

For others, the motivation for seeking second opinion from traditional healers was because of the negative experiences they had encountered with conventional healthcare professionals. Three mothers, all from Lusaka opined that professionals were not interested in children. Esther shared her experience:

> Esther [L]: the staff at the health centre were harsh to me […] but when I went to seek help from the traditional healer, he welcomed us very well. I could tell that he was interested in helping us. I have respect for him, and I would recommend people to seek help from him.

Another mother described the positive reception she received from the traditional healers:

> Bo ma Chikombe [K]: the traditional healer was good, he smiled. He made me feel welcome and appreciated. And the conversation was two-way.

The narratives above reflected the views and concerns of other participants as it relates to their relationship with the medical professionals and traditional healers during the early stages of their child's condition. Bo ma Kaimbu [K] turned to traditional healers because of a lack of healthcare services near her village. My findings have direct parallels with previous research. Baskind and Birbeck (2005), alluded to non-availability of modern healthcare especially in rural Zambia as one of reasons people sought the opinion of traditional healers. McKenzie et al. (2013) highlight this view by stating that their review of literature showed that a significant number of people in Africa rely on traditional healers in the diagnosis and management of disabilities.

From the accounts of mothers in both research sites, it was evident that traditional healers were held in high esteem and seen as integral members of their community, local culture and heritage. Scholars (Chinsembu 2016, Audet et al., 2015) have highlighted the view that traditional healers are often a patient's first and preferred line of treatment in rural areas of sub-Saharan Africa. My study findings, revealed that even in situations where healthcare services were within reach, people still turned to traditional healers. As explained by Esther [L], one of the factors that led her to seek help from traditional healers, as earlier stated, was the poor attitude of conventional medical professionals towards patients.

Where some mothers consulted traditional healers, their level of education played an important role in their healthcare seeking behaviour. None of the eight mothers (seven from Lusaka and one Kaoma) who had secondary education consulted traditional healers. For example, a mother with a degree and a professional job narrated:

> Chilinda [L]: people were advising us to seek help from the witchdoctors […] but we saw that the advice was not going to help us. The only help we could get was from the hospital, so it made us start seeking medical attention.

Similarly, Mwila [L] stated:

> Mwila [L]: I knew it was just a waste of time and money going to the traditional healer.

This view was also shared by other participants such as Tandiwe [L] and Astridah [L] who both had higher education. Hence, all these participants rejected the notion of seeking the help of traditional healers. It was evident that mothers with higher education sought public health care for their child's condition but more than this; they were seeking a meaningful explanation from medical and health professionals.

5.7 Mothers' Attitudes towards informing others of the Child's Diagnosis

The majority of mothers in this study found explaining the condition of their child to others quite challenging after obtaining diagnosis from either health professionals or traditional healers and in the context of lack of information they received as detailed above. The willingness of mothers to discuss their child's condition with others varied among the women of different age groups. Sixteen (eight from each site) out of twenty-one mothers aged 30 years and above revealed they had less of problem explaining the condition of the child to others. For example, Hilda [L] aged 59-years, provides a good example of this:

> Hilda [L]: I had no problem talking about his condition. I told my husband, relatives and friends. There was nothing to hide.

Similarly, Astridah stated:

> Astridah [L]: it wasn't an issue telling family and friends that Chota was diagnosed with a debilitating condition.

All the nine (five from Lusaka and four from Kaoma) mothers below the age 30 years and who were first-time mothers felt more uncomfortable talking to others about their child's condition. For example, Emma [L] aged 22 years and a mother of a child with cerebral palsy revealed:

> Emma [L]: I didn't tell anyone about his condition at first. I didn't want anyone to know […] I didn't feel nice; it was bringing a lot of bad memories.

Fortunate [L] aged 28-years concurred with Emma's sentiments. She found that each time she explained the condition of her child, most people struggled to understand the nature of the condition due to stigma attached to disability. Mothers recounted:

> Fortunate [L]: they at times ask useless and thoughtless questions, and they offer worthless suggestions.

> Bo ma Charity [K]: it was hard for me to break the news, knowing the kind of response I was going to receive from friends.

It was apparent that the mothers were concerned with how they were perceived by members of society, as well as their child, and that some people had wrong assumptions about the causes of disability. Hence, their accounts were consistent with the social presentation perspective. This approach *'supports the notion that certain kind of thoughts underlie social anxiety and that modifying people's cognitions about themselves and their social worlds reduces their social anxiety'* (Leary and Jongman-Sereno, 2010:475).

5.7.1 Reactions of Partners to the Diagnosis

The reactions of the partners of the participants from both research sites about the news of their child's disability varied. In Kaoma, seven out of ten participants who spoke about their spouses' reactions reported that their husbands initially accepted the condition of the child:

> Bo ma Angela [K]: my husband accepted the child as a gift from God, and that there was nothing he could do if that was God's desire.

Bo ma Charity's [K]: husband also believed that it was God's will that they had such a child. There were also cases where a husband did not say anything. For example, Bo ma Chikombe [K]: indicated:

> Chikombe [K]: the father didn't say anything when I told him that the child had cerebral palsy.

At the same time, two out of the ten participants (who spoke about their spouses' reactions) experienced a negative initial reaction accompanied by isolation the first time they broke the news to their partners. This might have been caused by stigma attached to the children with disabilities as well as the mothers who give birth to them. For example, fathers who were informed of the diagnosis sometimes disapproved of the mother and the child. Some mothers explained:

> Bo ma Kasweka [K]: when the child was okay, he accepted him but when he was diagnosed with cerebral palsy, he rejected us both, the child and me. I felt lonely and miserable.

In Lusaka, eight out of fifteen participants who shared their accounts about their partners' initial reaction to the child's condition stated that their spouses could not accept the condition of the child, as Tandiwe narrated:

> Tandiwe [L]: The first 8 days, I think it was difficult for him because even when he came to the ward you could see that he wasn't happy. It was the first time he was experiencing it, so it was like why this happening to me […] so it was not easy for him to accept.

For Emma [L], she was not in communication with her partner for almost 2 years after he was informed of their child's condition. She stated that his immediate reaction was to deny the child on the grounds that it had never happened before in his family. Mwila [L] and Zion [L] explained their situations:

> Mwila [L]: so, he didn't accept the child, I should say. He said that they didn't have such children in his family.

> Zion [L]: he told me he was not ready […] I think he couldn't take it. It was too much for him to take. He told me it had never happened in his family.

The accounts given by mothers revealed that most partners in the rural area, Kaoma were more supportive and accepting of the child's condition when told about the diagnosis than those in the urban area of Lusaka. There was a strong belief that a child inherited a disability from the mother, hence, some spouses decided to disown both the mother and the child with disabilities. As Shefer et al. (2013) submit, these beliefs coupled with the patriarchal family system exacerbate the challenges that mothers experience in most sub-Saharan African countries.

5.8 Initial Reactions of Family

Participants shared their experiences of how having a child with disabilities affected them beyond their nuclear family. Nearly all the participants (twenty-five out of thirty) talked about the initial reactions of their families. Three out of the five first-time mothers from Lusaka explained that initially the child's condition affected their relationship with the family. For example,

Sophia [L] and Zion [L], both of whom had a child with cerebral palsy reported having strained relationships with their in-laws:

> Sophia [L]: his family didn't accept the child. For example, one day his cousin got upset and started saying this is not my cousin's daughter and from our family we don't have children that are disabled.

> Zion [L]: I remember what Naku's grandparents said when they first saw her. Her grandpa told me that the child was a curse, he said a lot of trash and saying in my family we would never have children like her: this is coming from your family. I doubt if this is my son's child.

This type of reaction from the two participants above was indicative of the emotional strain that such an experience brought on the family. The situation was similar for married mothers in Lusaka. Two out of four mothers in Lusaka who were married at the time of the interview, said they experienced strained relationships with their in-laws. They stated:

> Dorcas [L]: my mother-in-law did not accept the baby the first time I told her about the condition. She said that out of the six children she gave birth to none was disabled. She refused to come and see the baby and even to assist me with the other children. She said she couldn't leave her village to come and look after a disabled child. She could only do that if the child was able-bodied.

> Violet [L]: it was a big problem, his family rejected my daughter because of her condition.

In the case of Susan [L], she lamented that her former husband's relatives never visited her neither did they accept her daughter's condition. The above experiences demonstrated the reality of the suffering mothers experienced when families denied them and their child. These accounts also confirmed the stigma attached to both the caregiver and the disabled child. These narratives provided valuable insights into how distressing it can be for mothers when they are rejected by their significant others. This

reflected an understanding of disability by their in-laws within the context of a medical model (Oliver and Barnes, 2010, Thomas, 2004).

Despite these distressing moments, four out of the eight mothers of Kaoma who were married at the time of the interview, reported receiving support and encouragement from their in-laws. For example, Bo ma Cleopatra [K] spoke of receiving support and encouragement from the family. Similarly, Bo ma Kanyanga [K] explained:

> Bo ma Kanyanga [K]: my then husband's relatives were quite understanding and supportive. They even suggested that we take Mary to the traditional healer that could see what was happening. They often helped taking caring of her.

My study findings revealed that in the initial stages of the diagnosis of the child's condition, in-laws of mothers of Kaoma were more supportive than those of Lusaka. Nevertheless, twenty-five out of the thirty (eleven in Lusaka and fourteen in Kaoma) participants in both research sites reported receiving support from their own families. In the case of Bo ma Barbara [L] her family told her there was nothing she could do about her daughter's condition and they encouraged her to remain strong. The situation was similar with Bo ma Kasweka [K] who reported that her family advised her to leave everything in God's hands, as she did not have control over the condition of her child. Similarly, some participants in Lusaka reported:

> Gertrude [L]: when I first told my relatives about Gideon's condition, they accepted him. My aunt even bought a buggy for him because I had a problem with my chest so it was a challenge to carry him on my back. My brothers, sisters and the extended family members used to come and visit us and check on how he was doing.

The above accounts of the families of mothers and their spouses reflected variations in reactions. What emerged from my study in terms of reaction to initial diagnosis was that the mothers' families were more accommodating and more easily accepted the condition of the child than their in-laws. These

reactions of not accepting the child's condition by the mothers' in-laws highlighted the socio-attitudes and historical realities of the wider society where a mother is blamed for her child's condition (Blum, 2015, 2007, Panitch, 2008).

5.8.1 Initial Reactions of Friends

Fourteen (ten from Lusaka and four from Kaoma) out of thirty mothers reported experiencing negative initial reactions from the community. Faggy [L] described such reactions as painful. Dorcas [L] stated that initial reactions from the community were unbearable. Violet [L] explained that her neighbours used to laugh at her daughter, suggesting that she had a big head. Emma [L] and Bo ma Gideon [K] also narrated:

> Emma [L]: my neighbours used to laugh at Albert when they knew that he was disabled

> Bo ma Gideon [K]: people in this village used to laugh at him when they knew of his disability. They called him all sorts of names like he has a big head, things like that. I used to get hurt very much. I found it to be quite offensive.

Sixteen women (five participants from Lusaka and eleven from Kaoma) had a positive view of their initial experience with their communities: they reported receiving support and encouragement. Bo ma Kanyanga [K] stated:

> Kanyanga [K]: the people in the village were very supportive and they visited me frequently to encourage me to accept and appreciate that my 2 disabled children were like any other child in the village.

Faggy [L] shared her experience of how her friends and neighbours reacted when they learnt that she had a second child diagnosed with muscular dystrophy:

148

> Faggy [L]: most of my friends felt pity for me, some would even cry because of what I was going through raising two children who had muscular dystrophy […] each time I gave a testimony at church, people would cry. They told me we don't know God's plans and why he had given me two disabled children. I was encouraged to take care of them.

These findings demonstrated that more mothers from rural Kaoma than the urban Lusaka received a positive response from the community during the initial stages of the child's condition. These findings are in stuck contrast with an earlier study by Kelly et al. (2012) in Malawi that found that mothers of children with disabilities in rural Malawi were banished from society.

5.9 Conclusion

This chapter extends the existing body of literature on caring for a child with disabilities in Zambia and globally in specific ways. As discussed in chapter three, the literature reviewed indicated that little attention had been paid to the experiences of mothers raising children with disabilities in Zambia. This chapter explored this area in order to begin to establish mothers' experiences and life trajectories, including during the sometimes ambiguous, protracted and painful process of becoming aware that the child was disabled. This also encompassed the factors that influenced their choice of healthcare services or other services, and their relationships with healthcare professionals, as well as with traditional healers. In recounting the early days, weeks and months after birth, mothers' accounts told of the importance of early diagnosis, and this featured prominently. During this stage early after birth and in relation to early diagnosis, the significance of the nature of the relationship between healthcare professionals and mothers was also strongly emphasised.

As well as presenting findings about initial reactions of mothers, this chapter has also explored from the mothers' perspectives the reactions of the families to an initial diagnosis of a disability. In the context of both urban and rural Zambian society, and dominant ideas about childhood disability, these

reactions profoundly impacted on mothers and the degree of acceptance and support that was offered to them. In eliciting the perspectives of mothers during the early stages of knowing about their child's condition, the chapter drew on the theoretical and methodological approaches highlighted in chapters three and four. The narratives in this chapter revealed the nature of mothers' feelings and expressing their emotional progression as they became aware that their child had a disability. It showed that there was a dichotomy with regard to accessing healthcare services. One group of mothers had greater faith in medical and health professionals and maintained this faith; some mothers, however, started with medical and then moved to traditional healers. Other mothers preferred traditional healers from the start as they believed this is where they would find out with certainty the condition of the child; what the cause was; and the nature of the child's condition. These latter mothers were looking to exert a form of revenge for their child's condition if they could be given information about the person who may be responsible, which may serve to make them feel better, a point that has not been recognised before now.

As indicated above, some started with conventional medicine before switching to traditional healers. This discovery counters the findings of the most recent studies (Chinsembu, 2016, Audet et al., 2015) in this area which elucidate that women of rural communities opt to go to traditional healers over medical professionals as their first line treatment, but that this is not the case in urban areas. My study demonstrated that traditional healers are an important cornerstone in the diagnosis of disabilities across the rural-urban divide.

Findings from this chapter revealed that whilst it is possible that health professionals felt that they were being protective of mothers, this denial of information was indicative of women's initial powerlessness although many subsequently fought against this on behalf of their children.

Mothers' accounts also highlighted new insights into the complexity and depth of decision-making at family level. My study findings revealed that mothers cannot make decisions regarding healthcare needs instead families' played a significant role in determining the type of help required for the child. In situations where the couple was still together, the husband made decisions, and again limiting women's agency. This chapter presents new insight into the reaction of mothers to a diagnosis of the disabled child's condition. Mothers viewed their initial experience of a child becoming disabled as a very disruptive event and responded differently depending on whether they were drawing on the family and friends, resources or healthcare professionals. For first-time mothers the disabling condition of their child was experienced as a serious biographical disruption, which they described as a shock and saying that they felt like their lives had come to a sudden standstill. Much as the participants were initially confused and shocked at the condition of their child, some were able to accept this more readily than others.

This chapter has developed a new understanding regarding initial reactions to disability. Contrary to previous research in Zambia (Traini and Loeb 2012, Mung'omba, 2008) that indicated that negative reactions are more pronounced in rural areas than in urban areas, my study findings demonstrated that families were more supportive of mothers of children with disabilities in the early stages of the diagnosis in rural Kaoma than in the urban Lusaka. The reasons for this are as yet unclear and further research is needed to explain this. Finally, the experiences of mothers in my study might provide a good reference for future parents as it has provided an insight into what it is like to obtain a diagnosis relating to a disability in Zambia. The importance of being made to feel disempowered in the face of seeking help from medical professionals cannot be overstated.

Chapter Six

Transitions and Critical Thoughts: Trajectories and Shifting Circumstances Over Time

6.1 Introduction

Chapter five acknowledged what it means to become a mother of a child with disabilities. The chapter focused on the early lives of children with disabilities and highlighted how mothers and their significant others reacted to their child being defined as disabled. For mothers, this discovery was often shocking and for inexperienced mothers was often prompted by family members or other mothers. The importance of the mother-professional relationship was also noted as significant as mothers were often frustrated in finding out about their child's condition. Partners and family reactions were not always positive and many mothers who participated felt disempowered, their commitment to their children enabling women in very difficult circumstances to try to exercise agency. Chapter six builds on chapter five, drawing on the data to outline how the mothers were able to adapt to the condition of their child over time. It explores the beliefs surrounding disability and how mothers perceived themselves and their child's disability as their child grows.

Chapter six is divided into three sections. The first part places a focus on the beliefs about disability among both the research participants and their experiences of commonly held societal beliefs within their respective communities. It addresses how mothers came to understand more about the condition of their child over time, as well as how they perceived themselves. It also explores the myths and beliefs about disability in society that mothers were aware of. The second section investigates the impact of a child's disability on mothers' relationships with their spouses and significant others, as the process of biographical disruption introduced in the previous chapter continues. It highlights how these relationships change

within the context of changing circumstances, the growing recognition of the child's condition, and dominant social attitudes and ideas about disability. The third section focuses on the caring roles, exploring how mothers juggled competing roles of caring for a child with disabilities and doing other household chores. Finally within this section it looks at the available social support networks mothers had at household level.

6.2 Beliefs, Attitudes and Perceptions of Disability

Research suggests that different beliefs about the causes of disabilities are held in many countries (Shefer et al., 2013, Munyi, 2012, Shabo et al., 2011). However, these studies tend to focus on how society perceives people with disabilities and less is known about how carers, who in most cases are mothers, perceive themselves and the condition of their child. Other studies have revealed that discussion about the causes of disabilities in many societies are to a larger degree shaped by either the social or medical model of disabilities (Panitch, 2008, Gabel and Peters, 2004), as discussed earlier in the thesis. This section focuses on the theme of beliefs as it emerged from the accounts of participants during the interviews I had in both research sites; Lusaka and Kaoma. While the mothers shared their thoughts about their beliefs, attitudes and perceptions of the condition of their child, these varied significantly. The beliefs ranged from believing that the child was bewitched to believing that the child was God-sent, to neuro-scientific beliefs. In Lusaka, the mothers I interviewed predominantly pointed to both biomedical and metaphysical causes while mothers in Kaoma mainly believed in metaphysical causes, with little reference to biomedical causes.

6.2.1 Belief in Sorcery

A range of literature (Munyi, 2012, Edwardraj et al., 2010, McCabe, 2007) has shown how traditional beliefs have perpetuated the belief in witchcraft in many developing countries leading to the families with children with

disabilities facing difficulties in their daily lives. These beliefs, coupled with the patriarchal family systems in most sub-Saharan African countries, have made the lives of most mothers of children with disabilities very hard.

A recurring theme expressed by eleven (five from Lusaka and six from Kaoma) mothers across the urban-rural divide and across the age groups was that their children were bewitched. Across both sites the mothers who mainly spoke of witchcraft were those whose child had cerebral palsy, autism and Down's syndrome. Bo ma Shenda [K], a 40 year-old mother of a child with Down's syndrome said:

> Bo ma Shenda [K]: people were jealous of me and that's why they bewitched my daughter […] they were jealous because I'm happily married and lived well with my husband.

Bo ma Barbara [K], a 40 year-old mother of a child with cerebral palsy, also mentioned jealousy as the reason people bewitch others. She noted that they were jealous during pregnancy and they tried to harm the unborn baby but God protected the child and hence they could only succeed in bewitching her after it was born. One mother succinctly stated:

> Bo ma Charity [K]: disability that results from witchcraft is only possible after the child is born. If it is witchcraft, the condition is hard to cure […] because their aim is to kill […] the child is born normal then when they reach a certain age they start getting sick and from that point they start changing […] when that happens then it is a sign that the child has been bewitched.

The mothers who believed in witchcraft also reported that the other reason people bewitch is because they want to use a child in rituals. Four out of fifteen mothers from Lusaka reported that people suspected them of using their child with disabilities to boost their businesses. For instance, one mother stated:

154

Faggy [L]: people were accusing me of using my 2 disabled children in my business […] there was a lot of talking.

Some mothers believed this to be true in some cases. For example, Fortunate [L], whose education level was grade nine, reported that some parents bewitch their own children and use them along with charms to attract more clients to their business. All this is allegedly done in order to get rich quickly. Her views were supported by Dorcas [L], who had no formal education; she stated:

Dorcas [L]: yes, some parents sacrifice their children to Satanism so that they can prosper […] putting their disabled child into their business.

The belief was that children with disabilities had supernatural powers to attract customers. One mother succinctly remarked:

Emma [L]: yes, some parents do that, they use charms so their child can become disabled and then these would use supernatural powers to attract customers to their business. The more severe the condition of a child, the more successful the business will be. The traditional healer also confirmed it.

According to another mother:

Esther [L]: I was told that someone within the family was using her in business and that she goes to the graveyard […] her condition will get worse, she will be drooling and when that happens, then she will be bringing in more money into business.

The belief that the child was bewitched because of jealousy was a common thread in the accounts of mothers from Kaoma across all age groups. From the accounts above, it was clear that most participants from Kaoma considered themselves able to identify conditions that were due to witchcraft. This view was shared across all age groups. However, this was not the case with the participants from Lusaka; none of them mentioned jealousy as a

reason for witchcraft. It was, however, evident that mothers from Lusaka believed that not only did other people bewitch children, but some parents did it too. They also believed that a child with disabilities could be used to boost business.

My study findings expand on (McNally and Mannan, 2013) study on cultural beliefs about disabilities in Tanzania that identified ignorance, neglect, witchcraft and belief in supernatural forces as some of the socio-cultural factors that are seen as causing disability. Further, findings of a study by Gona et al. (2015) in Kenya on the perspectives of parents and professionals on the causes of autism reveals that autistic children were believed to possess a spirit that enables parents to have money. Other scholars such as Hartley et al. (2005) attribute such negative attitudes to a lack of knowledge, and strongly entrenched traditional and social norms that are prevalent especially among the less educated in some developing countries. Thwala et al.'s (2015) study participants in Namibia associated their child's disability to witchcraft. My study was the first in Zambia and it revealed that lack of accurate information culminated into beliefs that disability was caused by witchcraft. These beliefs were common particularly amongst those with lower levels of education.

Seven (three from Lusaka and four from Kaoma) out of thirty mothers believed that eating certain types of food such as the yolk of an egg, when pregnant could also cause disability. One mother stated:

> Bo ma Gideon [K]: I have grown up knowing that certain types of food such as a yolk of an egg are not good for pregnant women.

The same group of mothers (three from Lusaka and four from Kaoma) further spoke about the link between quarrelling and disability:

> Bo ma Namutondo [K]: it is important that people who are pregnant avoid picking quarrels with their in-laws because

this affects the unborn child. There is a high risk of having a disabled baby.

This type of reasoning appeared to be common among mothers from rural Kaoma and the high-density areas of Lusaka. The findings highlighted a link between knowledge (beliefs) of the causes of disabilities and socioeconomic status. Participants from a low socio-economic status were superstitious. Mothers from a high socio-economic status in terms of educational background and residential areas, were asked how they perceived their child's challenges and what their understanding of the child's troubles were. Four mothers (all from Lusaka) who either had professional jobs or worked as volunteers in disabled peoples organisations (DPOs) rejected the notion that disability was caused by witchcraft. One mother said:

> Chilinda [L] there are a lot of misconceptions about disability among families of disabled children. Some rush into believing that the child was bewitched. Disability isn't caused by witchcraft, these are physiological conditions.

Similarly, Astridah [L], an activist for people with disabilities, explained that she knew that disability was not due to witchcraft, and that she did not even believe in traditional medicine as a way to curing her son's condition. Another mother who had a university degree, remarked:

> Tandiwe [L]: those who believe in witchcraft do not take time to read, because there is a lot of literature on the causes of disability. I do research to find out what the causes are, the effects and things like that […] it requires effort to know these things.

It was evident that mothers from a high socio-economic group took time to research their child's disability. Hence, they did not believe in witchcraft. Overall, it was clear that most participants had multi-causal explanations to explain their child's condition. The mothers who were drawing on socio-cultural factors took the view that witchcraft was the main cause of disability especially conditions such as cerebral palsy, autism and Down's syndrome.

Mothers with a high socio-economic status, such as those with professional jobs believed that disability was due to neuro-scientific factors. Mothers also believed that God gave them the child with disabilities. This view is explored further in the next sub-section.

6.2.2 Religion/Faith and Understanding of Disability

A common thread running across all interviews was the belief that a child with disabilities was a blessing from a Christian God, send to them for a purpose. Interestingly, this was a common belief regardless of whether mothers believed in metaphysical or neuroscientific. For example, twelve out of fifteen mothers from Lusaka believed that God gave them the child with disabilities. For example, some mothers stated:

> Sophia [L]: it's rare to find women of my age having a disabled child; some of the women dump or kill their child […] she is a blessing to me. God saw something special in me for Him to give me such a child […] I have a strong belief that I'm not an ordinary person, I'm special to have such a child.

> Dorcas [L]: God ordained me to have this child, and when he ordains, there is nothing you can do.

Nine out of fifteen mothers from Kaoma had similar views to those of Lusaka. They explained that much as society viewed them as unlucky, they felt it was a blessing to have been chosen by God to parent such a child. Others stated that they were learning a lot from parenting a child with disabilities:

> Bo ma Angela [K]: I thank God for giving me 'a precious gift' and the wisdom to care for the child.

However, four mothers (three from Lusaka and one from Kaoma), all mothers of children with cerebral palsy, had a different view. For example, one mother remarked:

> Bo ma Kaimbu [K]: it's a problem. It's a problem, a challenge
> and a test from God to see if I'm able to take care of a disabled
> child. I ask God, why? Why did it have to be me?

Emma [L], a 22 year-old mother of a child with cerebral palsy, and Esther [L], a 29-year-old mother of a child with cerebral palsy, lamented that they never thought they would have a child with disabilities in their lives. Another mother of a child with cerebral palsy stated:

> Mwila [L]: I wouldn't say I have accepted her condition even now
> 8 years down the line […] even if friends encourage me to do
> so […] she is still in this state so acceptance is something that
> is difficult. I don't think she's a gift.

It was evident that with time, religious and cultural beliefs of a family and societal beliefs influenced how mothers viewed the causes and expected outcomes of their child's disability. This fatalistic view of disability was linked to the religious beliefs of the parents, that it was God's will that they had a child with disabilities. Mothers who believed their child's disability was the manifestation of a plot against their destiny had lower expectations of the treatments used to improve their child's disability. The accounts revealed that mothers had multi-causal beliefs of disabilities. My findings extend on the findings of a study in South Africa by Masasa et al. (2005), which provides evidence that participants believed disability was the result of God's will. Their findings also show that these beliefs about disability were influenced by wider societal beliefs in fate. In some instances, society blamed mothers for their child's condition. This is explored further in the subsequent section.

6.3 Society Blames Mothers for the Condition of their Child

One of the themes that emerged from the mothers' accounts was mother-blame. This cut across age and rural and urban divide. Mother-blame is a

term that *'describes mothers being held responsible for the actions, behaviour, health and wellbeing of their (even adults) children'* (Jackson and Mannix, 2004:151). Interestingly, other scholars contend that mothers and not fathers often tend to *'share the stigma of impairment'* (Blum, 2007:203) and are consequently blamed for the condition of their child (Blum, 2015, Strega et al., 2008).

Fourteen (nine from Lusaka and five from Kaoma) out of thirty participants raised the issue of being blamed by their spouse. Faggy [L] whose two children had muscular dystrophy and Bo ma Musuwa [K] a mother of a child with cerebral palsy narrated their experiences:

> Faggy [L]: he says I'm responsible for these children's condition. He would say that you weren't paying attention to these children that's why they are like this. You don't do physio on them […] all he thought was that I caused the condition of the children […] he says a lot of bad stuff like you carry a gene that causes these conditions.

> Bo ma Musuwa [K]: my former husband says that I was responsible for the child's condition.

The above accounts suggested that mothers were blamed for the condition of their child even by the child's other parent. The mothers further reported that children with disabilities were perceived as belonging to the mother, while the able-bodied belonged to the husband. For instance, Sophia [L] narrated:

> Sophia [L]: he accused me of being negligent. He said he had nothing to do with her because he would never have a disabled child.

The tendency for the husband to blame the mother for their child's condition was more prevalent in Lusaka than in Kaoma. Mothers' accounts illustrated that broader societal beliefs that blamed women were also mediated by family members. Mothers explained that their in-laws also blamed them for

the disability in the family. This was the case in both Lusaka and Kaoma with eight mothers (five in Lusaka and three in Kaoma) saying that their in-laws blamed them. For example, mothers explained:

> Bo ma Gideon [K]: my mother in-law said that this disability was from my family. She said that none of her grandchildren had such a child.

> Mwila [L]: his sisters were blaming me. They said all sorts of rubbish that I was the one who was carrying the baby in my womb so I'm responsible for the condition.

Some participants confirmed that they were accused by their in-laws of being negligent especially when they were pregnant. This is illustrated in the following quotes:

> Susan [L]: my sister in-law once told me that it was because of the contraceptives I was using that damaged his brain.

> Emma [L]: I overheard my mother in-law saying my son had a brain damage because I might have been taking something that detrimental to my son's brain.

It also emerged that the disability of a child was associated with unfaithful wife. A case in point was Mwila [L] who recounted:

> Mwila [L]: I have never had peace with his family from the time she was diagnosed with CP (cerebral palsy). They suspect that I was sleeping around with other men when I was pregnant.

The mothers' narratives reflected the common societal tendency to blame the mother for the condition of the child and in some cases associating it with sexual promiscuity. The accounts above reflected the assertion by scholars such as Landsman (2009:15) that *'the birth of a disabled newborn is linked to parental, and particularly maternal misconduct.'* The intertwining nature of social networks (significant others) and societal beliefs suggested that these

made the lives of these mothers challenging. In other words, the combination of social stigma and myths about disability contributed greatly to the isolation and marginalisation of these women as a mother explained:

> Bo ma Barbara [K]: disabled people are generally despised. It is not easy for my daughter and me in this village. Many people here avoid me. I don't have a friend. It's tough for us.

Findings suggested that the blame and pervasive criticism levelled against mothers of children with disabilities, ignored the increasingly difficult and complex conditions in which these women were under. A mother explained:

> Susan [L]: I endured negative reactions mainly from my in-laws who thought I was demon-possessed […] my family thought I was just unfortunate she had this condition.

Similarly another mother explained:

> Sophia [L]: recently, an old friend visited me, I told her I was a single parent of a 5-year-old who has severe cerebral palsy. I instantly received a look of shock which was followed by 'that's really bad luck'.

This view was held more common among young and first-time mothers of children with cerebral palsy. Surprisingly, none of the mothers from rural Kaoma mentioned that they were considered to be cursed or had bad luck. They mainly spoke of witchcraft.

Mother-blame seemed to have led to self-blame and a sense of guilt for many of the mothers in the study. Seven participants (five from Lusaka and two from Kaoma) out of thirty mothers spoke of feeling that they contributed to the condition of their child. For example Bo ma Kaimbu [K], aged 26 years-old at the time of the interview and a mother of child with cerebral palsy, lamented:

162

> Bo ma Kaimbu [K]: I thought that maybe it was my fault that the child was disabled. I think partly it was because my husband kept on saying I was responsible for the child's condition. So I started thinking that maybe I made a mistake by going to deliver at the health centre in the army barracks.

Bo ma Kaimbu [L] described how she found it difficult to maintain her self-esteem in the face of mothering a child with disabilities. In the case of Emma [L], aged 22 years-old at the time of the interview, said that her son was disabled partly because she had given birth to him when she was very young. Similarly, Sophia [L], a 23 year-old mother of a child with cerebral palsy, blamed herself for her daughter's troubles. Like Emma, Sophia thought that her age could have contributed to her child's disability. Susan [L] aged 27 years-old, used an indirect phrase to blame herself for the troubles of her daughter. She remarked:

> Susan [L]: some of the things we did in the past are manifested in our kids. I wish I knew the consequences.

When asked to clarify what she meant by her statement, she elected not to explain any further. My findings further suggested that self-blame was common among young and first-time mothers. This self-conception by mothers reflected the concept of the "*looking glass self*", a cornerstone of sociological theory of socialisation coined by Charles Horton Cooley in 1902, and developed subsequently by others (Jones, 2015, Downey, 2015). This metaphor (looking glass self) states that:

> We are constantly imagining what others think of us, and responding to these imputations. The status of the other person plays a role, as everyone is not equally equipped to make us experience shame, pride, envy, or appreciation (Downey, 2015:537).

At the same time, none of the mothers aged 30 years and above in either of the research sites blamed themselves. For instance, Gertrude [L] aged 49 years old and a disability activist; Hilda [L] aged 59 years-old, and Bo ma

Musuwa [K], a 30 year-old mother of a child with cerebral palsy, all stated that they did not blame themselves.

> Bo ma Musuwa [K]: there is nothing wrong I did to blame myself for his condition.

My study findings demonstrated that those mothers, who were disability activists and many of who mothered more than one child, had a greater understanding of the child's condition and concomitantly they did not blame themselves because they had a different understanding of how disability was caused.

6.4 Development of Relationships with Significant Others Over Time

6.4.1 Relationships with Spouses over time

This section builds on the previous section to highlight the implication of the child's disability and mother-blame on the mothers' relationship with their significant other over time. Studies have revealed that social networks have an influence on motherhood (McCabe, 2010, Kingston, 2007), and they are key in providing support to mothers and *'conceptually, social support overlaps with friendships, and both with family and, kin and neighbourhood relations'* (Oakley, 1992:24). The relationship of mothers with their spouses, family and friends in my study varied with time and across generations. Sixteen (eight from each research site) out of thirty mothers stated that they considered that their relationship with their spouses was gradually damaged because the child's condition was not improving:

> Bo ma Gideon [K]: 'Nili na chikonko' (closest translation in English - I'm grieving). I ask myself why I married this man and had a child with him. He never says anything good about my child and me.

164

Similarly, Fortunate [L], a 28-years-old mother of child with autism noted that at times her spouse scolded her in public and in the presence of her children. She reported feeling humiliated, despised and experienced 'constant sorrow.' This kind of treatment had an impact on the emotions of both mothers and their children. Another participant, aged 22 years-old and a mother of a child with cerebral palsy stated:

> Emma [L]: I feel abandoned and robbed of my youth. He impregnated me then he rejected the child and stopped communicating. I'm grieving at losing my relationship with him.

Similarly, a 27 years-old mother of a child with cerebral palsy narrated her experience:

> Susan [L]: first he tortured me mentally. I can't erase those memories from mind. He became very aggressive, insulted and threatened to sort me out. That experience broke my heart into small pieces that can't mend anymore.

The situation was similar in Kaoma where Bo ma Angela [K] bemoaned the impact of her child's disability on her relationship with her husband:

> Bo ma Angela [K]: our relationship went down the drain. It's hard to believe but such is life.

Mothers reported that tension with their partners emerged gradually. Sometimes this was because the husband did not see any improvement in the condition of the child over-time, and this exacerbated the mother-blame because mothers felt that their partners were suggesting that they were not doing enough to help the child as narrated:

> Bo ma Mwila [K]: he was getting agitated because the child's condition was not improving. We initially thought the child would get better. He felt that I was not doing enough to help the child get better.

Mothers reported strained relationships with their partners also reported varying behaviours in their spouses. For example, one mother reported:

> Violet [L]: our marriage has been marked by fighting. Its confusions all because of the child's condition. He is using the child's condition against me.

According to another mother:

> Dorcas [L]: we fight a lot because of her condition. He once beat me up badly […] things are not okay even if I'm still with him. There's no peace at home. We quarrel almost daily […] I have a miserable life.

The accounts of mothers, especially in Lusaka suggested that some husbands used violence and verbal abuse against their spouse. In some cases these verbal and physical abuses resulted in divorce. Divorce was often instigated by the male partner. Eleven participants (five from Lusaka and six from Kaoma) out of thirty mothers at the time of the interview reported that their partners divorced them. Of these, five divorced women were first-time mothers and all of them were from Lusaka. They gave varying reasons for becoming divorced: from their husbands abhorring their child with disabilities to interference from their in-laws. A mother explained:

> Susan [L]: he used to abuse me physically. He would beat me even in public. He also complained about the cost of caring for my daughter. He saw the child as a burden. His relatives also played part in our divorce.

Another mother stated:

> Bo ma Musuwa [K]: he went away and said that by the time he returns he should not find a disabled child. After a few months, he came back and packed his clothes and that's how he left us.

Similarly, Bo ma Kasweka [K] reported that her husband left her because her child was not getting better. Mothers in my study narrated the ways in which having a child with disabilities led to strained and broken relations. Their accounts reflected how negative societal perception and attitudes can lead to feelings of powerlessness. Traditionally, families in Zambia are organised on patriarchal lines. Hence, mothers often felt that they were blamed and abused by their partners and in-laws. Mothers who were divorced experienced shock, and this exacerbated the impact of biographical disruption (Wilson, 2007, Bury, 2001, Williams, 2000) in their lives as their future was irrevocably altered. Everything changed for these women; they suddenly became single-mothers and had to play both roles of mother and father figures in the lives of their children, some mothers put it:

> Mwila [L]: he was heartless, he left me at a very crucial time when I needed him most. I have been going through a crisis. It was like an abrupt end of my life. I'm now both her mom and her dad. It is simply not easy to balance the two roles.

> Susan [L]: I have had to re-organise my life. Divorce is a very disruptive experience one can ever go through. My world is turned upside- down.

These stories revealed an intersection of disability, gender and power that is prevalent in most patriarchal societies, and which both disempowered women and placed them in marginal social locations (Moodley and Graham, 2015, Risdal and Singer, 2004, Glenn et al., 1994). Some mothers remained married despite having a child with disabilities. Two out of four married mothers in Lusaka reported having a good relationship with their husbands. Chilinda [L] a mother whose daughter had osteogenesis imperfecta stated that she enjoyed a good relationship with her husband. Another mother remarked:

> Tandiwe [L]: the presence of my son hasn't brought problems in my family. Yes, initially just after the diagnosis he was a little unsettled but he did his research and he has now

understood the child's condition. Jay has actually brought us together.

Five out of eight participants from Kaoma who remained with their partners said that they had no problems with their husbands, they also reported not being abused by their partners. Bo ma Kanyanga [K] reported:

> Bo ma Kanyanga [K]: neither he nor my in-laws have ever used abusive language towards me nor the child. They have been supportive.

Bo ma Namutondo [K] had similar views to Bo ma Kanyanga's. Interestingly, three out of the eight married mothers in Kaoma said that they were in polygamous marriage. They said that because of the amount of time needed to care for a child with disabilities, their husbands felt neglected hence they married another woman. When asked if they were consulted, the three mothers said they discussed and agreed with their partners:

> Bo ma Anne [K]: so, with time when we saw that she was not improving we knew that I would be spending more time attending to her […] Instead of divorcing he decided to take on another woman. So, we are now two […] it's fine because I'm still married […] better than suffering alone with the child […] and we have six children together so what would have happened to these children had we divorced? […] So, we are raising these kids together.

The accounts by these mothers provided evidence to suggest that some mothers felt marriage was important regardless of their experience of being in a polygamous marriage. This was mainly done to maintain both status and economic security. My study findings extend the findings of other studies that have shown that polygamous marriages are common in many societies especially in sub-Saharan Africa. For example, Delius and Glaser (2004) in their study affirm that polygamous marriage exists in some African societies, such as among the Zulu speaking people of South Africa and Lesotho.

168

Indeed, findings in this section have revealed how the presence of a child with disabilities in the family had an impact on the marriage especially on first-time mothers. In some cases, mothers' relationships with other family members and friends were altered because of the disabled child's condition. The next section highlights how this evolved over time.

6.4.2 Impact of Disability on Relationships with Families and Friends over time

This section builds on the previous section to demonstrate the impact of the child's disability on the mothers' social relations with their families and friends. Seventeen (eleven from Lusaka and six from Kaoma) out of thirty participants reported experiencing strained relationships with families and friends over time. One mother narrated:

> Susan [L]: with the passing of time, it has become very difficult for my family to accept my daughter. We all had hope initially that she would get better, the family thought that the child's condition would improve but when they did not notice any improvement, they started saying that the child was an embarrassment to the family. My mother and my siblings have nothing to do with Mtambo.

Mwila [L], a divorcee endured the negative attitudes towards her and the daughter from her former partner's family. She narrated that the relationship was getting worse with time. Another mother explained:

> Faggy [L]: my sister-in-law was very blunt. I requested for my former husband's niece, she was 16-years-old. She stayed with us for less than 5-months. Her mom came to pick her up saying she was too young to look after *vilema* (a local Zambian language derogatory term used to refer to the disabled). She used the word *vilema* without any fear. That's when we even stopped visiting each other.

Nevertheless, two mothers from Lusaka who were married spoke positively about how their relationship developed with their extended families and in-laws over time. For example:

> Chilinda [L]: my in-laws have been supportive throughout this journey of raising Deborah. I can simply say we have been together in this journey for the past 17-years or so. My family too has been very supportive.

Tandiwe [L] too said that the extended family had always been helpful. Interestingly, Chilinda and Tandiwe were the two mothers with the most social class advantage in terms of their education and professional careers. These findings revealed that families of mothers with high socio-economic status in terms in education were more understanding and supportive to mothers of children with disabilities over time. In Kaoma, six out of fifteen mothers reported having a strained relationship with their extended families and their in-laws over time. Bo ma Cleopatra [K] reported:

> Bo ma Cleopatra [K]: my relationship with my in-laws got damaged gradually because my daughter's condition wasn't improving.

In terms of their relationships with friends, eight participants (three from Lusaka and five from Kaoma) out the thirty participants stated that they still enjoyed good relationship with neighbours and friends from the time the child was diagnosed with a disabling condition:

> Bo ma Mwila [K] I have a good relationship with the people in the village. Most people have accepted her condition.

The words of Bo ma Mwila were echoed by another mother who stated:

> Bo ma Angela [K]: they are now used to her. They have come to see her as someone God created and gave me. They encourage me not to despair.

170

Fortunate [L] also explained that she had a good relationship with her neighbours. However, Twelve (eight from Lusaka and four from Kaoma) out of the twenty mothers who reported about their relationship with friends stated that their old friends began to gradually shun them when they saw the child's condition getting worse. Sometimes this was because their friends believed that some form of disability was contagious. Some mothers reported being excluded from certain activities and occasions they previously participated in. Zion [L], a mother of a child with cerebral palsy represents the best-case:

> Zion [L] both relatives and friends tease me that I have a child who's constantly drooling […] because they see that my daughter isn't getting better, they stopped visiting me […] I don't have friends anymore apart from mothers who are members of our support group.

This stereotyping and marginalisation of mothers and their child with disabilities resulted in limited opportunities for the mothers to socialise with others who did not have children with disabilities. One mother remarked:

> Mwila [L]: my relationship with my old friends has deteriorated with time- […] because of the stigma I experience in society […] some people say, *alifyala umwana ichipuba* (Loosely translated as she gave birth to a 'mad' child). I have heard some friends say if my daughter shared the same plate with their children, they (their children) would also develop the same condition as my daughter's.

The above accounts suggested that disabilities were sometimes seen as contagious. Stigma and discrimination appeared to be more pronounced among participants from Lusaka than those from Kaoma. Overall, the above comments reflected the social stigma and social isolation that mothers felt. Mothers reported feelings of increased isolation over time, because of stigma and myths attached to disability. For example:

> Sophia [L]: I feel lonely, my friends forsook me [...] they are drifting away each day that passes.

Thus, this feeling of isolation was a testimony to the social power of both social networks and societal beliefs. These views extend on the work of other scholars to highlight the stigma and isolation experienced by mothers of children of disabilities. For example, Shih's (2012) study in the United Kingdom drew on Erving Goffman's conception of stigma to argue that mothers of children with disabilities experience courtesy stigma. According to Shih, this type of stigma refers to:

> …when parents associate with their disabled child. The courtesy stigma is not only about face-to-face interaction within situational contexts when their child is present […] the influences can expand to the relationship between parents and their child, and parents' identity as a parent of a disabled child' (Shih, 2012:25).

The stigma and isolation that mothers experienced in my study had the potential to have long term damaging effects on both mothers and their child with disabilities, especially because they (the mothers) were the primary carers of these children. The next section discusses the trajectory and the dynamic nature of caregiving roles that mothers had to perform.

6.5 Multiple Dimensions of Caregiving

The difficulty of caring for a child with disabilities alongside taking care of other household members and chores was one of the important themes highlighted throughout the study. However, the impact of caregiving on the wellbeing of mothers varied. Most of the mothers in my study reported that they had difficulties fulfilling what they considered as their gender roles due to the heavy demands of caring for a child with severe disabilities. Within the theme of caregiving, there were many sub-themes that emerged from the interviews with mothers.

6.5.1 *What Good Mothering Constitutes*

Motherhood is one of the most important discourses in feminist writing (Laney et al., 2013, Cowdery and Knudson-Martin, 2005) and motherhood was one of the key themes related to caregiving that emerged from the discussions with the mothers. The accounts given by mothers confirmed that gender and mothering were closely linked. Literature has shown that for feminists, gender is a central concept in theorising motherhood (Boyer and Spinney, 2016, Bhattacharjya et al., 2013, Oakley, 1992). In the context of my study, disability was one of the factors found to shape motherhood. Fifteen (eight from Lusaka and seven from Kaoma) out of thirty mothers who spoke about good mothering were consistent in their description of what it constitutes. Below were some of their descriptions:

> Faggy [L]: a good mother would try and give her child a skill. It's not all about looks; it's not about education […] it's about someone's character.

> Bo ma Kanjengu [K]: a good mother is one who takes care of her family, one who wakes in the morning and does all the household chores.

All the participants who talked about what constitutes good mothering, expressed the desire to be a good mother to their disabled child:

> Bo ma Cleopatra [K]: I work hard to provide for my daughter under very difficult circumstances. I strive to be a good mum to all my four kids, but especially to the disabled.

> Bo ma Mwila [L]: I want my child to be happy, to be proud that I'm good and a loving mum to her. I try to make her happy considering her condition.

It was clear from their narratives that love for their child with disabilities permeated this description. The views of the participants in my study were consistent and extended on the earlier literature on motherhood which

states that despite having diverse backgrounds, mothers are said to experience similar struggles, joys and desires for their children (Datta, 2011, Miller, 2005). Some mothers such as Violet [L], talked about the roles of a good mother:

> Violet [L]: I wake up at 5am I start preparing, I sweep, fetch water because there is no one to help me. If there is laundry that needs to be done I do it. I take care of my children. Anyway, that's what is expected of a good mother.

The accounts by the participants suggested that society played a critical role in the construction of the identity of a good mother. It was evident from the mothers' narratives that caregiving roles were closely linked to motherhood. As earlier feminist theorists (Smyth, 2012, Raskin, 2006) submit, mothering is a social construct that involves various activities and relationships that include nurturing and caring for their children. This view of mothers being carers of their children is explored in detail in the next section.

6.5.2 Mothers as Custodians of Children

Although the participating mothers were from diverse backgrounds in terms of age and socioeconomic status, they all expressed a sense of responsibility towards childcare:

> Bo ma Barbara [K]: it is something that comes naturally, it's a woman thing, you know.

> Zion [L]: as a mother, I'm expected to look after my daughter. Her dad's duty is to bring food on the table.

It was clear that this sense of responsibility for childcare impacted on women from a young age. They reported that society expected mothers to take care of their child with disabilities. For example:

> Bo ma Shenda [K]: it is something that we women have to do. I
> have to take care of my family.

The findings of my study revealed that gender roles were socially defined with mothers assuming the responsibility of caring for the child with disabilities. For instance, mothers recounted how they shared responsibilities at home. Eight out of twelve mothers (three from Lusaka and five from Kaoma) who were still living with their partners remarked that they practised a traditional way of doing things, where the husband's responsibility was to provide materially for the family while the mother took care of the children and did household chores. For example:

> Bo ma Kanyanga [K]: husbands and wives have different roles.
> The man is the one that clears the field when it's time for
> planting crops. At home, the woman cannot thatch the roof
> that's the man's responsibility. Bathing children, cleaning the
> house, and cooking are the woman's responsibilities.

The above narratives suggested a lack of caregiving support by partners with mothers undertaking most of the household chores. Most of the women, especially first-time single mothers, had to juggle between competing responsibilities at home with little or no support. Hence, they found that the assumptions about motherhood did not resemble reality. The situation appeared different among mothers from a higher socio-economic class. These women saw the role of caregiving as the shared responsibility of both husband and wife. This could be because their partners were better able to understand the condition of the child as they had access to information. Below is an example of an account of one of the two women who had university level education at the time of the interview:

> Chilinda [L]: my husband is very supportive in every aspect.
> Helps me a lot. When I'm busy with other things, he gives me
> a helping hand in attending to other household chores.

All the three married mothers from Kaoma whose child had a severe form of cerebral palsy, reported that their spouses were not helping with caregiving roles. For example:

> Cleopatra [K]: my husband always says he has nothing to do with the child; hence he doesn't help with caregiving roles.

Similarly, Bo ma Kanjengu [K] stated that her husband hardly supported her in caring for their child.

The findings from my study are consistent with previous research (Blackburn et al., 2010, White and Hastings, 2004) especially in the United Kingdom, which outlines how families receive social support, and how social support acts as a buffer when a mother finds herself in the challenging situation of providing lifelong care to a child with disabilities. However, the findings from my study extend this by demonstrating that social support at home with regards to these mothers was determined by the socio-economic status of a family. Caregiving in the absence of social support was a heavy load to most of the mothers as the next sub-section will show.

6.5.3 Burden of Caregiving

The burden of caregiving was one of the most important themes that emerged from the interviews. During interviews, I attempted to disentangle the complicated and entwined nature of gender and class advantages and disadvantages from the accounts of mothers with regard to caregiving. The discussions with the participants revealed that fourteen (seven in both study sites) out of sixteen mothers whose child had cerebral palsy reported that they were significantly overwhelmed by looking after their child. This was, however, more pronounced among first-time mothers. For instance:

> Zion [L]: it's hard because you have to feed, lift, bath and put her to sleep. So, it's tough because you have to do everything for her. You can't ask her to lift something or feed herself. You

can't feel lazy not to feed her, though some time back I used to, but she would not be like this if I didn't take care of her. Even if I am not feeling well I still must get up and take care of her, change the nappies, feed her. It's tough to take care of children like Naku.

Similarly, Emma [L] a first-time mother of a child with cerebral palsy explained:

> Emma [L]: I don't have time to do anything else apart from caring for him. It's been a tough journey. It's like you are into a never-ending problem. He just lies down. You can't do anything, you can't work, its difficulty to have friends. Life comes to a standstill.

Other mothers such as Esther [L] reported feeling overwhelmed with the amount of work involved in looking after her daughter with cerebral palsy. This left Esther with very little time to have a life of her own or do other household chores. These mothers complained of facing immense pressure to balance family and social life. When these children grew older yet still required the same help and attention as when they were infants, mothers had to face the harsh reality that their child would most likely require lifelong care. This led to increased and acute maternal stress among the participating mothers. One mother aptly explained this:

> Hilda [L]: it's been a roller coaster [...] it is intense raising Shadreck compared to the other eight children. I have suffered for the past 17-years, doing everything for him. It's very exhausting, you can imagine lifting a 17-year-old boy. I must take him to the toilet. It's very tough, very tough.

Another mother remarked:

> Bo ma Anne [K]: I always worry about her. I'm 51-years-old now, I'm getting weaker and weaker. At times when I try to lift her, we all fall because I'm no longer strong enough to lift her.

These findings concur with Reichman et al. (2008) argument that as a child with disabilities ages, parents encounter unique set of challenges such as increased demands for caregiving. The impact of this responsibility for the caregiver meant that some mothers were inundated to a point of often contemplating committing suicide:

> Susan [L]: I have on many occasions considered committing suicide because of the stress associated with looking after her.

Similarly, Esther [L] reported entertaining thoughts of suicide because she was overwhelmed with the demands of looking after her daughter. These findings suggested that mothers whose child had severe cerebral palsy experienced daily challenges in providing care to their child. The increasing complexity and responsibilities of caregiving had an impact on the wellbeing and health of some mothers. The next sub-section discusses this aspect in greater detail.

6.5.4 Caregiving Role: The Impact on the Mothers' Wellbeing

As highlighted in the previous sub-section, the stress of providing care to their child was greater for single parents who were expected to provide both materially and emotionally for their child. Over time, the health of eighteen (nine from each site) out of thirty mothers began to deteriorate. It was clear from the discussions with mothers, that there were many factors that impinged on their emotional and physical health. The demands of caregiving as in the case of Bo ma Gideon [K], and the societal and social stigma as in the case of Susan [L], had an impact on their health and emotional wellbeing. For example, negative societal attitudes and the agony of knowing that caring for their children was lifelong, led to mothers expressing high stress levels and social isolation. This in turn had an impact on their mental and physical wellbeing, as explained:

Susan [L]: I have developed hypertension because of worrying too much about the worsening condition of my child.

Bo ma Gideon [K]: I carry him on my back and because of that, I have persistent chest pains.

Bo ma Musuwa [K]: I went to the hospital […] I was admitted for 2 days and then the doctor advised me not to be worrying so much about my child's condition.

It was evident from the accounts that as time went by, the demands of looking after their child with disabilities took a toll on the wellbeing of mothers. As highlighted in chapter five, some mothers initially thought that the condition was short-term and as they came to grips with caring for a child with disabilities day in and day out for years, this increased their maternal stress levels leading to developing conditions such as hypertension. Mothers also indicated that stress limited their capacity for positive interaction with their families. However, mothers who had strong social support explained that they were able to cope with the demands of taking care of their disabled children. For example:

Gertrude [L]: I'm not stressed because the family supports me, my daughter and my son are very supportive, so that has reduced my stress levels.

Bo ma Kanyanga [K]: I'm not stressed have enough social support. My husband and other kids are there for me.

These findings on the importance of social support in reducing stress among carers expand on the assertion by Domma and Giordano (2012) that individuals experience stress when the support resource base available to them is inadequate or unhelpful. Trute et al. (2010) have also highlighted this argument by stating that parents who have strong social support base experience positive emotions in their daily activities. Similarly, the social model of disability articulates how families experience stress due to various socioeconomic and environmental factors that impact on their lives and

resources (Blackburn et al., 2010, Goddard et al., 2000). These can be a result of poverty, negative societal attitudes to families with children with disabilities, inadequate social support and, hostile and inaccessible physical environments. In relation to Blackburn and colleagues (2010) assertion, three mothers from Lusaka reported that not only did the demands of caring for a child with disabilities cause stress, but it robbed them of the opportunity to advance in their career. For example, Mwila [L] said that there was never enough time to look after the child and continue working. Similarly, another mother reported:

> Esther [L]: the problem I face like I said I can't work properly because there is no one to stay with her. I even had to stop working so that I could be taking care of her.

Similarly, Susan narrated that she stopped working to focus on looking after her daughter who had cerebral palsy. All first-time single mothers said that they found it difficult to work or look for employment whilst looking after a child with disabilities over time. However, five mothers in Lusaka indicated that they were working. Three of the five mothers had full-time professional jobs while two were volunteers:

> Chilinda [L]: I work for the government. My daughter's condition hasn't affected me in terms of work. Like I said, my family is very supportive.

> Astridah [L]: I work full time. He is an independent person, he looks after himself.

The interviews with the mothers also led to interesting insights into their lives. One of the key issues raised by single mothers related to issues of poverty over time. It was evident during the discussions that across backgrounds, single female-headed households had more financial challenges than those that still had their partners. Mwila [L] a divorced mother reported:

> Mwila [L]: everything is hard. There is nothing that I see to be better. I'm parenting her with a lot of problems. Food, how to find food because leaving her is a problem, clothes, everything it's tough raising her. At times, I ask for help from my brother.

Similarly, Susan [L] a divorced mother, explained:

> Susan [L]: I have a problem with food and I want her to get better but I can't manage to provide her with everything. She does not have blankets and clothes. But once in a while my parents help me.

The absence of a spouse and income led to most of these first-time mothers to turn to their families for support. However, this was not the case with the four (three from Lusaka and one from Kaoma) widowed mothers who had other children. These mothers were engaged in some income generating activities. For example:

> Hilda [L] I sell vegetables at a market to support my children. I have to work hard in order to provide for the family. My husband died some time back.

Some mothers felt that they had little choice but to leave their child alone to support their family. Bo ma Angela [K], also a divorcee and a mother of five explained:

> Bo ma Angela [K]: these are hard times but I can't just be complaining because I have to look after my five children. So, every morning I lock her (child with disabilities) in the house then I go to do some part-time jobs as a maid. I also work on people's farms. So that's how we are surviving.

Other studies have demonstrated the link between poverty and disability. Hatton and Emerson's (2009) research in the north of England, confirms this link. Their findings show that mothers of children with disabilities are more distressed and suffer greater socioeconomic deprivation. Parental separation, rates of which were higher in families with children with

disabilities, was a critical factor in plunging mothers and children into poverty.

Some mothers reported that their husbands were responsible for providing at home. Both Dorcas [L] and Violet [L] stated that without their husbands, life would have been more difficult especially since they spent most of their time providing care to the child with disabilities. Dorcas [L] explained:

> Dorcas [L]: he supports the family especially the other non-disabled kids. It would have been difficult without his support […] I have had to persevere although he is a very abusive man.

It was evident from their stories that the significant social and material benefits of marriages meant that mothers such as Violet and Dorcas persevered in unjust, abusive and strained marital relationships. The perceived benefits included: improved social standing in society, improved economic resources and most of all respite from social isolation and stigma arising from caring for a child with disabilities. However, none of the two mothers who had professional jobs complained of facing hardships. They reported that they were comfortable and able to provide for their families.

6.6 Conclusion

This chapter outlined a number of significant themes that emerged from the interviews with the mothers of children with disabilities about their lives over time. The women's accounts highlighted their understanding of their child's condition, and the impact that societal stereotyping had on them. It also illustrated the effect of having a child with disabilities on their relationship with significant others. The findings presented a range of beliefs by mothers and society regarding causes of disability.

The accounts by mothers in this chapter highlighted how mothers understood the condition of their child. Their understanding can be summed up as split between metaphysical and biomedical. Metaphysical understandings were fueled by belief in sorcery where extended family and friends were suspected of being responsible. Some mothers believed that their extended family and friends inflicted suffering on them in the form of a child with disabilities. Others believed that evil people had cast a spell on them; hence they had a child with disabilities. Often resentment and jealousy were considered to have motivated the sorcerers to cast a spell.

One of the significant contributions of this study is that it adds to the existing body of knowledge with regard to beliefs: as explained by mothers in rural Kaoma they were able to identify conditions that resulted from witchcraft. Another important addition to the existing literature was the explanation that disability is caused when a pregnant woman has committed adultery and then failed to confess to her husband. Such social taboos relating to pregnant women, including not eating certain types of food and, a woman committing adultery and not confessing to her husband pointed to the patriarchal nature of society.

Overall, the evidence about the knowledge of causes of disabilities pointed to the biomedical understandings on the part of mothers. Participating mothers from Lusaka who believed in biomedical explanations were mainly of high socioeconomic status and women who were members of parent-support groups (the role of social groups is explored further in the next chapter). Their understanding and construction of disability meant that they perceived many causes, some of which were due to medical conditions, and other factors such as abnormality in chromosomes. One of the most important findings was that generally mothers of low socio-economic status believed in socio-cultural factors such as witchcraft as the main cause of disability. The mothers also believed that parents could sacrifice their own child in a quest to become wealthy. These belief systems in society and by mothers accumulated the adversity and eventually led to self-blame in some

cases. These belief systems had long-standing impacts and consequences on children with disabilities and mothers, some of whom were not supported and were isolated.

This chapter furthermore, provided significant insight into the lives of mothers. For example, it outlined the shock of the situation for women who had never had a child before. The condition of the child and response from their significant others began to impact on them and they were isolated in some instances. They described their lives as being in a state of suspension; they experienced biographical disruption in their lives. Most of these first-time mothers started to blame themselves over time for the condition of their child because they internalised the negative attitudes of their significant others.

The mothers also suffered biographical disruption in their lives when the child's condition negatively impacted their relationship with their partners. What these experiences suggested was that disability as a sort of biographical disruption was not an event that occurred at once but instead something that occurred and had a developing impact over time. This knowledge was like a shadow cast into the future and mothers could not entirely anticipate what the future would hold until they started living it. There were many factors such as the condition of the child, their social standing in society in terms of socioeconomic status and gender that appeared to be intertwined resulting in poor emotional, mental and physical wellbeing of such mothers. In addition, when a child's condition appeared not to improve or got worse, this precipitated great social disapproval, mother-blame and even rejection by spouse, family and friends.

The chapter highlighted that most of the mothers especially single mothers, never recovered entirely from the initial shock of having a child with severe disabilities. This suggested that recovering from such a shock especially when it was the first-child took time. The demands of and the consideration of caregiving being a lifelong responsibility took a toll on the mothers' health

and psychological wellbeing especially for those who did not have strong social support. The findings furthermore, demonstrated that first-time single mothers of children with cerebral palsy suffered the worst economic outcomes.

In the face of these challenges, the participating mothers needed to be resilient and adopt some coping strategies to overcome the difficulties they were facing. This together with other issues such as how they perceived their future and that of the child with disabilities are explored in-detail in the next chapter.

Chapter Seven

The Present and the Future: The Lifelong Journey of Mothering a Child with Disabilities

7.1 Introduction

Chapter five highlighted what it was like for mothers in the early period after having a child with disabilities and how mothers navigated health and social services and tried to obtain information about the child's disability. Chapter six focused on the trajectories and shifting circumstances of mothers' lives over time. A number of key themes were presented and it emerged that a critical turning point for many mothers (and indeed, their partners) was when they realised that their child's condition would not improve. In this chapter, I discuss themes related to the coping and survival strategies that mothers were able to develop in the face of their difficult circumstances, and their perception of their child's future.

The first section of this chapter, explores the range of strategies that mothers adopted in order to overcome or mitigate the challenges associated with parenting a child with disabilities. In this section, I explore the importance of parent-support groups and how mothers felt empowered by their use and how parent support groups fostered a positive sense of identity and sense of belonging. This was evident when a number of mothers reported being able to cope with the child's condition, and experiencing a reduced sense of loneliness and guilt. The section further demonstrates how mothers used social comparisons as a coping strategy to compare their child to other children with disabilities. The significance of religious beliefs has been identified in previous discussion and this section also explores how some mothers used their Christian beliefs and faith in the clergy's ability to heal their child's condition as a coping strategy.

The second section looks at mothers' expectations of the outcomes for their child with disabilities as he/she made a transition from childhood to adulthood. It highlights how mothers perceived this transition as a significant stage in the child's life. The section highlights the impact of the relationships mothers had with their peers and analyses how these relationships were instrumental in the mothers' ability to plan for the transition of their child with disabilities into adulthood. The accounts of mothers in this section demonstrate that the different concerns they had regarding the child's future depending on the gender of their child and their belief in ascribed gender roles.

The third section of this chapter explores the formal support that had been available to mothers, such as social transfer programmes which the Zambian government provides to the vulnerable members of society and the perceptions mothers held about these (Handa et al., 2016, Adato and Bassett, 2009, Gooding and Marriot, 2009). It also highlights the accounts of mothers with regard to what they would want the government to help them with in order to have a secure future for themselves and their child with disabilities.

7.2 Resources and Strategies: How Mothers Coped

Parenting children with disabilities can be challenging to family relations and it can put a drain on the family resources (Woodman, 2014, Schilling et al., 1984). One of the significant themes that emerged from the discussions were the strategies that mothers adopted or developed in order to overcome the challenges of raising a child with disabilities. Woodman and Hauser-Cram (2013) define coping as a process of changing cognitive and behavioural efforts with a view of responding to demands that might arise. In the section that follows, I discuss the different strategies that mothers employed in their quest to overcome the challenges associated with raising a child with disabilities.

7.2.1 Parents Support Group Membership as a Coping Strategy

There is no agreed upon definition of support groups although their positive impact has often been noted. Seebohm et al. (2013: 392) find that membership of peer-support groups *'is associated with a range of health-related benefits including improved health outcomes and more efficient use of health and social care services [...] increased self-esteem; improved relationships; better ability to cope and decreased levels of isolation.'* Based on Seebohm and colleagues' (2013) description of support groups, they can be said to comprise of informal structures for mutual assistance in meeting certain needs such as the social and material needs of the members (Hall, 2013, Craig and Mayo, 1995). Within the context of my study, as discussed in the methodology and methods chapter, these groups compromised of mothers who came together for mutual aid in meeting various needs and overcoming common challenges, and some of these groups were also formed to bring about social change especially attitudinal change towards people with disabilities. This was also one of the mechanisms through which participating mothers, especially those in Lusaka, described adjusting to the heightened challenges of parenting a child with disabilities. Mothers in Kaoma, however, did not meet often in their support groups. Six out of the fifteen participating mothers from Lusaka, narrated that contact with other mothers of children with disabilities was mainly achieved at the physiotherapy centres:

> Gertrude [L]: I was introduced to parent support group by the staff when I used to bring my daughter for physiotherapy. They explained to me that I would be meeting fellow parents who had disabled children and that together we would be encouraging and learning from each other.

Participants in this study stated that mothers who were already members of the support groups visited them in their homes to encourage them to become members of the parent support groups. In turn, some of the participants in the study went on to visit other mothers to encourage them to become involved. Zion was one of the first members:

Zion [L]: I was one of the first people to join the support group. We were then trained and encouraged to recruit other members […]. I was involved in the recruitment of many members. We would go to their homes and explain what the aims of parent support group were.

Four out of six mothers who were members of the support groups spoke highly of their weekly meetings. In Lusaka, there were two organisations that supported the parent support groups that I visited and observed. These were Archie Hinchcliffe Disability Intervention (ADHI) and the Special Hope Network. In the case of ADHI, they trained some of the parents in physiotherapy. Two mothers who participated in this study were among those who were trained. These mothers benefited, not just from attending a support group, but also being a volunteer, as Faggy illustrated:

Faggy [L]: I offered myself to be helping disabled children. We had a meeting then the manager asked those of us who wanted to become volunteers. I didn't hesitate, I offered myself to be trained. I do it out of love for these children and their mothers who go through a lot in life. I also gained a skill.

The parents who were trained also offered home-based care services to children who could not be brought to the nearest health centres, that is, a form of outreach service. The two volunteers explained that ADHI gave them K35 (GBP 3.50) per day whenever they were working within their residential areas, and K50 (GBP 5.00) each time they travelled to another residential area to provide physiotherapy services to children with disabilities.

The mothers I interviewed spoke about the many and diverse benefits they derived from parent support groups. Susan [L] spoke about feeling relieved by the support of her peers at the parent support group meetings. She revealed:

Susan [L]: I go to the support group meetings […] we teach each other how to take care of our children and encourage each other, how to show love to the child. Special Hope has helped

189

me a lot, they organise workshops where we learn what causes problems like this (her daughter's condition).

As noted from the mothers' accounts, whilst they derived different benefits, there was evidence to suggest that belonging to parent support groups mitigated caregiving roles and maternal stress. Their stories suggested the significance of parent support groups in enhancing the ability to cope with the challenges that come with parenting children with disabilities especially among first-time mothers. For example, one mother stated:

> Zion [L]: I can count on the mothers in many ways […] they are a source of support […] we learn from each others experiences. It's a very good platform for connecting with mothers who share the same challenges.

Parent support groups enabled mothers to share their experiences and to give each other a unique quality of emotional, social and practical support such as coping and problem solving. It was a means by which mothers connected with their peers and this fostered a sense of belonging and companionship. My study expands on the findings of previous researches. For example, Hall's (2013) study in South Africa found that support groups are key in connecting parents of children with disabilities. Findings from Aldersey et al.'s (2016) study in the Democratic Republic of Congo also show that social support from peers is an important contributor to family's ability to support the needs of the children with disabilities. The groups further provided a platform for carers to exchange ideas on a myriad of issues such as support services, and because of the support from peers, carers became more resilient. Other studies (Greeff and Van der Walt, 2010, Hastings et al., 2005) suggest that parents turn to their peer groups to assuage the difficulties associated with parenting children with disabilities.

Tandiwe [L] spoke about how attending these meetings provided children with disabilities with an opportunity to interact with other children. However, as much as mothers spoke about the importance of attending parent-

support group meetings, there were stark differences in the manner mothers perceived the support they received. These accounts highlighted the importance of social capital in promoting cooperation and reciprocity for the mutual benefits of the members. Interestingly, all the three mothers in Lusaka who were members of the Special Hope Network parent-support group emphasised the material benefits they derived from the organisation. A case in point was Violet:

> Violet [L]: being a member at Special Hope has helped me a lot. I used to have problems providing for my children but that is no longer the case. They give us food every month-end provided one doesn't miss two to three meetings in a month.

Susan [L], similarly spoke about the material benefit she derived from being a member. When asked if they were able to remember what they were learning at the parent-support group, they both said they could not remember much but emphasised the importance of subsistence support. In contrast, mothers who were members of ADHI did not receive material support, but rather therapeutic support for their children with disabilities. Tandiwe [L] like many mothers who were members of the ADHI described the support she received as priceless:

> Tandiwe [L]: I have learnt a lot from Archie, they have been very supportive to us. The support I receive here can't be equated to anything. And we don't even pay anything […]. I have gained knowledge about my son's condition and how to look after him.

Mothers who belonged to the parent-support group that did not provide material support were able to remember most of what they learnt regarding caregiving responsibilities and the causes of disabilities.

The accounts of the mothers that belonged to Special Hope Network demonstrated that one of the motivating factors for joining parent support groups was to meet material needs. These mothers were drawn from low socioeconomic status. However, the mothers that belonged to ADHI were

from across the economic divide in terms of residential areas. It appeared that these mothers exhibited the desire to learn about their child's condition as basic subsistence was not much a problem for them:

> Faggy [L]: Archie normally organises workshops where they teach us about disabilities […] so we have a doctor that teaches us, we have workshops I think every quarter.

The parent-support groups further played a significant role in social action. Mothers in my research, revealed how the parent-support groups had been instrumental in advocating for the rights of people with disabilities and raising awareness in society on the need to respect both people with disabilities and their carers. Faggy [L] reported:

> Faggy [L]: we have an association we parents formed to advocate for the rights of our disabled children. It was formed so that we the parents become the mouthpiece for our children; we fight for our rights and that of our disabled children […] in a way we help alleviate the difficulties that come with caregiving.

Gertrude [L] cited an example where the parent-support group played a role in protecting the rights of children with disabilities:

> Gertrude [L]: we had a case of a disabled girl whose mother died so the dad started looking after her. However, with time he started abusing her sexually. One day she shouted so people came to her rescue. We took up the matter and reported the father to police and he was eventually taken to court, tried and convicted. We used to attend all court sessions to give solidarity to the girl.

The narratives of mothers in my study provided valuable insight into the significance of parent-support groups in advocating for the rights of children with disabilities and their carers. Thus, parent-support groups provided mothers with a chance to not only exercise control over the experiences of their children with disabilities but also helped to transform what happened to them as evident from the above account by Gertrude. This view has also

been highlighted by other scholars (Hall and Graff, 2012, Boyd, 2002) who have argued that parent-support groups play an important role in speaking for their members who in most cases are 'voiceless'.

7.3.1   Self-Social Isolation as a Coping Strategy

As much as social isolation has been associated with old age, evidence shows that this is also evident in younger generations arising from a number of social and other factors (Tomaka et al., 2006). A considerable number of studies have been undertaken in the developed world have mainly focused on the elderly (Shankar et al., 2013, Steptoe et al., 2013). Social relationships are regarded as an integral part of the holistic wellbeing of an individual, and isolation is often a manifestation of reduced social interactions as, with ageing, network decrease. However, there are other contributory factors that relate to social isolation (Grenade and Boldy 2008).

One of the themes that emerged from the discussion with participating mothers in this study was the social isolation that was associated with having a child with disabilities. My study discovered that three first-time mothers in Lusaka who did not belong to support groups experienced high levels of stress and depression. For these mothers, they resorted to self-imposed isolation as a coping strategy because the social responses to which they were subject caused greater distress. For example:

> Esther [L]: there is a lot of talking, a lot of stigma, just a lot of stuff, so most of the time I would rather be alone with my child and let the world also be. That is how I ended up not having friends.

Similarly, another mother said:

> Sophia [L]: my friends and the people in the neighbourhood look down upon me because my daughter has cerebral palsy. Because of that I avoid having friends and I think it has helped me, because when you have friends in the neighbourhood

that is when lot of talking come from. To avoid that, you just distance yourself somehow.

Although self-imposed isolation was not widely used by mothers as a coping strategy, it appeared that non-parent support group members saw it as a form of coping strategy especially in resisting stigma and discrimination perpetuated by society and as a response that was within their control. As evident in Sophia's account, social isolation was a result of dissatisfaction with the quality and type of social interaction received from peers. Similarly, Emma [L] resorted to hiding her son because of fear of being stigmatised and discriminated against. Similarly one mother explained:

> Zion [L]: I have most of the time stayed inside the house because of what I go through with people around. I would rather be alone with my child, and then let the world also be. That is how I ended up being like that. I only associate with mothers at Special Hope.

In Kaoma, mothers stated that they did not meet regularly in their parent support groups except when it was time to receive farming inputs. They gave the reason of distance to their meeting place. For example:

> Bo ma Mwila [K]: we don't meet that often […] distance between villages makes it difficult to have regular meetings […] the frequent shifting of people makes it difficult for people to know each other.

The above account revealed that the increase in frequent shifting of people resulted in inadequate time and opportunity to build a sense of belonging and togetherness among mothers of children with disabilities in the village. None of the mothers in Kaoma adopted self-isolation as a coping strategy.

7.3.2 *Informal Loan Scheme and Agrarian initiatives*

As alluded to in chapter six, mothers of disabled children suffered economic hardship, as most of them were unable to engage in economic activities

such as formal employment or entrepreneurship. Findings from my study revealed that mothers who belonged to the Special Hope Network support group came up with an interesting strategy to overcome the financial challenges that the members were facing. They devised an informal loan scheme locally known as '*chilimba*'. This seemed to have been an interesting discovery. Chilimba was an informal arrangement of group saving by mothers. They agreed on a weekly contribution of K5 (GBP 0.50), each mother contributed this amount every week to one member of the group. This rotated around the members in the group until every mother had received it. The mothers divided themselves in groups of ten so that they contributed K50 (GBP 5) per week which was received by each member on a rotational basis. Mothers who participated into this arrangement stated that it instilled financial discipline in them and enabled them to have enough money to buy necessities and surplus in bulk:

> Zion [L] we all recognise that we received someone else's money and we have an obligation to reciprocate even at the expense of our personal hardships […] then the other money, we save it just in case one of our members has a funeral or if the disabled child is sick, then we use the same money to buy medicine or pay bills. It calls for discipline and since most of the mothers don't have any other form of support, we rely on each other. It is a personal sacrifice.

The above account demonstrated an example of reciprocity, agency, and trust among mothers that was embedded within their social relations. All the three mothers who were members of Special Hope Network support group reported that they also had a special fund where every member contributed an agreed amount of K10 (GBP1.00) per month that was meant for emergencies like serious illnesses involving children with disabilities or to provide for a bereavement:

> Susan [L]: if we have one of our members' child in hospital, we use the same money to help them or if a disabled child dies, we use the same to help pay for the funeral expenses.

However, the situation was different in Kaoma. As earlier stated, as a means of coping with socio-economic challenges, members of the parent support group lobbied the government for farming inputs such as fertilizer and seed. One mother stated:

> Bo ma Barbara [K]: we live far from each other and most of the time it's difficult to go to town with a disabled child on the back. So, what we do is that during the farming season, we come together and lobby the Ministry of Agriculture to give us farmer support inputs.

Therefore, in contrast to the mothers of Lusaka, the primary focus of coping with socio-economic challenges among the members of the parent-support group in Kaoma was through non-monetary assistance.

7.3.3 Comparing Conditions as a Coping Strategy

One of the themes that emerged from the narratives of mothers was the way in which they were coping with their child's condition, and comparing the child's condition to other children with disabilities. For example, across the economic divide from well-off Chilinda [L] to Bo ma Kaimbu [K] a homemaker (housewife) in Kaoma, mothers spoke about it. Twelve (eight from Lusaka and four from Kaoma) out of thirty mothers compared the condition of their children with disabilities.

> Chilinda [L]: yes, there are times when I look at other children, and I feel like ahaa…why should I complain? Deborah is much better. I feel my situation is lighter.

> Bo ma Kaimbu [K]: when I took my child to Kaoma District Hospital, I realised that there are many children who have his condition. I felt somehow relieved that I was not alone with such a child.

Interestingly, mothers whose child had other forms of disabilities compared them to children who had conditions such as cerebral palsy, autism and

Down's syndrome. Faggy [L] whose two children had muscular dystrophy explained:

> Faggy [L]: yes, I do compare the condition of my two sons and then I see that my children are much better than children with cerebral palsy and other invisible disabilities. It brings a bit of comfort to me.

Others such as Chilinda [L] and Gertrude [L] saw their peers, especially those with cerebral palsy to be in worse situation. This served as an encouragement and a form of personal empowerment. Other mothers compared their child to others with a similar condition:

> Violet [L]: when we go for parent-support group meetings, I look at other kids with hydrocephalus and realise that my daughter is much better. I feel relieved.

> Hilda [L]: it is encouraging to see that my child is actually better off than other children who have cerebral palsy, and even the nurses say my child is better.

The tendency by mothers to compare their child's condition to other children with disabilities appeared to have been a new finding that my thesis discovered as mothers were creating a hierarchy of disabilities. Eight out of fifteen mothers of Lusaka reported that seeing their peers' cope well inspired them to have a positive view about themselves:

> Emma [L]: I was encouraged to see that there were mothers whose children were worse than mine but they carried on with life as if they did not have a disabled child.

While comparing child's conditions brought relief to many mothers, some felt that it was depressing to see what they perceived as other children functioning better. Cases in point are that of two mothers who both had child with cerebral palsy. In the case of Mwila [L], she complained that she had suffered the last eight years comparing her daughter's condition to that of other children especially those in wheel chairs. Another mother remarked:

> Sophia [L]: it affects me whenever I see children of her age who have a similar condition but look much better. I feel deflated.

My study findings revealed that mothers of children with cerebral palsy experienced significant psychological difficulties compared with mothers whose children had other forms of conditions such as muscular dystrophy. Furthermore, these comparisons had significant implications for mothers. As demonstrated from their accounts, mothers either developed a positive or negative outlook for the future. This comparison of children's conditions fostered a positive outlook for their child's future among mothers who felt that their child was better. Most of them started to reason that they and their child would cope well with the disability:

> Dorcas [L]: when I saw the condition of other children, I developed the feeling that my daughter's condition wasn't that bad. I even had hope that she would get better in future.

Hodges and Dibb (2010) in their study in the United Kingdom also show that parents of children with muscular dystrophy experienced positive effects when they compared their child's condition to children with other forms of disabilities. However, in my study, mothers especially of children with cerebral palsy experienced negative effects when they compared their children. This study therefore fills a void in the literature on using comparison as a coping strategy within the context of Zambia.

Only three mothers in Kaoma compared their child's disability to that of others. One of the reasons for this was that there were no physiotherapy sessions for children with disabilities in Kaoma; hence, most of them were isolated and had little contact with other children with disabilities. For example, mothers stated:

> Bo ma Chikombe [K]: I used to compare Blessed's condition to that of other children

> Bo ma Angela [K]: when I see other children, I feel relieved that I'm not the only one with such a child.

7.3.4 God and Religion as a Coping Strategy

The teachings of the bible and belief in the miraculous power of the Christian God is a very significant coping strategy in many African communities (Gray, 2006). This knowledge is acquired quite early in one's life. Life is viewed as sacrosanct and precious to God regardless of the form in which it is (Mwale and Chita, 2016). Many afflicted persons have used this belief in the sanctity of life, and the belief that God always provides sanctuary as a coping strategy (Zulu, 2016). This belief was one of the recurring themes in my study as mothers talked about how they coped and the hopes and fears for the future. Thirteen (seven from Lusaka and six from Kaoma) out of thirty participants in both research sites stated that faith in God was helping them to cope with the challenges of raising a children with disabilities. This faith acted as a buffer that reduced the sometimes harsh reality of their child's disability. Just like the twenty-one mothers cited in chapter six who believed that they were God chosen, the thirteen mothers cited in the current chapter also drew courage and comfort from the belief that they were special mothers chosen by God. For instance, Bo ma Charity's [K] belief that God provided comfort was also shared by mothers such as Fortunate [L]. These mothers turned to their pastor for prayers for healing their children with disabilities. One mother narrated:

> Fortunate [L]: you can't manage without God who helps us carry the burden of caregiving. I surrendered my child to God. He strengthens me; I have energy and courage to look after this child because God is on my side.

Bo ma Cleopatra [K]: similarly emphasised the importance of having faith in God as the healer of every sickness and this reduced her stress levels. Mothers drew encouragement from believing that God chose them. Bo ma Charity [K] said:

> Bo ma Angela [K]: I have had serious problems in my life, having her, marriage break-up, and financial challenges. What has kept me on the rails is believing that God gave me this child.

The mothers spoke highly of the clergy especially their pastors. Interestingly, this belief in healing was common among members of the Pentecostal churches. The participants portrayed the clergy as men and women who were chosen by God to manifest his (God's) work. For instance, Bo ma Gideon [K], a member of a Pentecostal church stated:

> Bo ma Gideon [K]: every Sunday when I go to church, the man of God (pastor) calls me to go to the altar to be prayed for. He also prays for Gideon to be healed of his condition […]. Yes, the man of God has been a source of inspiration. I have made it thus far because of his encouragement. He (pastor) has this healing power in him.

The belief in the healing power of the clergy as highlighted above has been cited as a coping strategy in previous research. In Mwale and Chita's (2016:63) study in Zambia, one of the coping strategies used by the patients was to have a strong belief that *'divine healing […] can heal any illness whatsoever.'* Similarly, Zulu's (2016) research in Zambia discovered that the belief in healing by pastors occupies a significant role in most Pentecostal churches and was seen as an effective coping strategy to any affliction that church members found themselves in. Similar to previous studies (Mwale and Chita, 2016, Zulu, 2016), as already alluded to, mothers in my study who were members of the Pentecostal churches had a strong belief that the clergy were capable of healing disabilities. This belief seemed to have brought relief to mothers:

> Tandiwe [L]: as much as the challenge of raising him seems bigger, I focus on Jesus and doing that has made the situation to be lighter and this reduces the pressure. I throw my burdens to God and he has been able to sustain me, God uses the pastors to strengthen us.

All the thirteen mothers in my study just as in the previous chapter, who saw their children as a gift from God over time, they reported receiving moral and spiritual support from their fellow church members. Bo ma Shenda [L] reported:

> Bo ma Shenda [L]: I receive encouragement from my church members. Every time I go to church, they tell me to always trust that God is there and he won't let me go through beyond what I can bear.

These stories of coping strategies employed by mothers of children with disabilities in this study expand on the findings of a study in Botswana (Nkomazana and Tabalaka, 2009) that revealed that women with disabilities turned their distressing situation over to God for comfort. In their study the women noted the positive transformation they had experienced since turning to God.

This strong belief in healing led three (two from Lusaka and one from Kaoma) out of thirteen mothers to stop seeking conventional healthcare services and instead took their child with disabilities for prayers. For instance:

> Dorcas [L]: I draw comfort by taking my daughter to the pastor for prayers. I have found it to be more beneficial than going to the hospital. If you have strong faith, the child can be cured. I also get counselled.

> Bo ma Kasweka [K] I stopped going to the health centre, I prefer going for prayers. I even feel better now. It's refreshing going to seek the help of the pastor than the doctors.

The findings demonstrated that mothers' ability to cope with their child's condition was influenced by their Christian beliefs and that this bolstered their resilience. The mothers also reported feeling empowered and encouraged by their fellow church members and that they were able to transform and overcome their child's condition. It can thus be argued that

Christianity enhanced their coping capabilities. However, in the case Faggy […], it was her personal faith and not her fellow believers who were a source of comfort.

7.4 Transition from Childhood to Adulthood: Perceptions of the Future

Faith in God to a larger extent determined how mothers perceived the transition of their child to adulthood. This was a critical stage in development and was one of the themes that were prominent in the discussions with mothers. Twenty-five (eleven from Lusaka and fourteen from Kaoma) out of the thirty participating mothers expressed fear about the future of their child's transition into adulthood. However, there were variations in the concerns of mothers based on the type of disabilities their child had and other factors such gender of a child. Fourteen (seven from each site) out of sixteen mothers whose child had cerebral palsy saw little or no hope for their child's future. One mother stated:

> Mwila [L]: this issue of my daughter's transition to adulthood is mind-boggling. At her age, she could have been doing some things on her own such as cooking, doing laundry and other house chores […]. At times, I fear that her door closed at childhood (she lost hope of her child getting better). There is no hope or expectation about her future except to be cared for throughout her life.

Mwila's [L] concerns reflected views of some scholars (Broach et al., 2016, Stewart, 2009, Hudson, 2006) who assert that the transition from childhood to adulthood by children with disabilities can be complex and challenging for parents. My study pointed out that there were many challenges relating to transition of the child with disabilities to adulthood. One of the challenges children with disabilities faced were social networks outside the family. Again, this view was especially common among mothers whose children had cerebral palsy. For example:

> Bo ma Kasweka [K]: she is incapable of forming relationships with her peers. It's not just possible; there is no hope of her having friends not even in future. She will be lonely throughout her life.

Besides the fears that their children would be lonely, mothers of children with cerebral palsy had no hope that their child would be able to go to school and later on fulfil their (child's) aspirations of entering the job market. They saw their child as having significantly fewer opportunities:

> Bo ma Chikombe [K]: my worry is that she is getting older but she doesn't have friends. The body is growing but the mind is not, and because of that she can't be admitted to school and teachers can't handle such a child. I fear that this lack of education will affect her future.

> Zion [L]: all I want is for her to go to school. Nowadays children need to go to school […] I really want an education for her; because without it her future is doomed, she will suffer. But again, looking at her condition, she can't start school; who would take care of her?

The above accounts suggested that mothers were grappling with internal conflicts of wanting their children with disabilities to be educated, but at the same time worrying about who would take care of their child at school. The above views also confirmed that education remains one of the most important hopes for people with disabilities in Zambia and the sub-Saharan African region to achieve greater independence and integration within their communities (McKenzie et al., 2013, Hetherington et al., 2010). These findings further suggested that the type and severity of the disability was a key determinant in the career possibilities available to children with disabilities. Mothers often experienced uncertainty surrounding the quality of professional and personal life that can be had by their child.

However, others such as Bo ma Barbara [K] felt that her daughter who had cerebral palsy was able to start school and that he had potential to do well in school. Her concern was that the only school that would admit her

daughter was in another town, quite far from her hometown. Similarly, another mother of child with cerebral palsy stated:

> Tandiwe [L]: I'm determined in ensuring that my son starts school in order to secure his future. I certainly can't lose hope. And you know once he is educated, in future, he may get a job. It's through education that I can empower him.

During interviews, I discovered that for most mothers in Lusaka whose child had a form of disability other than cerebral palsy, their child was or had been to school or they were contemplating enrolling the child in school. For mothers such as Gertrude [L] her son who had scoliosis completed his secondary school. However, she had worries that he still faced considerable barriers to the labour market and that this might have an impact on his ability to be independent in future.

Similarly, another mother whose two children had muscular dystrophy lamented:

> Faggy [L]: one of my sons will be graduating from secondary school soon. I would like him to go to college and start working for the government but it's tough for the disabled to get employed. And this will affect his financial status when he is old enough to be independent. Anyway, God will provide.

An interesting finding was that whilst some mothers trusted that God would take care of their children with disabilities, when it came to their child starting school and getting employed, mothers admitted that their children with disabilities had limited opportunities compared with non-disabled children and there was no hope for their future without an education. This finding, demonstrated that there was conflict between the mothers' religious beliefs and their acknowledgement of social reality. That is, their idealistic religious expectation was that God would take care of their children with disabilities but practically these mothers knew that their child with disabilities needed skills to survive in life. Overall, these findings revealed that mothers viewed this transition phase as a significant development stage in their child's life,

and it was not without challenges to both the child and the mother within the social contexts within which they lived.

7.4.1 Mothers' Perceptions of the Prospects of Marriage for their Children

This was one of the most important themes that emerged from the discussion with mothers of daughters. Mothers expressed concern for the social status as well as the future of their daughters with disabilities especially with regard to the prospects of getting married. All the ten (five from each site) mothers of daughters with cerebral palsy were concerned about their child's future. They expressed doubts about the chances of their children getting married. One first-time mother said of her daughter:

> Esther [L]: she is growing up; I keep worrying because she is not going to get married. There is no man who can marry her.

Zion [L] a first-time mother expressed similar sentiments to the above. Mothers such as Susan [L], also a first-time mother lost hope that her daughter would ever get married. This fear of the child not getting married was more pronounced among first-time mothers. However, five mothers whose child had other forms of conditions were optimistic about their child getting married. Chilinda [L] whose child had osteogenesis imperfecta remarked:

> Chilinda [L]: I see my daughter going to university, starting work and getting married in the next 10-years. She will have a family of her own I actually don't doubt that.

Another mother said:

> Bo ma Angela [K] I'm optimistic that at the right time she will get married.

Interestingly, all the mothers who were confident that their child would get married had other children prior to having a child with disabilities. It appeared that the experience of motherhood and understanding of child development, and the interaction of the child and society could have shaped the mothers' perception of the possibility of a child with disabilities getting married.

Surprisingly, other mothers were worried that their child with disabilities would marry a fellow person with disabilities. The fear was that their (children's) life would be difficult. A mother stated:

> Astridah [L]: I think the fear I have is that he is going to marry a disabled person, probably a person who is deaf just like himself. Yes, I want him to marry but I don't want him to marry someone who is disabled.

Another mother said:

> Bo ma Namutondo [K]: the chances of my daughter getting married to a fellow person with a disability are high. Who is going to marry her? Do you think a non-disabled person would marry her?

The above stories by mothers were reflective of the many conflicts that plague mothers concerning the future of their children with disabilities as reflecting their awareness of social factors and attitudes. Thus, while mothers were cognisant of the social limitations that accompanied their children, they desired that their child gain some level of normalisation by marrying a non-disabled person, that is, they believed this would lead to social acceptance and integration of their children with disabilities as someone without a disability. They therefore, perceived that marrying someone with a disability would prevent social acceptance and integration.

These findings are similar to Day and Evans' (2015) study in Zambia that focused on young people's experiences of transition. The study shows that marriage and parenthood were regarded as key elements of the transition

process. However, much as there is a lot that has been written on the transition of disabled young adults in other countries such as the United Kingdom (Judd, 2012, Odom, 2007, Olsen and Clarke, 2003), my study extends on transition in terms of a mother's perspectives, and this area has been insufficiently explored in Zambia.

7.4.2 Fears of Abuse of Children with Disabilities

Apart from concerns about the prospects of their children with disabilities getting married, some mothers were worried about the risk of their children with disabilities being abused. For example, all the nine mothers of daughters who had cerebral palsy feared that their child was at risk of being sexually abused either in the near or distant future:

> Mwila [L]: I have got this fear that my daughter would be raped at some point in future, and maybe end up having a child. I don't know if the law allows but I would prefer that they close her womb so that she doesn't conceive. Who is going to take care of her and the child? Because of that fear, I would rather die with my daughter at the same time.

Two (all from Lusaka) out of the nine participating mothers in the study who spoke about the worry of their daughter being molested said that this fear was a result of their own past experience. One mother narrated:

> Zion [L]: my child being a girl, I fear for her future because of what I went through when I was growing up. I was sexually abused […] and she can't talk or do anything, she is more susceptible to being defiled by men […] I don't know what will happen to her now or in future.

Many reasons about child sexual abuse and molestation in Zambian society were given. One key reason was what ten (six from Lusaka and four from Kaoma) out of thirty participants called *'virgin cleansing myth'*. A mother elaborated this:

Faggy [L]: there is a lot of misconception in society. Some men believe that if they sleep with a disabled child, they would be cured of diseases like HIV/AIDS. That is why the girl child is at risk. We fear for the girl child's future.

From the stories of mothers, it appeared that girls with disabilities were often prey to sexual predators because of the presumption that they were virgins. The belief that virgins can cure men of sexually transmitted diseases such as HIV/AIDS resulted in the molestation of girls with disabilities since they were viewed as sexually inactive and therefore pure. Interestingly other mothers such as Bo ma Kasweka [K] added another dimension to the beliefs about why children with disabilities were sexually abused:

Bo ma Kasweka [K]: there are a lot of strange beliefs about having sex with a disabled child, for example the issue of HIV/AIDS […] some men are lied to that when you have sex with a disabled child, it would boost your business and bring in more money.

The fear of having their child sexually defiled led to four (all from Lusaka) out of nine mothers of daughters of cerebral palsy not wanting to get married. For instance, Esther [L] stated:

Esther [L]: I have got this fear that maybe if I remarry, my husband will be sexually abusing my daughter. And if that happened, her future would be destroyed further because even at the moment I'm not even sure of how her future will be […]. Men don't consider that she is disabled they will just go ahead and defile her thereby ruining her future further.

However, Gertrude [L] a disability activist reported that there were a few cases where boys with disabilities were abused sexually:

Gertrude [L]: child abuse is very common. Cases of men abusing girls abound but we also have had cases were women sexually abused boys although these are very rare cases. Often men take advantage of especially girls with severe cerebral palsy because they can't talk and are bedridden. We had a case of where a mother of a child with cerebral palsy was looking after her late sister's two sons.

208

> Unfortunately, they were abusing the disabled girl each time the mother went to sell at the market. That's how she was impregnated. What I'm saying is that we fear for the future of disabled girls.

Findings of my study revealed power and gender differences and how these differences impacted on mothers and their daughters with disabilities. My study's findings expand on earlier research (Leclerc-Madlala, 2002) in South Africa that found that there is widespread belief that having sex with a virgin cures HIV/AIDS. This belief resulted in increased cases of rape of children in South Africa. This led to mothers to worry about the independence of their children with disabilities.

7.4.3 Mothers' Concerns about the Independence of their Children

The mothers of sons with disabilities also expressed concern that it was becoming difficult to perform caregiving roles. For example, five out of eleven mothers of sons spoke about the fears they had, as the child grew older. One of the mothers said of her son who had cerebral palsy:

> Hilda [L]: he is growing and there will come a time when he will need to bath himself because he is a boy. But at the rate things are going, it won't be easy […] so sometimes, I can't bear the thought of how he is going to take care of himself in future. I can't manage to take care of him when he grows up because he is a boy.

It was also discovered that mothers feared that in the case of the death, their children with disabilities would suffer. Overall, twenty-five (eleven from Lusaka and fourteen from Kaoma) mothers expressed this fear. A mother stated:

> Bo ma Gideon [K]: I'm worried about his future. What is worrying me a lot is I don't know how he will survive on his own. There is death and I don't have anyone in mind that can take care of him in an event that I die.

Bo ma Kanjengu [K] expressed the same worry when she stated that she was constantly worried about her son's future if she died. This concern about the child's future was however, more pronounced among first-time mothers.

Four mothers from both research sites reported preparing their children to be independent. For instance, Gertrude [L] a mother of a son with scoliosis reported:

> Gertrude [L]: in my case, Gilbert learned self-help quickly. I realised that I will not always be with him that is why I started teaching him because I know that one day he will grow up and he will want to do certain things on his own. He has to live independently in future.

These stories suggested that mothers faced challenges of safeguarding as well as providing a sustainable future for their children with disabilities. This raised a lot of fears and concerns among many participants. In the face of economic challenges, mothers needed not only informal support but also formal in order to address their present concerns and secure the future of their child. They realised that the absence of formal support would increasingly limit the chances of their child becoming independent in future. The next section discusses the form of formal support that mothers could access.

7.5 Formal Support Services Available to Vulnerable Members of Society

The concept of social protection has become popular in many developing countries. Many governments, donors and non-government organisations are providing support to the vulnerable members of society deemed as not being able to provide for themselves (Ellis, 2012, Slater, 2011). According to Vincent and Cull (2009:4) social protection programmes are *'initiatives that provide income or consumption transfers to the poor, protect the*

vulnerable against livelihood risks, and enhance the social status and rights of the socially excluded and marginalised people.' They further identify social transfer as one of the most important and relevant areas of social protection. Social transfers come in different forms: cash, food vouchers, and agricultural inputs among others.

Zambia has been implementing social transfer in form of cash transfers which involve predicable cash transfers to recipients (Standing, 2008). There were two categories of people who were eligible to receive support under the social cash transfer programme in Zambia. The first category was for people living under abject poverty conditions, but who were physically fit. This category included the aged, and these were given K70 bi-monthly (K140 Zambian Kwacha) at the time of this study. The second category was geared towards families that had a disabled member and these received K280 bi-monthly. Money was paid bi-monthly because there were high administrative costs attached to the dissemination of money. The money was a meagre sum but it was more useful to the mothers when it was added together.

As parent support groups were said to be a vehicle for information sharing (Staub-Bernasconi, 2010) on all aspects of the wellbeing of the disabled, none of the participating mothers stated that they or their child with disabilities were recipients of this financial support from the government. Only five (three from Lusaka and two from Kaoma) mothers reported having knowledge about the existence of the programme, but they did not know how to access the money. The mothers stated:

> Chilinda [L]: I have heard about the support that the government gives to people like my daughter but there is scanty information with regard to how to access it or the eligibility criteria they use. I feel that there is too much secrecy associated with its administration.

> Bo ma Kanyanga [K]: I have heard about it but I think it is just a conduit used by politicians for syphoning public resources in

> the name of helping the vulnerable members of society. Why hasn't there been publicity of the same programme? Why doesn't the government want to work with the disabled people's organisations? There are many questions than answers.

The rest of the participating mothers were ignorant about the existence of social protection programmes implemented by the government that were aimed at alleviating poverty among vulnerable members of society:

> Esther [L]: I have never heard of the social cash transfer programme, I had no idea that there is support for the disabled from the government. They need to recognise our presence, that's why we don't know things that are happening and end up missing out on help from the government.

Bo ma Musuwa [K] was equally not aware of the existence of social protection programmes neither did she know how to access information about these programmes. Interestingly, studies (Vincent and Cull, 2009, Freeland, 2007, Schubert and Slater, 2006) undertaken all point to the success of the programme. Vincent and Cull's (2009) study findings show that the social cash transfer programme has had significant positive impact on the recipients in Zambia. They further state that all the participants in their research reported having a positive outlook on the future and were able to plan for their future using the money received from the programme. As stated earlier, on the contrary, the findings of my study revealed lack of awareness of the programme as only five out of the thirty participants were aware of its existence. This could have been because of inadequate publicity of the programme. In the case of Vincent and Cull (2009), their study targeted the beneficiaries of the programme; hence all of their participants were aware of it. However, my study focused on the perspectives of mothers of children with disabilities with regard to their parenting experiences and accessibility to formal support among others. Moreover, an earlier study by Shubert and Slater (2006) in Zambia revealed the lack of awareness of the programme and the authors attributed this to the inadequate number of staff involved in its implementation. The study,

like my study, did not target the beneficiaries but the people residing in the districts where the programme was being implemented. Furthermore, it must be noted that my study was not intended to evaluate the implementation of social cash transfer programme, but rather it was one of the issues that emerged from the narratives of mothers during interviews which addressed the need for financial support from the government. For example, twenty-four mothers across economic divide spoke about the need for support:

> Zion [L]: if the government can assist me with capital so that I can start business. I need money to take care of Naku. The government should be providing financial support for mothers like me. We have no means of supporting our children because we can't work. These children require being cared for the whole day.

Chilinda [L] spoke about the need for the government to be giving parents some soft loans to help them start a business, and to train them in income generating activities […] to pull them out of poverty. Dorcas' [L] views were:

> Dorcas [L]: the government has neglected us carers and our disabled children. They should consider giving us skills and capital to start our business ventures so that we can be supporting these children. If not, they should consider giving us an allowance every month to help us support these children.

Fortunate [L] bemoaned the lack of support for parents from the government in raising and ensuring that the future of both the child and the mother were secured:

> Fortunate [L]: with the help of the government, my son can achieve his dreams […], as a single mother, I can't manage. I need money for food and for his other needs. The government needs to provide us with shelter or with land and money so we can build houses. If I die, my son should have shelter. And in fact, the government should be providing free education and medical services to these kids.

For others such as Violet [L] there was a need for the government to help children with disabilities get into school. She explained that she felt the rights of people with disabilities and their carers were being violated because they were often denied school places. For Mwila [L], she suggested that the government builds more schools that would only cater for children with disabilities. However, ten participating mothers from Kaoma voiced the need for empowerment:

> Bo ma Kasweka [K]: all I need from the government is farming inputs like fertiliser. I would also appreciate if the government provided us with food, blankets and clothes.

> Bo ma Charity [L]: I need fertiliser so that I can have crops to make us food secure. And if I have enough crops, I will sell some and the money raised from this venture can be used to buy what she needs and it can also enable me to start a business so that I can be self-reliant.

As demonstrated from the accounts of the mothers above, comparatively, the needs of the mothers from the two areas in this study were different. The mothers of Lusaka were more interested in being given capital to start a business. It appeared that the possibility of ownership and access to capital and credit facilities were limited. Hence, the mothers' desire for the government to support them with capital to start a business. This lack of access to capital, land and other facilities may have contributed to the perpetuation of poverty among some of the participants. However, the mothers of Kaoma were more interested in being helped with farming inputs, which they hoped would boost their agricultural produce. Increased harvest would in turn enable them to sell surplus and use the money to support their children. One of the reasons for the differences in needs by participants in the research sites could have been because Kaoma was a predominantly rural area with the main occupation being farming whilst Lusaka was a cosmopolitan city (CSO, 2011).

For others such as Bo ma Kanyanga [K], she complained that the assessment services were only provided in Lusaka. This meant that most

of the mothers could not take their children for assessment because of the cost involved. One mother stated:

> Bo ma Shenda [K]: I can't afford to be talking my child to Lusaka for assessment. It's too expensive.

Another mother echoed the above sentiment:

> Bo ma Anne [K]: the process takes long, as long as 2 years. Who can manage to be travelling to Lusaka for 2 years?

It was evident from the accounts of mothers that they often felt discouraged to finish the assessment process for their children. Distance and the time it took to be attended were highlighted as some the factors that discouraged mothers.

7.6 Conclusion

This chapter has provided new understanding in which mothers responded to the impact of the child's condition as the child grows and moves towards transition to adulthood. Once mothers became clear about the long term implications of their child's condition, new fears and anxieties had to be confronted at the same time. One of the themes that emerged from this chapter was the importance of social support especially from other mothers of children with disabilities. As noted from the mothers' accounts, there was evidence to suggest that belonging to parent-support groups can mitigate caregiving roles and maternal stress. This chapter has demonstrated the significance of parent-support groups in enhancing the ability to cope with the challenges that come with parenting a child with disabilities especially among first-time mothers. These were also crucially important in enhancing social identity among members. First-time mothers who were members of these peer groups learnt from the experiences of others especially from mothers who had other children besides the child with disabilities. In this chapter, I have also highlighted how parent-support groups promoted

personal growth and how members support each other in reciprocal and innovative ways. The groups further provided a platform for carers to exchange ideas on a myriad of issues such as support services, and because of the support from peers, carers became more resilient. Parent-support groups were also cardinal in fighting negative societal attitudes towards people with disabilities and their carers, often having a social action role. In this sense, they played an important part in advocacy. Parent-support groups provided a platform sharing of ideas and strategies to advocate and protect the rights of their children with disabilities.

In terms of perception of the child with disabilities, some mothers especially experienced mothers accepted the child's condition but they spoke in religious terms. For example, some felt themselves as special women who were chosen by God to parent a child with disabilities. Hence, they saw the child's condition as destined by God. This gave them a great sense of responsibility to caring for the child with disabilities. This chapter has further, demonstrated how mothers had to engage with their awareness of social expectations in relation to gender. Mothers with disabled daughters were worried about their daughter not getting married, but at the same time they held grave fears about their daughters' vulnerability to sexual abuse. To these mothers, marriage was a dream. Those who had disabled son feared for the independence of their child and that their sons would not be able to attain the requirements of masculinity and economic independence. Like the mothers of children with disabilities across the globe, mothers' most instance fears and anxieties related to who would love and care for their child after they were gone. In light of this, the next chapter will evaluate the findings of this chapter and the previous two chapters within the context of the theoretical frameworks.

Chapter Eight

Motherhood, Mothering and Children with Disabilities: Understanding their Experiences using Theoretical Frameworks

8.1 Introduction

The preceding three findings chapters presented an analysis of the data and illustrated the impact of having a child with disabilities on mothers across the urban-rural and economic divide in Zambia as exemplified by these two quotes:

> Zion [L]: having a disabled child is as good as me a mother being disabled

> Bo ma Shenda [K]: my life has stagnated. I can't do anything. I'm as good as disabled

This chapter evaluates the three theoretical perspectives used in this study in relation to the findings. The use of the three theoretical frameworks (social model of disability, feminist intersectionality and social empowerment model) concomitantly was to allow for a greater depth of understanding of the experiences of mothers through the lens of the three perspectives which appeared from the literature review to have validity. In addition, these theoretical frameworks allowed me to reflect on the relationship between social conditions, oppression and identities of the participating mothers as their perspectives unfolded. Interestingly, the reading of the existing literature suggested that a combination of these theoretical perspectives would enable me to comprehensively explore the mothers' experiences and that in turn the data from my study would help to extend the pool of theoretical knowledge in the given areas.

Furthermore, an extensive literature review revealed that, to date, no study had used them as an integrated framework in understanding mothering a child with disabilities. Studies (McConkey et al., 2016, Shih, 2012, Blackburn et al., 2010, Mung'omba, 2008, Thomas, 2002) have used the social model of disability. For instance, Parson et al's. (2015) study used social model of disability to investigate the link between stigma and disability among the people living with HIV/AIDS in Lusaka, Zambia. Other studies have been undertaken that employed feminist intersectionality theory (Crammer and Plummer, 2009, Yuval-Davis, 2006). For example, Yoshida et al's. (2014) research used feminist intersectionality theories to explore the experiences of people living with HIV/AIDS and a disability in Zambia. Studies have also been undertaken that used theories of empowerment (Couch et al., 2015, Thomson, 2007) in investigating the relationship between poverty, disability and power among the marginalised groups in society. For instance, Wilson (2011) carried out a systematic literature review to understand the impact of disability on families using theories of empowerment, finding that instruments of work and livelihood which are the mothers' physical bodies and minds, are often compromised in their demanding caregiving role.

This chapter is divided into three sections and there are reflective of the three theoretical perspectives that were used in this study. The first section focuses on the social model of disability in understanding the levels and nature of oppression prevalent in relation to disability in Zambia. It also highlights how the model helped in elucidating how mothers and society in general perceive and understand disability. This section will illustrate how incorporating biographical disruption enhanced the use of the social model of disability within the socio-economic, cultural, political and religious context of Zambia. This was a biographical research, and as I read the stories, the significance of biographical disruption emerged more strongly from the data than anticipated. It will also shed light on how the theory (biographical disruption) fitted very closely with what the mothers were

describing about the impact of disabilities not just on their child but on themselves.

The second section reveals the relevance of the feminist intersectionality theory in this study in understanding the context of gender inequality, the power dynamics between men and women, and to understand how different identities intersect to disadvantage women within the context of Zambia. This theoretical perspective also exemplified how disability and motherhood combined to impact upon these relations, at individual, household and societal levels and also socioeconomic position. The third section focuses on the social empowerment model as postulated by John Friedmann (1992). This section shows how the framework was used in exploring and understanding the impact of having a child with disabilities on these women's living conditions. This section furthermore, illustrates how the model sheds light on aspects of poverty and the impacts experienced by mothers. A conclusion will summarise the chapter.

8.2 Gleaning the Perspectives of Mothers using the Social Model of Disability and the Theory of Biographical Disruption

As highlighted in the three findings chapters, the impacts on the child's condition on the first-time mothers were profound. This section draws on the social model of disability to explore the living conditions of mothers of children with disabilities. This model (social model of disability) which has mainly been developed in the United Kingdom and United States was not only useful but relevant to the situation of women in Zambia. The social model of disability was enhanced by incorporating biographical disruption within the socioeconomic and cultural context of Zambia. As already stated in chapter two, the social model of disability was a reaction to the medical model that medicalises disability, and which explains disability as a consequence of physical or mental impairment and views it as a personal tragedy (Mushi et al., 2012, Goodley, 2000). The aetiology of disability within the medical model is seen within the context of biological defects or

dysfunctions within an individual and is treated like medical conditions. The medical model does not identify social and environmental factors as hindering people with disabilities from performing social roles (Shakespeare, 2006, Barnes et al., 2002, Goodley, 2000).

A social model of disability provides a route for understanding disability as a social construct involving ideas that marginalise and disqualify people with disabilities (adults and children) on the basis of their impairments (Thomas, 2002, Goodley, 2001). In Zambian society generally, as in other sub-Saharan countries, people draw on many factors in understanding disability. These factors include but are not limited to religious and cultural beliefs that may be societally specific. This view was demonstrated in my research when mothers across the urban-rural divide discussed their understanding of the child's disability. This social construction of disability had wider implications on mothers. For example, my study findings revealed that following the diagnosis and initial reactions by mothers, these women developed various beliefs about the causes of their child's condition:

> Fortunate [K]: disability is linked to many things like to the dark spirit world, to the occult and some people say this is evidenced by the presence of a child with disabilities in a family.

> Bo ma Kanyanga [L]: children are from God, it's Him that provides regardless of a child's abilities.

This social construction of disabilities had profound implications on the mothers. For example, what appeared to have emerged strongly from across economic and urban-rural divide was a hierarchy of disability in which some mothers anticipated a greater impact of the child's condition on the carer's life depending on the nature and severity of impairment. Astridah [L] highlighted this hierarchy by stating that *'some conditions are worse, conditions such as cerebral palsy and Down's syndrome. People with such conditions can't be compared to say, someone with a condition that affects his or her feet.'* My study findings further demonstrated that despite the fact

220

that these mothers were ranking disabilities, the diagnosis was disturbing to them, regardless of the child's condition. Some of the mothers suffered *'resentment, anger […] a sense of loss'* (Shakespeare, 2006: 190) following a diagnosis. My research revealed that most mothers reacted in an emotionally negative way to the diagnosis of the child's disability. As evident in chapter six, following the news that conditions such as cerebral palsy were permanent, mothers reacted differently depending on whether it was their first child or not. One thing that was striking among single mothers in both urban and rural areas was their inability to imagine a bright future for themselves and their child with disabilities. For example, Emma [L] stated:

> Emma [L]: I was thinking that he would get better but when I saw that he was not getting better, that's when I realised that this was an ongoing problem and it would have implications on my future.

> Bo ma Chikombe [K]: it just stops everything dead.

There was a general feeling especially among first-time mothers of children with cerebral palsy that their lives had come to a standstill to an extent that they were described as having experienced a biographical disruption (Carricaburu and Pierret, 1995, Bury, 1982). They now had to reorient their plans to a new and different future that involved the new demands of providing lifelong care for their child with disabilities and the relational, social and economic impact associated with this. Their expectations were turned upside down, as evidenced from the two quotes from first-time mothers:

> Fortunate [L]: it felt like a nightmare, my life was just thrown into disarray when I was told that I would have to care for him for the rest of his life. Why me? Why did it happen to my son?

> Sophia [L]: I felt shattered […] traumatised that I would not be able to do anything else in life but to care for her.

The findings highlighted that the child's condition was as debilitating to the mother as it was to the child. Most first-time mothers had a question of *'why me?'* This view carried a symbolic connotation of uncertainty, a biographical disruption, in relation to their lives and that of their disabled child's future life trajectory. The above view of *'why me?'* further demonstrated a clear fit between social model of disability and biographical disruption. As much as in a sense biographical disruption relates to the impact of bodily changes involving long term illness (Navon and Morag, 2004, Reeve et al., 2004, Williams, 2000), in the case of my study, it was not only the child with an impairment who was disabled but the mother as well. Therefore, the experiences of mothers could be better understood by drawing more on concepts of both social model of disability as well as biographical disruption.

Social model of disability is a relevant framework for exploring how people with disabilities and their carers often suffer *'feelings of being undervalued […] and a sense of loss'* (Shakespeare, 2006: 190). What was evident from the findings was that disability can bring barriers, as the case of Bo ma Barbara [K] who stated: *'I feel like my opportunities are restricted in all spheres of life.'* Findings revealed that mothers and their child with disabilities faced various forms of barriers that transcended the physical to include prejudice, attitudes and stereotyping. Just as McConkey et al. (2016:180) submit that *'it is within the family that the child first experiences acceptance or rejection,'* my study established that in both research sites, first-time mothers and their child with disabilities experienced rejection from their significant others when news of their child's condition filtered to the extended families and their friends. *'they made me feel sad'*, Bo ma Barbara [K] said about the intolerance that she faced from her significant others such as her partner, extended family members, neighbours and the community at large.

Bo ma Barbara's story resembles the biographies of many other first-time mothers in both Lusaka and Kaoma. Deteriorating family relationships impinged on these mothers for a number of them to the point of divorce.

There were a range of impacts that mothers then suffered because of being divorced. Those who were divorced described the experience as tormenting and stagnating, and it was evident from the findings that divorce to many was an unexpected disruptive event. They had to unexpectedly end one biography (being married) and start another (being a divorced woman). Bo ma Kasweka described her experience in the following words:

> Bo ma Kasweka [K]: divorce is a big incidence […] today you put your trust and hopes, you build your whole life around this man, then the next thing he divorces you. It hurts, it's a nasty experience.

The above narrative by Bo ma Kasweka demonstrated that the disability of a child was a triadic experience to many mothers. It involved an intersection of the child's disability, the mother and the social world. Following divorce, these mothers' future was disrupted and they had to reorder their social life of despair and dissatisfaction. The disruptive force of divorce was something that had long-term ramifications. These mothers passed through 'crisis points' as they struggled to adjust and adapt to being divorced mothers. They experienced stress, hopelessness, shock and feelings of depression, not knowing what had hit them. Furthermore, these mothers had imagined that their child would grow up and leave home, and then they would look after them (mothers). That was the future trajectory these mothers had hoped for but there was a biographical disruption because they were now always going to be the carer. This sudden disruption in their biography caused uncertainty to their future, they were in a state of suspension which is referred to as a liminal state (Mahon-Daly and Andrews, 2002, Murphy et al., 1988). Liminal state is a concept that describes a state of ambiguity or disorientation, being between two social worlds; the new and the old social world (Mahon-Daly and Andrews, 2002). Liminal state was evidenced in Mwila's ordeal:

> Mwila [L]: it was very depressing (sighs), everything was up in the air, and it's too hard to believe that I'm divorced (cries). I never thought it would happen.

Findings of my research revealed that the life transition phase (from being married to being divorced) had implications in their social life not just in relation to marital status, but also in terms of finances, housing, family support and sole responsibility for tiring practical tasks. For example, one of the participants, Susan [L] moved back to her parents after being divorced because she had nowhere else to go, and she had no capacity to provide materially for her daughter. Her moving back to her parents was experienced as a biographical disruption since her parents' expectations of her being married and independent of them could no longer be realised. Divorced mothers were also stigmatised not only because their marital biography was derailed, but also because of the negative connotations associated with being a divorced woman. They internalised the stigma attached to both divorce and disability that emanated from society. This revealed that an interplay of disability and divorce can result in the stigmatisation of the victims which took the form of isolation. Bo ma Angela lamented:

> Bo ma Angela [K]: it's very difficult and hard to cope with the divorce status and the same time having a child with disabilities.

It was by proxy that these mothers experienced discrimination and stigma through the disabling conditions of their child. My research findings further demonstrated that mothers who had other children besides their child with disabilities were not as dismayed as the first-time single mothers when they learnt about their child's condition. They quickly bounced back from the disappointment of having a child with disabilities, and they maintained a positive outlook of their child's future. They also had a realistic view of their child's situation. Faggy was one such mother who used her past experience to overcome destress of having a child with disabilities. She stated:

> Faggy [L]: when I had my first born who was diagnosed with muscular dystrophy, I was shattered. When my fourth born was diagnosed with the same condition, I handled the situation quite well because I learnt from my experience.

These mothers recognised how they dealt with their past crisis and difficulties in their lives and they could thus handle the condition of their child with disabilities aptly. Furthermore, from their past experience, they valued their child with or without a disability as one mother described:

> Bo ma Kanyanga [K]: I actually love my two girls with disabilities more than my other children who are not disabled, I accepted them as God given.

Both Bo ma Kanyanga and Faggy's narratives reflected a combination of biographicity and agency. According to Alheit and Dausien (2007) biographicity is a term that refers to how people cope with the current situation using their individual knowledge resource. The concept of biographicity is thus, helpful in understanding how these mothers responded to their child's disability. This reflected the extent to which these mothers were drawing on their experiences and using their past biography to move and cope with the situation. Some mothers who were partnered and those that had other children used their history to reclaim agency and they could involve family members as well to cope with the diagnosis and subsequent prognosis of their child's condition.

Mother-blaming also emerged significantly across urban-rural and economic divides. Dominant assumptions that mothers were responsible for their children meant they were blamed for the condition of their child. The mother-blame reflected the dominant patriarchal society common in most peri-urban and rural areas of Zambia. It appeared that mothers were judged based on their child's abilities. Again, this was more pronounced among mothers of children with severe cerebral palsy. Thus, using a social model of disability (Simkiss et al., 2011, Barnes et al., 2002, Thomas, 2002, Oliver, 1996) allowed for an exploration of the experiences of the mothers that established that some mothers were wrongly accused by their significant others of attempting to abort but were unsuccessful and this was why the child had a disability. For example:

> Zion [L]: there is a lot of talking around, some accuse me of attempting to abort […] lots of accusations. It's unbearable.

I found that mother-blame was a significant problem in women's lives, and this impinged on how they perceived themselves, especially first-time mothers. For example, Esther narrated:

> Esther [L]: because of too much accusations against me concerning his condition, at times I feel like I'm not doing enough for him.

My research findings also established that mother-blame was more pronounced among mothers from high density areas. This could have been due to lack of awareness among the dwellers of rural Kaoma and peri-urban Lusaka on the causes of disabilities. This mother-blame in some instances resulted in abuse of these women. This abuse was more pronounced among mothers from Lusaka, and it took the form of physical and verbal. For instance, Susan stated:

> Susan [L]: he used to shout at me every day, and at times he would beat me and he never provided for the family because he thought I was responsible for the child's condition.

These findings highlighted the value that underpin how good mothering is socially constructed. Mothers were blamed and abused for conditions for which they had no control. Going further than mother-blame, I discovered, somewhat to my surprise, that mothers internalised this blame and they shared the stigma and discrimination associated with their children with disabilities. However, one thing that was striking among most partnered mothers in both Kaoma and Lusaka was their ability not to blame themselves for the condition of their child with disabilities. These mothers were building on their capacities to overcome mother-blaming as Tandiwe explained:

226

> Tandiwe [L]: I can't allow people to blame me for his condition, I
> have other four children who are able-bodied. I often explain
> to people how these conditions are caused.

This experience of these mothers who had other children and/or were partnered helped them to look at things differently and they became unwaveringly positive about their child's condition and took time to educate others about disabilities. From their experience they were able to preclude the idea that something was wrong with them (mothers). So in a way, they had some protection in terms of their individual biography as people who had different ideas about disabilities. However, there were many socially constructed categories that impinged on the mothers who participated in my research. The next section explores the impact of an intersection of identities on the mothers and their children with disabilities.

8.3 Exploring the Mothers' lived Experiences using Intersectionality Theory

The impact of intersecting oppressions shapes lives and experiences of individuals. Theories of intersectionality allow for an exploration of an interplay of different categories (Carbin and Edenheim, 2013, Cho et al., 2013, Tsouroufli et al., 2011, Crenshaw, 1991) that result in some people being disadvantaged. Walby et al. (2012a) opine that it is vital to theorise an intersection of inequalities that are so prevalent in society. This involves going beyond focusing on class and include other categories such as age, race, ethnicity and disability. This section uses theories of feminist intersectionality to explore the experiences of mothers raising children with disabilities. It highlights the themes that emerged from this study and are discussed in relation to feminist intersectionality and disability. Other scholars who have attempted to incorporate theories of feminist intersectionality in the study of disability have focused on an intersection of HIV/AIDS, gender and disability within the context of Zambia (Parsons et al., 2015, Yoshida et al., 2014). Attention has also been given to the interaction of disability, gender, age and socioeconomic status of individuals

(Njelesani et al., 2015, Wickenden et al., 2013, Emmett, 2006,). In order to develop a nuanced understanding of lived experiences of participating mothers in the current research, it is important to locate their experiences within the context of the political, economic and sociocultural context of Zambia.

Findings of my study provide some insight into how oppressions are intertwined impacting on identities and resulting in the disadvantages faced by some mothers in this study; a cross cutting issue that emerged from my research was about how different combinations of oppressions intersected to disadvantage mothers. This view is also highlighted by other scholars (Gillborn, 2015, Pearson, 2010, Yuval-Davis, 2006) who examine the interrelationship of class, ethnicity, gender and social divisions. Winker and Degele (2011) submit that one of the ways of grasping the living experiences of the marginalised people in society lies in *'identifying concrete relations of power and then analysing their interrelatedness and changes'* (2011:54) and how these impact on them.

The work of the above cited scholars was reinforced in the findings across the rural-urban divide, mothers from low socioeconomic status in terms of their education who were still partnered reported that their spouses made decisions regarding the welfare of their child with disabilities. For example Bo ma Anne stated:

> Bo ma Anne [K]: he is the man, the head of the house, he makes decisions at home […] I follow even when I don't agree with his decisions at times.

This transcended decision making to include caregiving roles. Some of these mothers especially those from low socioeconomic status across rural-urban divide had to bear the burden of caregiving without the support of their partners. This highlighted the significance of gender dynamics underlying caregiving roles, and it also revealed that social divisions are deeply rooted within social structures in Zambia, such as families and society at large.

These findings were also a demonstration that within a patriarchal society more power is allotted to men than women. My findings further revealed that social divisions and power dynamics are embedded within the family and society, and these women were affected in various ways which included but not limited to poor social relations and weakened social positions. This was a revelation of how power dynamics were sustained through social divisions like gender and class. However, this was not the case with mothers (all from Lusaka) from high socioeconomic status in terms of education. For example, Chilinda and Tandiwe, both university graduate explained:

> Chilinda [L]: we make collective decisions […] we consult each other.

> Tandiwe [L]: I have a supporting husband who values my contribution at home. He consults me when making decisions at home.

Theories of feminist intersectionality are significant in providing a direction on the interaction of disability, gender and class and how these are experienced by marginalised groups of people in society (Moodley and Graham, 2015, Shields, 2008, Grillo, 1995). In exploring the impact of having a child with disabilities, my study demonstrated that the consequences (divorce, prejudice and stigmatisation) of having a child with disabilities shaped the life trajectories of the mothers. A combination of divorce and their child's disability shaped the social and health trajectories of the mothers across both research sites. An excerpt from the interview below revealed the extent to which this (divorce and the child's disability) was a consequence:

> Susan [L]: Every time I'm with her, everybody turns to look at me.

> Researcher: Why do you think people do that?

> Susan [L]: His condition catches the attention of everybody.

Researcher: How has that affected you?

Susan [L]: I feel bad because I get reproached for having a child with disabilities and the fact that I'm no longer with my husband.

Drawing on the theories of feminist intersectionality, the account by Susan provided an insight into how the impact of oppressions and their impact on identities can disadvantage mothers of children with disabilities. It also provided another aspect of feminist intersectionality called intra-category. These are small neglected groups that are hardly given a voice to be heard despite experiencing discrimination, stigmatisation and inequality (Yoshida et al., 2014, Walby et al., 2012b). Intra-category was relevant in examining the lived experiences of the participating mothers on how an interface of being a single mother and at the same time parenting a child with severe disabilities resulted in these mothers experiencing a *'double burden'* which exacerbated their marginalisation. Particularly, first-time single mothers of children with cerebral palsy were often banished by their own families because they were no longer seen as potential wives. The loss of a future dowry meant that these mothers had no worth to the family. In some cases, divorce added another dimension to their situation, and they experienced a *'triple burden'* (being a single mother, having a child with cerebral palsy and being divorced). Bo ma Musuwa explained:

Bo ma Musuwa [K]: people in the village call me all sorts of names: a divorcee, a mother of a disabled child, and others laugh at me for being a lone mum.

My research findings further illuminated that the social location of these mothers was not the same, they lost their economic power, and had less support because of their child having disabilities. Their identity as a mother was shifted as well because they had desired to be mothers of an able-bodied child but the child had disabilities. Drawing on their experiences, these mothers felt guilt and that their identity as a mother was compromised.

This illustrates that there was an interplay between location, oppression and identity.

The use of feminist intersectionality theories also allowed for the exploration of how different aspects of social categories such as gender and disability had implications on the socioeconomic status of these mothers (Moodley and Graham, 2015, Cramer and Plummer, 2009, Davis, 2008). It also allowed for nuanced understanding of the experiences of mothers by looking at the different connections such as age, type and severity of the child's condition. Findings of my thesis demonstrated just how difficult it was for mothers as illustrated by stories of two first-time single mothers:

> Mwila [L]: it has been hard, you know nursing a child time after time. I must bath her, feed her and she is a big girl, I don't manage to lift her. It's really challenging.

> Susan [L]: it is difficult to balance taking care of her and doing house chores, now you can imagine that coupled with not working? I had to stop working. It's tough for women who have such children to engage in other activities.

The above accounts exemplified the link between disability and poverty. The lives of these mothers were shaped by different social structures such as socioeconomic, cultural and political issues within the context of Zambia. Overall, the above accounts by mothers highlighted an interplay between gender, disability and poverty (Couch et al., 2015, Cho et al., 2013, Davis, 2008, Yuval-Davis, 2006) and how the three social divisions are interwoven. Understanding the lived experiences of the participating mothers while drawing on an intersectional approach, helped in gleaning how repressive social structures intersect to create different classes in the Zambian society. Furthermore, drawing on a feminist intersectional approach helped in understanding the impact of multiple identities on mothers, especially first-time single mothers. Particularly, my research demonstrated that poverty and disability were inextricably linked. This connection is explored in detail in the next section.

8.4 Understanding Mothers' Experiences using the Social Empowerment Model

This section will espouse mothers' perspectives using the social empowerment model as a lens. This model asserts that poor households lack social power which is necessary for improving the household economy (Wilson, 2011, Friedmann, 1992). In this sense, it will show how the study findings illuminated how parenting a child with disabilities within the political, sociocultural and economic context of Zambia determined a mothers' ability to have access to bases of social power as postulated by John Friedmann's social empowerment model.

The social empowerment model provides a framework for understanding the importance of financial resources in improving people's livelihood without which people are considered to be poor (Schischka, 2008, Mitra, 2006, Robeyns, 2005, Friedmann, 1992). In drawing on the experiences of mothers, this study shed light on the significance of financial resources (or lack of them) in their caregiving role. This study deciphered that financial resources were determined by the mothers' capacity to engage in formal or informal work in order to earn an income necessary for their household economy (Friedmann, 1992). Despite the diversity among the participants who took part in my study, parenting a child with disabilities affected the mothers' ability to have access to financial resources in various ways. There were differences in which the demands of caregiving had an impact on mothers from Lusaka and those from Kaoma. In the case of mothers from Lusaka, the demands associated with caring for a child with disabilities and the demands of workplace had profound implications on these women's ability to juggle between being in full time employment and looking after a child with disabilities. There were stories of some participating mothers giving up their employment in order to look after their child with disabilities. This meant that there was loss of income in the family, and most of the mothers described themselves as experiencing financial deprivation. This was more pronounced among first-time single mothers of children with

severe cerebral palsy. Mothers were caught in a pincer movement, they earned less, but the needs of their child cost more. As Susan and Mwila described:

> Susan [L]: I can't manage to juggle between doing business and looking after the child. I stopped working because I had to care for her. And now I have no income.

> Mwila [L]: It is difficult to balance taking care of her and doing house chores, now you can imagine that coupled with not working? I had to stop working. It's tough for women who have such children to engage in other activities

Findings from my study yielded significant insights in the financial realm. For instance, these first-time single mothers were particularly hard pressed financially. For example, the mothers' inability to either engage in business or employment resulted in low income and difficulties in adequately providing materially for their children. In addition to this pervasive sense of helplessness, these mothers expressed more negative feelings about their situations. For the mothers from rural Kaoma, the demands for caregiving had a bearing on their ability to engage in agricultural activities which was the mainstay of their livelihood. Their agriculture yields were often too low to have surplus to sell in order to raise the much-needed income for the family. This also had an impact on their food security at household level. Bo ma Angela [K] stated: *'ever since I had Angela, it has been very difficult to focus on farming, this has affected my ability to harvest enough to feed my children and a surplus to sell.'*

Overall, the cost associated with caregiving was beyond the reach of many lone and unemployed mothers from Lusaka, but it was more pronounced among participating lone mothers from Kaoma. My study findings are in congruent with the argument by Dolan (2007:726) that the *'differences in income and material circumstances may impact differently on people depending on their position in social structure.'* Findings further revealed that this poverty especially for mothers in rural Kaoma added significantly to

levels of maternal stress. These mothers from Kaoma had even greater challenges accessing social services such as health facilities due to their limited resources and distance to these facilities. In addition, these mothers struggled just to get basic necessities for their families. Other scholars have reinforced the above view that most parents of children with disabilities have challenges providing materially for their families. These scholars affirm the view that the costs associated with caring for a child with disabilities drives many carers into economic deprivation (Read and Harrison, 2002).

With regards to women who were divorced, findings from my study revealed that mothers from Kaoma lost their fields for cultivation to their partners after being divorced and this compounded their already challenging situation. These mothers reported greater maternal stress because of the struggle to find land to cultivate and at the same time provide for their child with disabilities. This reflected the dominant patriarchal society that is prevalent in rural areas of Zambia. In the case of mothers from Lusaka who were initially married but were not working, this lack of income had a negative impact on their independence. These mothers were dependent on their husbands but they suffered poor economic outcomes especially after being divorced. Some mothers continually cited their despair over their dependence on their partners to provide materially for the family left them in difficult situation after being divorced. This growing dependence of some mothers on their husbands reduced their *'autonomy and strengthened male control'* (Friedmann, 1992:110). The mothers that were divorced described themselves as having descended into poverty. Divorce was thus *'seen as a transition that potentially shapes the economic […] trajectories of individuals'* (Couch et al., 2015:1489). This impact of divorce on the economic circumstances of mothers can be seen from the two quotes from divorced mothers:

> Bo ma Musuwa [K]: life has been difficult since I got divorced. I'm fighting for the needs of my son. I could work only if there was someone to help me with caregiving roles. As it is, I face difficulties in life.

> Bo ma Mwila [K]: I'm struggling financially. Life is hard for me and my daughter [...] I would describe myself as poor.

However, some mothers from Lusaka who remained partnered and were from high socioeconomic status in terms of education were able to work full time. This was also attributed to the support they received from their significant others especially their spouses in caring for their disabled child, as Chilinda described:

> Chilinda [L]: I work as a head teacher, Deborah's condition has not affected my ability to work full time, and my husband and the kids are very supportive. And we also need an income because my husband is retired so it's just imperative that I work full time.

The study demonstrated that mothers from Kaoma who were partnered reported that their spouses were supportive especially with regard to providing for the family. While their spouses focused on farming, they (mothers) cared for the children. This highlighted the division of labour that existed at household level especially in families from low socioeconomic status. The support these mothers received from their partners was very significant in their coping with stress associated with raising a child with disabilities. Findings of my study revealed that the mother received more social support from the spouse when the (spouse) believed that the child would eventually become better with some help.

The social empowerment model is also relevant for examining the relationship between time as a resource and the capacity of people to engage in activities that could help improve their living circumstances (Friedmann, 1992). This view is exemplified by other scholars (Emerson, 2003, Park et al., 2002, Zimmerman, 2000) who assert that because of the demands and burden associated with raising children with disabilities, carers of these children *'need additional money and time'* (Sen and Yurtsever, 2007:240). In this case, Friedmann defines surplus time as the

time that is available to individuals in a household aside from the time for gaining a subsistence livelihood.

From the above definition of surplus time, the social empowerment model draws attention on the relationship between time as a resource and what happens when people have less time (Friedmann, 1992). Exploring the living circumstances of the participating mothers demonstrated that mothers whose child had severe cerebral palsy had little time to pursue equally important activities that could have enhanced their living standards, as Zion [L] lamented: *'her condition has changed my life, it will no longer be the same. I won't be able to do things I had planned to do. I can neither go back to school nor start business.'* Zion's view reflects that other equally important activities that mothers could do suffered when they had less time. The mother has to share her time between housework and caring for other children. First-time single mothers, with little or no social support, cited their despondency over their child's lack of independence, and that meant they spent much of their time juggling between assisting their child with mobility and doing other household chores.

Across the research sites (Lusaka and Kaoma), mothers who described themselves as not having enough time to do other activities, had high stress levels especially as the child grew older, and this in turn negatively affected their mental and physical wellbeing. Wilson (2011:44) buttressed this view by stating that *'mothers expect to expend much energy on helping small children, but when children age and still require as much help as when they were infants, the reality sets in that this child will likely need life-long care.'* Mothers in my study, particularly the first-time single mothers realised that because of the lifelong care that the child with disabilities required, they would not have time for themselves as they age. This study highlighted the difficulties and impact associated with caregiving roles such as lifting, carrying, dressing and bathing of their children with disabilities. The findings of this study, further, illustrated that most first-time single mothers in both research sites had poorer health outcomes than mothers who were still

living with their partners. For example, my study findings revealed that most of the first-time single mothers developed health conditions and they attributed this to among others the worries associated with the condition of the child, and associated hardships. As Susan described her situation:

Susan [L]: everything is blocked, it's very hard

Researcher: Kindly elaborate on that point

Susan [L]: what I'm going through is worrying me a lot. And it makes me think a lot

Researcher: how has it affected you?

Susan [L]: I'm always busy attending to my daughter, there is literally no time to do anything else. And because of worrying too much, I have developed hypertension […] having a disabled child and not being able to provide food for her makes me worry a lot.

As much as mothers from both research sites experienced psychological challenges, findings revealed that these (psychological challenges) were more pronounced among participating mothers from urban Lusaka than those from rural Kaoma. Most of the mothers from Lusaka spoke about worrying about finding money for among others paying rent and providing food for their children. These concerns about providing for their children increased maternal stress, depression, feelings of hopelessness and despair. In terms of accommodation, participants of Kaoma stated that they did not have to worry about paying rent because they were able to build their own houses. Divorced Mwila [L] stated:

Mwila [L]: you appreciate having a husband when you experience how difficult it is to find money to pay rent and buy food for the child.

Furthermore, findings of my study demonstrated that some first-time single mothers from Lusaka especially those whose child had cerebral palsy

reported experiencing sleep deprivation and some of them appeared to have lost the sense of meaning in life. These mothers had at some point contemplated committing suicide:

> Esther [L]: It's really a challenge, there's hardly time to rest […] lack of sleep has taken a toll on me […] yes, thoughts of suicide cross my mind at times […] maybe if I died, Cheshire Homes would look after her.

The feeling of harbouring thoughts of committing suicide among mothers from Lusaka was more pronounced among mothers who did not belong to parent support groups which resulted in limited social networks. There was a general perception among some of the mothers from Lusaka that their child with disabilities would be taken on by orphanages in an event that they (mothers) died. These orphanages were mainly found in urban areas and were mostly run by faith-based organisations such as the Catholic Church. However, some mothers moved on from that (thought of suicide) after joining parent-support groups. They were able to learn from other experienced mothers, and they were, hence, able to exercise their agency. Participation in social organisations therefore, increased their social support and social capital. One of the major findings was that these parent support groups were one of the key coping strategies for mothers. As Dumont and Provost (1999) assert, social support *'gives an individual a general positive context without regard for actual experiences of stressful events'* (1999:346).

The findings further revealed that belonging to social organisations was beneficial to many of the participating mothers. For example, parent-support groups played an instrumental role in changing their understanding of both the nature and impact of disability on their lives as well as the life of their child. For example, some mothers explained:

> Gertrude [L]: being a member of the support group has helped me a lot especially with regard to my son's condition. We often have classes were doctors and physiotherapists teach

us […] I can't be cheated that my son was bewitched. I
understand his condition quite well.

Susan [L]: my journey of being a mother of a disabled child was
more painful before I joined the parent-support group but now
it is better.

Zion: [L] I'm happy, I have nice friends at the Special Hope
Network. The mothers are very good to me.

Indeed, it was significant for these mothers to have appropriate knowledge
of their child's condition because they felt that this was going to help them
know what to expect of a child with disabilities' life trajectory. Like one
participant (Zion [L]) posited, she sought information from professionals and
fellow members of parent support groups about cerebral palsy because she
wanted to know if her daughter had the potential to develop fully. Thus,
membership to parent-support groups was significant in understanding their
child's condition. Sharing experiences enabled mothers to give each other
a unique quality of mutual support and a pool practical information and ways
of coping.

The findings demonstrated how some members of the parent support
groups in Lusaka were trained to conduct basic physiotherapy on children
with disabilities. They were also trained in advocacy. This shifted the
balance of power towards mothers as they did not have to rely solely on
healthcare professionals to conduct physiotherapy because they could do it
themselves. These groups of women had more power collaboratively than
they had individually. These groups facilitated the feelings of social
companionship, belonging and community with other mothers. Membership
to these groups also reduced feelings of loneliness and enabling mothers to
share ideas and strategies to advocate and protect the rights of their own
and that of their children with disabilities. These mothers collectively were
able to resist dominant suppressive ideas that placed them on the margins
of society. *'The starting point is to remove fear in their (mothers') head and
teach them that they and their disabled child have rights which have to be*

protected', said Astridah a member of disabled people's rights activist in Lusaka. The study revealed that these parent-support groups were raising awareness among mothers and at the same time engaging relevant organisations on the need to observe the rights of people with disabilities such as their right to education. Findings of my study suggested that most mothers in Lusaka felt that their children with disabilities were denied their right to education. Faggy [L] noted: *'as a support group, our vision is to ensure persons with disabilities enjoy their rights like any other person.'* The above comments were also a revelation of a link between power and empowerment that these mothers collectively had. However, these parent-support groups were more organised and stronger in Lusaka than in Kaoma. One of the reasons for this was because of the presence of many non-governmental organisations in the urban Lusaka that supported the activities of parent-support groups. For example, Special Hope Network and Archie Hinchcliffe Disability Intervention were some of the organisations in Lusaka that trained mothers to conduct basic physiotherapy and advocacy.

Just as Winker and Degele (2011:54) argue that *'individuals constitute their identities in the delineation from others, while at the same time creating a sense of belonging.'* The findings of my research highlighted that parent-support groups helped mothers to build interpersonal relationships, and some of the participants described it as significant in helping them adapt to situations that could have been more distressful and difficult to cope with. The study also revealed that parent-support groups helped in building cohesion and expressiveness among members:

> Tandiwe [L]: there are a lot of benefits being a member of the parent-support group. I have been able to find new friends whose children also have disabilities. We support each other because we understand what it means to parent such children. I feel more relaxed when I'm with the mothers. I'm able to identify with my own.

These parents-support groups were a source of encouragement as they provided emotional, moral and physical support to members and my study

240

findings indicated that members of these groups expressed satisfaction with the support they received from their peers.

However, as much as not all bases of social power could be used to explore the living circumstances of mothers who participated in my study, the social empowerment model helped in understanding various facets of the mothers' experiences of parenting children with disabilities within the sociocultural context of Zambia.

8.5   Conclusion

Having set out to present findings from my study in the three previous chapters, this chapter extended these discussions by focusing on exploring the nuances of social categories through the accounts of participating mothers. Of particular interest was exploring whether they believed that they had been impoverished (or were stigmatised) because of the negative societal attitudes surrounding women and childhood disability. This chapter used social model of disability, feminist intersectionality theories and social empowerment model to explore the mothers lived experiences. However, there was a reciprocal relationship between the theoretical frameworks and the findings of my study. As much as the theoretical perspectives enabled me to apply a lens to women's experiences, from my study findings, a theory of biographical disruption emerged from the data which resonated with the social model of disability. This enhanced the utilisation of the social model of disability in understanding the lived experiences of mothers of children with disabilities within the political, economic and sociocultural context of Zambia.

There was also a close connection between social power, and, equality and diversity in society. Hence, this chapter explored an interplay between disability and gender within the context of poverty. As Emmett (2006) argues, *'an awareness of the cumulative impacts of social disadvantages is essential to full understanding of poverty in its various dimensions, of the*

impacts of disability and impairments on impoverished people' (2006:445). Thus, this chapter has revealed that disability can be located within the context of other social inequalities such as poverty, gender and family structure and social networks. The interconnection of such inequalities have implications for the wellbeing of mothers and their children with disabilities. The in-depth stories of mothers revealed and highlighted much of what it means becoming and parenting a child with disabilities. The study findings have also elucidated how gender is enhanced by looking at the profound implications for women about becoming divorced, and the impact of being blamed. These women were blamed for things that were not their responsibility. This mother-blame took a particular form because of particular value system within the socio economic, cultural and political context of the Zambian society.

Chapter Nine

Conclusion

9.1 Introduction

This research on which this thesis was based, explored the meaning that mothers attach to raising children with disabilities from their own perspectives, at the time before the child became diagnosed as disabled, their present situation and what their future expectations were. Although studies have been undertaken within the area of disability in Zambia (Parson et al., 2015, Yoshida et al., 2014, Mung'omba, 2008), the literature reviewed at the outset indicated that little research had been conducted on mothering, particularly from their own perspectives. The previous chapter evaluated the theoretical frameworks (social disability model, feminist intersectionality theory and social empowerment model) and their relevance in terms of understanding this study's findings. The study reported in this thesis sought to explore the experiences and perspectives of thirty mothers parenting children with disabilities in Lusaka and Kaoma. This study has generated and extended knowledge in the area of parenting children with disabilities in both Zambia and globally.

In conclusion, this chapter reviews the study's key findings and considers its contribution to scholarship on mothering children with disabilities in Zambia, and internationally. It will also reflect on the process of research and my development as a researcher. The chapter is divided into eight sections. The first section briefly summarises literature on parenting and disability that formed the basis for this study. This is followed by the review of the theoretical framework and research questions with the view to indicating the ways in which this research has confirmed, extended and challenged these perspectives. The third section will revisit the methodology and methods used in this research in order to provide a critical evaluation of their appropriateness and their limitations. Within this section I will also

reflect on my journey as a researcher in order to develop critical reflections on the whole research process. This is followed by a discussion of the key findings. This study section will also highlight the implications of the findings and this is followed by a section of the contribution of this thesis to the scholarly body of knowledge on parenting children with disabilities. Throughout this section, I outline my claim to originality. The seventh section will focus on areas for future research that have indicated by this preliminary study in Zambia. Finally, a conclusion of the chapter is drawn.

This thesis critically evaluated literature on disability, families of the disabled and parenting children with disabilities related to practice, research and policy in both developed countries and sub-Saharan Africa. This literature review was critically evaluated and complimented by the three theoretical frameworks; the social model of disability, feminist intersectionality and the social empowerment model. The proceeding sections will discuss these frameworks in detail.

9.2 Revisiting Literature: Mothering Children with Disabilities and Mother-Blame

This thesis and my research journey started with the review of literature and therefore, it is worthwhile to briefly summarise it in this section. A detailed literature review revealed that there is no work that has been undertaken on the views of mothers on what it is like to parent a child with disabilities within the Zambian context. Furthermore, findings showed that little research has been conducted on disability in Zambia, although much could be learned from reviewing the research and literature from other countries. The scholarship on disabilities has also focused on how the family is affected/impacted by the presence of a child with disabilities (Goodley and Runswick-Cole, 2015, Hodge and Runswick-Cole, 2013, Stuttard et al., 2014). At a global level, studies have been undertaken that have focused on parenting children with disabilities, and that in the context of children with disabilities parenting is often synonymous with mothering. Sometimes

obscuring the significance of gender and the unequal nature of parenting. Indeed, in the literature that I reviewed, I noted that this revealed how mothers of children with disabilities were oppressed within the context of male domination and patriarchal family structures. Both the social model of disabilities and feminist theories (intersectionality) that underpinned this work sought to recognise that caring for children especially children with disabilities has been seen to be the responsibility of the women particularly in sub-Saharan Africa (McKenzie, 2016, McKenzie and McConkey, 2016). One of the implication of this, is that in being attributed with this major responsibility, the mother is readily blamed for the child's condition, and in some cases, this is used to banish them from society (Mushi et al., 2010, Wilson, 2011). This work has also shown that because of discrimination, many families with children with disabilities suffer poverty, and that lone mothers of children with disabilities were over represented amongst families living in poverty in many societies. Literature illustrates that mothers, who in most cases are the exclusive carers, have had to give up their jobs in order to look after their child with disabilities. This means loss of income at home and further marginalisation (Traini and Loeb, 2012, Hatton and Emerson, 2009, Emerson et al., 2006).

The review of literature indicated that mother-blame, which Blum (2015) defines as the process by which mothers are criticised for their child's condition, is a significant theme in literature on parenting children with disabilities. While there are efforts to protect mothers from being blamed (Caplan, 2013, Friedman, 2015, Sen and Yurtsever, 2007), it appears that especially in some sub-Saharan Africa countries, cultural values and norms combine to perpetuate the gender discrimination and stigma against mothers and their children with disabilities (Labie et al., 2015, Masulani-Mwale et al., 2016, McKenzie, 2013). In some instances, this stigma starts from within the family, and there is a general agreement in literature that the cultural context and social location can exacerbate mother-blame (McConkey, 2015, Mung'omba, 2008). While literature has made useful contribution to knowledge by highlighting the link between disability and

mother-blame, Blum (2015) sums the argument by stating that there is need to understand the context and social location in which mother-blame takes place.

The review also established that there was religious and cultural understanding of disabilities, it was often attributed to witchcraft (Aldersey et al., 2016, Aldersey, 2012, Kelly et al., 2012, Hartley et al., 2005), punishment from God (Gona et al., 2010, Masasa et al., 2005) while others see children with disabilities as a blessing from God (Dave et al., 2017, Masasa et al., 2005). This has implications for the way carers and the people with disabilities are perceived by their significant others and the wider society and how they view themselves. The review has also found that the presence of a child with disabilities in the family often alters family relationship between couples. Mothers also often have to give up their jobs to look after a child with disabilities and this means loss of an income and this led to changes in their living circumstances (Blackburn et al., 2010, UNICEF 2008).

Existing literature has also shown that there is a general agreement on the importance of social support to carers of people with disabilities (Ryan and Cole, 2009, Read, 2000). Social networks are one of the key sources of support to families with a disabled member. Family and friends act as a buffer when a mother finds herself in the challenging situation of providing lifelong care to a child with disabilities (Barker et al., 2011, White and Hastings, 2004).

9.3 Theoretical Context and Research Questions

The theoretical framework developed from a review of a significant body of literature was based on three theories: social model of disability, feminist intersectionality theory and social empowerment model. This study was underpinned by social model of disability as an overarching framework which focuses on how disability is socially constructed (Shakespeare, 2006,

Barnes et al., 2002, Goodley, 2000). Stigma and discrimination that children with disabilities and their carers' experience, and how mothers understand and experience negative attitudes differs depending on their individual knowledge and experience (Simkiss et al., 2011, Spencer et al., 2010). Reviewed literature highlighted the significant impact of the child's disability on the life course of their carers. It also demonstrated that the beliefs about disabilities were multiple and overlapping. Previous literature has revealed the significance of gender in caregiving roles especially and that these roles are socially constructed (Moodley and Graham, 2015, Yoshida et al., 2014). Drawing on feminist intersectionality theories provided the lenses for understanding the centrality of gender in caregiving roles. These roles are socially constructed and often they are expected to be performed by mothers. This study placed women at the centre of research using gender and socioeconomic status, age and disability as units of analysis. However, existing research that has focused on the experiences of parenting children with disabilities especially in sub-Saharan Africa has not theorised on the ways in which different social categories intersect to disadvantage mothers (Goethals et al., 2015, Gillborn, 2015, Yuval-Davis, 2006). This thesis therefore, drew on feminist intersectionality theories to explore the experiences of the participating mothers in order to recognise that they may be experiencing multiple and overlapping forms of oppression. This study was also underpinned by the social empowerment model. The rationale for using Friedmann's social empowerment model was that it not only looks at income poverty, but also on how lack of access to other bases of social power hinder people's ability to engage in various social activities (Friedmann, 1992). In relation to social power, this is the centre of every household economy. Therefore, *'poor households lack social power to improve the condition of their members' lives'* (Friedmann 1992: 66). Poverty is thus, viewed as lack of social power by a household (Staub-Bernasconi, 2010, Thompson, 2007).

A review of literature provided a rational for a conceptual framework, as outlined in chapter three, from the three theoretical perspectives in

understanding the lived experiences of mothers of children with disabilities in Zambia. This research had the following as research questions and these where developed following a critical review of literature: the overarching research question was: What are experiences of mothers in respect to parenting a child with disabilities in Zambia? This study also sought to answer the following:

1. How do mothers view their children's disabilities and the causes of them? And what are their reactions to the child's diagnosis?
2. How does having a child with disabilities affect the mothers' in relation to power dynamics at the family and society level?
3. What are the mothers' present concerns and sources of support, and what are their future expectations?

9.4 Methodology and Methods

This was a biographical study that was underpinned by interpretivist perspective, and it drew on the following paradigms: intersectionality (MacKinnon, 2013, Nash, 2008, Crenshaw, 1991) and grounded theory (Charmaz, 2006, Punch, 1999, Strauss and Corbin 1998). As this research aimed at making the voice of women central, the study was also informed by feminist perspectives and adopted some modest participatory elements by incorporating the views of mothers who were members of parent support groups in shaping the research process. Early in the research process, I relied on their insights in modifying data collection instruments and in accessing the field.

Prior to commencing fieldwork, ethical approval was obtained from HSSREC at the University of Warwick, which was an exacting process. All the mothers that participated in the study gave informed consent. Biographical interviews enabled me to explore mothers' own perspectives in some depth, and the process of the interviews also allowed mothers to reflect on their reactions to the child's diagnosis, their present situation,

sources of support and their future expectations. Since this study was based on first-hand experience of parenting a child with disabilities, purposive and snowball sampling were used to recruit participants. This thesis had a sample size of thirty mothers from two contrasting research sites; Kaoma, a rural town and Lusaka, an urban town. The participants were of a range of ages and socioeconomic statuses, and these mothers had children who had different impairments such as cerebral palsy, Down's syndrome, autism, and muscular dystrophy among others. These interviews also helped them to make connections between their past and the present situation, and how they perceive their future and that of their child with disabilities. The nature of this research required a high level of reflexivity because it involved a male researcher interviewing often marginalised women (Bryman, 2012, Polit and Beck, 2011).

9.4.1 Methodological Reflections

Looking at the whole period from the time I started my PhD programme in September 2013, I have developed research skills through supervision meetings, training in research offered by the doctoral training centre and other skills training programmes offered by the University of Warwick, and through fieldwork experience. Amongst the things I have learnt is the importance of developing well founded relationships based on mutual trust and respect for participants to disclose information concerning their lives. I was aware of the contrast in my position as a male researcher based abroad and the social position of the participating mothers. These mothers talked about sensitive issues and what they discussed might have been painful and difficult. Literature (Watts, 2008, Dickson-Swift et al., 2007, Duncombe and Jessop, 2002) highlights the importance of researchers undertaking such sensitive research to access professional support. My experience of carrying out this study especially in settings where such professional help was not available, is that researchers need to prepare self-care strategies. This psychological preparedness of how to handle sensitive issues that might arise during the interview sessions is essential before commencing

fieldwork. It is also vital to be reflective of the whole fieldwork process. Reflecting on every interview that I conducted helped me to know when to speak and when not to speak. I had to be an active listener.

My reflections on conducting this research made me realise that many mothers were willing to share their lived experiences but they needed guidance on the details required. It was not always that the participants stuck to the questions I asked them. Some were answering in their own way. I learnt to not interrupt them but to tactfully rephrase the same question. Most of them commented that they wanted to share their story, but they did not know what to talk about and what not to share. I learnt to use prompts and probes to help them elaborate on some issues they talked about. For example, I was asking them questions like *'How did you feel about it?'* Through these interviews, I discovered that many participating mothers had kept these stories to themselves. They appeared to have some relief after sharing their experiences like one mother (Susan) put it: *'I feel like I poured out all my frustration.'* I also felt privileged that these mothers shared their stories with me, most of which were centred on their private life.

Reflecting on data analysis process, first the interviews were long and this meant transcribing took longer than I thought. I learnt that transcribing the interviews myself brought me closer to the data. I knew the story really well and I was able to visualise the interview process. I realised that I was getting better in my interviewing skills with time. What helped me was to listen to the interview several times, transcribed and read it several times before the next interview. I was able to identify areas where I needed to improve and identified questions that were confusing to the participating mothers. I found transcribing to be the hardest aspect of the research process and it was not a mechanistic activity. Regardless of the challenges that where there in analysing data, I maintained the highest integrity and commitment to participants when analysing it. The whole process of analysing data helped me develop skills and insight that can be used to work to the highest levels of research integrity. My overall reflections on the whole fieldwork process

is that one can never be sure of what to expect. There is, therefore, a need for researchers to adjust and adapt to the situations as they arise. I learnt something about qualitative research methods more generally. During my doctoral training in research methods, I gained an understanding of the relationship between qualitative and quantitative research methods. Because of the nature of my research questions, I used qualitative methods for this study.

9.5 Limitations

The main limitation relating to this research project was the timing for fieldwork especially in Kaoma. I conducted fieldwork in Kaoma from September to December. This is the time when people cultivate and plant crops (farming season). Some interviews were rescheduled while in some instances, participants came late by as much as 2 hours for interviews because they first had to go to their farms. I once scheduled two interviews on the same day. The mother I was supposed to interview first left a word that I should wait for her because she had gone to her farm. She came one and half hours late. After discussing with her I walked for another hour to get to the next village for another interview. It was a lesson to not schedule two interviews on the same day.

In Kaoma, interviews were usually held outside in the shade. There were times when it was noisy, in one case, domestic animals such as dogs were barking in the background. There were other things that were challenging when the whole village came out and sat in on the interview. In both research sites, some participants went off at a tangent. The other limitation in Kaoma was distance to villages from where I was staying. Some places were impassable, I walked long distances in sand and very hot weather to get to the participants. This made data collection quite challenging. It would have been better if I had started with Kaoma in June when there are no farming activities taking place and that is the time when the weather is cool. Biographical methods yielded voluminous amount of data that meant I

continuously listened to, read, coded and created memos. This constantly comparing material that emerged from other participants was quite challenging.

One of the limitations of my study relates to the interview sample, as there were age differences between mothers in both research sites, married mothers from Kaoma had more children, meaning that they had different responsibilities. Moreover, the varied nature of the sample limited the ability to compare mothers in similar circumstances. I could have made use of interviews with participants whose children had a similar condition, and mothers from similar age groups with a similar number of children, as this could have provided me with data about the different experiences of mothers from different class backgrounds.

9.6 Key Findings

Findings from my study break new ground on research on gender and mothering children with disabilities in Zambia, and extend the knowledge within disability studies. The difficulties that mothers experience are as a result of an interaction of many factors such as the patriarchal nature of society, including social values, and ideologies in society, and also the negative perception towards these mothers and their children with disabilities meant that their living circumstances were challenging. Findings revealed that mothers are seen as custodians of children.

1. *Mothers' responses to diagnosis was related to their age, marital status, and reaction from significant others*

At the point of birth, none of the mothers across the research sites knew that their child had a disability. None of these mothers could notice that there was something wrong with their child. Findings were consistent across the study sites that first-time mothers relied on other older relatives to tell them that there was something wrong with the child. With time, mothers especially

252

that had other children prior to the child with disabilities started noticing that their child had some challenges. The discovery by most of these mothers especially at around eighteen months age that their child was not progressing as he or she should, played a role in mother's belief that there was something wrong, but even so most of them thought that the condition was temporary and would change as the child grew. Findings show that there was willingness on the part of mothers to know why their children had slow developmental progress but had challenges securing a diagnosis as professionals hardly ever provided information. In cases where they were told, this information was not enough to understand the prognosis of the child's condition. With regard to mothers in Kaoma, this was made worse by the long distance to health facilities. This left most mothers frustrated with some seeking a second opinion and in most cases they sought the help of the traditional healers because they were perceived to be able to tell the person who was behind the child's condition.

After repeated visits and persistence, some mothers were told by health professionals the diagnosis of the child. Mothers' reactions varied depending on their parenting experience. Findings demonstrated that there was a lot of expectations that the child would get over their condition. There was a phase of distress, uneasiness and uncertainty then some mothers went into a phase of hope that the child would improve. Findings were consistent across the study sites that first-time mothers experienced loss of control over their motherhood as their high expectations and joy of becoming a mother turned into a nightmare upon learning that they were required to provide lifelong care. Some of them froze and went as far as denying the diagnosis. The reactions of first-time mothers of children with cerebral palsy and those whose child had Down's syndrome were more similar than different. They all described their experiences as similar to those related to bereavement. However, this thesis has demonstrated that mothers who had other children prior to having a child with disabilities were able to build on their previous stock of experience to overcome some of the difficulties associated with the child being diagnosed with an impairment.

2. Mothers lost their agency and relied on others to make decisions for them regarding healthcare services for their disabled children

The diagnosis of the child's condition meant that families had to make profound decisions regarding the type of healthcare services. Findings show how mothers described losing their agency following the birth and diagnosis of the child's impairment. This thesis revealed that the commonly held cultural values, norms and ideologies in Zambian society, such as a husband is responsible for making decisions at home, meant that mothers were expected to consult regarding healthcare services for their child with disabilities. The study has demonstrated that single mothers depended on their relatives such as their parents, aunties and sisters while married mothers relied on their male partners to make decisions regarding the nature of treatment even against the mother's own will. The presence of a child with disabilities had profound impact on the power relations in the family. Based on my study findings, it is important to highlight that within the Zambian context, more power is allotted to husbands than mothers especially with regard to decision making involving the type of healthcare needed for the child. Mothers were passive, helpless as they were required to subscribe to the idea that decision making at home is the preserve of a husband. This reinforced the patriarchal family system. Furthermore, this revealed the significance of gender in power relations underlying caregiving roles in Zambia.

Findings show that mothers developed a range of strategies of responding to the child's condition. They juggled between conventional medicine and traditional healers depending on their belief system. Mothers, especially those from high socioeconomic status in terms of education in Lusaka, had greater faith in the medical professionals and maintained that, this was because they understood that the child's condition was physiological in nature. However, some mothers started with conventional medicine with a view to finding a meaningful explanation regarding their child's condition but then they started losing faith. The study findings show that one of the

motivating factors for this shift was that they were assured of consistency with the traditional healer unlike at the hospital where they were seen by different medical personnel. The study has demonstrated that the mothers who believed that their child was bewitched or was cursed preferred traditional healers from the start because they wanted to know the condition of their child, what was the causer, the nature of the child's condition within a discourse of witchcraft. To some mothers they sought the intervention of the traditional healers to get some sort of revenge that could make them feel better or appeased. These findings highlighted a contradiction of belief systems between scientific and superstition. However, with time, most mothers across age, socioeconomic divide and in both research sites turned to spiritual healing by taking their child to the clergy for prayers. This appeared to have been a new form of treatment that was especially entrenched in Pentecostal churches. This was evident by the fact that all the mothers who sought the intervention of the clergy identified themselves as being members of the Pentecostal churches. There was a belief that God gave them a child with disabilities because they were special mothers who had the skills to care for and value the child. Pentecostal churches have been gaining prominence in Zambia especially since the 1990s when Zambia was declared as a Christian nation (Mwale and Chita, 2016, Nkomazana and Tabalaka, 2009).

Overall, the study has highlighted the whole range of beliefs that was shifting overtime as mothers interacted with their significant others, fellow mothers of children with disabilities and as society came to know about the child's disability. One of the significant finding about shifting discourses was that in urban Lusaka, the majority of the mothers who sought intervention of traditional healers were of low educational status. My findings also revealed that some mothers from Lusaka mentioned curse and bad omen as the cause of the child's disability, while those from Kaoma mainly spoke about witchcraft. This study suggested that this could be attributed to the commonly held cultural views and beliefs about witchcraft that are more pronounced in rural areas. One of the striking findings was that there was a

belief among some mothers in Lusaka that their child was bewitched with a view of using the child in rituals such as boosting business whilst mothers in Kaoma believed that jealous motivated people to bewitch. Mothers and their child with disabilities experienced stigma and discrimination from their significant others and from society. This resulted in mothers feeling isolated and placed on the margins of society. One significant finding was that among some first-time mothers of Lusaka was that they resorted to isolating themselves in order to deal with their child's disability.

3. *First-time mothers were disabled by proxy by the disability of their child*

The study has demonstrated that the presence of a child with disabilities in a family brought significant changes especially in the mothers' life, constituting a serious biographical disruption in terms of current and future lives. Some first-time mothers particularly those from Lusaka, in the absence of social support had to give up their jobs in order to look after their child with disabilities. Most single mothers, especially those whose child had cerebral palsy, felt that their prospects of finding employment had been greatly reduced if not extinguished because they had to spend a substantial amount of time looking after their child with disabilities. This significantly reduced their household disposable income. The accounts of single mothers of Kaoma show that they were unable to engage in farming as much as they could before they had a child with disabilities. They hardly produced enough crops for consumption nor to sell to raise money to meet the needs of the child with disabilities or their own. They experienced extreme poverty, and this transcended income poverty, although findings generally revealed that income poverty was the main manifestation of it. The study showed that first-time mothers experienced a life of frustration and

disquiet. These mothers felt their child's disability was disabling them as well, in terms of their identity. The findings show that in both research sites, single mothers experienced a biographical disruption resulting from multiple impacts of having a child with disabilities.

This research has highlighted that the impact of the child's disability increased over time forming a process that in some instances had profound implications for family relations. This often resulted in divorce especially among some first-time mothers. This thesis' findings showed that divorce contributed to mothers' biographical disruption as their social position was altered from being a married woman to a divorcee, a status that was frowned upon by society across the study sites. These mothers experienced traumatising moments. This thesis argued that divorce for most of these mothers propelled them into greater poverty. Here the impact of being a single parent on mothers' livelihood was a common thread among divorced mothers. An interesting finding was that mothers in Kaoma who had children prior to having a child with disabilities preferred to be in polygamous marriage rather than to be divorced. These mothers endured these inequitable polygamous marriages all for the sake of being seen to be married. This thesis argued that that had to do with their status and economic security. Overall, the finding on biographical disruption experienced by mothers break the ground on research on the impact of the child's disability on the mother in Zambia and also extends the knowledge on disability globally.

4. Mothers are blamed for their child' disability

Findings indicated that the Zambian society, like others, placed an unequal responsibility for raising children on mothers, and this also created an unequal sense of responsibility on mothers towards their children. This thesis revealed that across the rural-urban divide, there was a tendency to blame mothers for a child's condition. Mothers were accused of being negligent and in some instances were suspected of having been involved in

some promiscuous behaviour at the time they were pregnant and this resulted in a child having a disability. Usually this was directed at mothers of children with cerebral palsy, autism and Down's syndrome. Mother-blame had a significant impact on how mothers, especially first-time single perceived themselves. These mothers often saw themselves as negligent and developed a profound sense of guilt about their child's disability. First-time mothers especially felt that they contributed to the child's condition because they conceived when they were young. Mother-blame made some mothers feel that they fell short of meeting standards for good mothering. Findings furthermore, illuminated how mothers internalised the dominant assumptions that they were responsible for their child's disability. This self-blame was more pronounced in Lusaka among first-time mothers of children with cerebral palsy. Some felt that they were on the fringes of society, with others, particularly those who did not have social support, resorting to isolating themselves as a form of a coping strategy. This thesis highlighted that mothers, across the study sites, who had other children prior to the child with disabilities, had a better understanding of the child's condition hence none of them blamed themselves.

Far from supporting the notion that stigma and discrimination is more pronounced in rural (Mung'omba, 2008, Noyoo, 2000) than urban areas, findings of this research demonstrated that mothers across the rural-urban divide were blamed for their child's disability. This was so prevalent in the densely populated areas of Lusaka. First-time mothers especially in Lusaka experienced negative social attitudes. These findings suggested that societal negative perceptions and attitudes had ramifications on mothers, for example, they felt that because of being on the periphery of society, they could not use their skills and abilities to the fullest to realise their potential. For instance, there was a general agreement among mothers that no one could employ them because of their child's disability. Many young first-time mothers experience social isolation mainly due to losing friends and relatives, social life and position in society. This study further demonstrated that as much as Lusaka has seen a shift in trend towards more western

values, negative perception of people with conditions such cerebral palsy, Down's syndrome and autism among others, remain deep seated, leading to some mothers withdrawing from social activities.

5. *Social support is critical in the mother's ability to cope with the child's condition*

The accounts of the of the mothers demonstrated that social support was very significant to their material, physical as well as emotional wellbeing as they parent a child with disabilities. The support mothers received in parent support groups from more experienced mothers significantly ameliorated the stress associated with caregiving. One of the striking issues that emerged from the study findings was that belonging to parent support groups led to feelings of an increased sense of empowerment and personal agency. These mothers realised that they were surrounded by fellow mothers who shared similar challenges but were able to cope with their child's disability. This study demonstrated that parent support groups especially in Lusaka, were crucially important in enhancing mutuality and social cohesion among mothers who were often left on the margins of society with little or no support from their families. Findings revealed that mothers at these parent-support groups, participated in different activities such as singing and telling stories. This strengthened the bond among them and some members especially first-time mothers developed a sense of belonging that they could not find in their families nor in the public social services, and most mothers felt that this was a good coping strategy.

This research revealed that these parent support groups in Lusaka played the role of social activism and advocacy. For example, findings of this research showed that members of these groups advocated for the rights of people with disabilities and their own. These groups recognised that they needed to initiate social change in society particularly with regard to raising awareness on the plight of people with disabilities and their carers. In some instances, they sought justice on behalf of children with disabilities who

were victims of sexual abuse. They also devised a venture of helping each other financially by coming up with an informal credit union. This venture enhanced reciprocity among participants by accessing financial resources from peers. On the other hand, this study found that the parent support group in Kaoma was mainly organising farming inputs for the members. This study has demonstrated that there was limited institutional social-safety nets such as social cash transfer in the Zambia. In both research sites, mothers were not aware of the existence of social protection programmes that the Zambian government was implementing whilst those who had heard about such support did not know how to access it.

6. *There is uncertainty and uneasiness among mothers regarding their own future and that of the child with Disabilities*

These findings highlighted that owing to limited formal support from the state, parents often expected that their children would look after them in their old age. This finding underscored the importance of an obligation placed on children to look after their parents in their old age. Most mothers felt that their future was altered and this consequently affected their self-image. The research findings further showed that many first-time mothers across the research sites were worried that their child with disabilities would not have friends. Furthermore, they were worried that their child would not be able to enrol in school because no school would accept such a child. Given the fear mothers had regarding the education of their child, they were pessimistic about the independence of a child with disabilities as they made transition to adulthood. This group of mothers had generally a negative outlook for their child's future.   They saw their future and that of a child with disabilities as bleak. Interestingly, educated and experienced mothers of Lusaka were more optimistic about their child's future and their own future. They had hope that their child would get an education and enhance the child's independence. However, mothers of Kaoma complained of distance to schools and most of them had no hope that they nor their child with disabilities had a bright future. This was compounded by a lengthy

assessment process that was only done in Lusaka. The findings revealed that the assessment process took as long as two years to complete before a child could enrol in school. Many parents from Kaoma gave up because of the time and cost involved. Findings show that mothers across the study sites were doubtful that their disabled daughters especially those with cerebral palsy would ever get married because of their condition while mothers of sons with disabilities (those other forms of impairments rather than cerebral palsy and Down's syndrome) had a belief that their child would marry a fellow disabled person. Further, findings of this study demonstrated that there was a strong and persistent fear among mothers that their disabled daughters were at risk of being sexually abused by men. This fear was exacerbated by the myth in society that having sex with a virgin would cure HIV/AIDS and other sexually related diseases. This made disabled girls especially those that could not disclose, to be targets of the perpetrators.

This study also demonstrated that a strong belief in a Christian God and prayers from the clergy were some of the source of strength, resilience and hope for the mothers across the research sites. Some mothers especially among mothers whose child had other forms of conditions other than cerebral palsy, had hope that the clergy were capable of healing their disabled child through prayers. Findings show that there were variations in the form of support that mothers in the two research sites wanted from the government. The mothers of Lusaka wanted financial support in order to enable them venture in business activities while those in Kaoma were interested in support in form of farming inputs which could boost their agriculture production so they could become food secure.

9.7 Implications of Study Findings

This research was not meant to evaluate social services in Zambia that were available for people with disabilities and their carers but rather to stress the importance of how mothers access and perceive these services. This

research offered some important insights in the lives of mothers and their child with disabilities, and even though the government had made positive strides in mainstreaming disability issues in both legal and policy frameworks, critical gaps still exist as I highlighted in the introduction. The needs of carers for people with disabilities have not been incorporated into either the policy or legal documents thus far. This is a significant concern, considering the significant role they play in the lives of children with disabilities. Caring for the disabled reduces the capacity of those in the caregiving role to engage in formal employment and other income generating activities. Much as there are social protection programmes in the country, findings related to lack of awareness about how to access programmes such as social cash transfer provide a strong endorsement for the relevant authorities to raise awareness through community based organisations. This would ensure that more people are aware and it would enable a good number of eligible people benefit from this support.

There is also a need to build on initiatives such as informal credit facility started by parent-support groups in Lusaka. The government needs to come in and empower people with disabilities and their carers. For example, through the provision of capital at reduced interest rates to help them start businesses that can help them become self-reliant. It also emerged from the accounts of mothers that they experienced constraints in accessing assessment services, which were centralised in Lusaka, making it expensive and difficult for those from outside Lusaka to access the facilities. This thesis found that many parents did not finish the process, they stopped because of the long process and cost involved. It is recommended that such services should be decentralised to make it easier for parents to access them.

Based on the above, my role as a social researcher will not end at producing a thesis, I see it to be part of my responsibility to further the process. I have already had preliminary discussions with my gatekeeper organisations and they have identified a necessity for the creation of a policy briefing note and

a basic family self-help information sheet for policy makers as key desired outcomes of my study. Therefore, one component of my knowledge dissemination plan is to work with the partner organisations to identify and develop the specific products linked to my research that they will find useful. So far, I have been in touch with the programmes officer at the Department for International Development UK- Zambia office, Zambia Association for Parents of Children with Disability, Leonard Cheshire- Zambia office, Special Hope Network, Archie Hinchcliffe Disability Intervention and the Ministry of Community Development and Social Welfare in Zambia.

9.8 Contribution of the Study

My research findings make a significant contribution to the scholarship within the area of disability, gender and parenting children with disabilities. A detailed and critical evaluation of literature revealed that this was the first empirical study that focused on the experiences of mothers of children with disabilities in Zambia. The critical significance of my study, at this time, is essential. The Zambian government enacted the Persons with Disabilities Act of 2012. Part III section 14 of the law prohibits discrimination and stigmatisation of people with disabilities. It also states that parents, guardians and custodians of children with disabilities should be given information about available services, such as early education and stimulation. But to improve their circumstances we must understand what their experiences are. I have in this thesis identified and outlined their unique experiences from their own perspectives using a range of methods.

The originality of this biographical study lies in it being the first to explore the perspectives of mothers of children with disabilities in both rural and urban areas in Zambia. This research has enabled me to describe the nature of their living circumstances based on their own narratives in a unique and distinctive way. It has outlined the following experiences: their reaction to the child's diagnosis, power relations at home and societal levels and their belief systems regarding disabilities. The study has also

highlighted the impacts of the child's disability on mothers' lives, their coping strategies and future expectations.

At a theoretical level, the original contribution of this research is its use of three theoretical frameworks (social model of disability, feminist intersectionality and social empowerment model) concomitantly. Again, a critical review of literature showed that to date it was the first study that explored the living circumstances of mothers of children with disabilities using the three theoretical perspectives simultaneously. What emerged from the study was the disruption of biographies especially of first-time mothers. I saw a clear fit between the social model of disability and disruption of biographies. This thesis therefore, extended the social model of disability by incorporating the theory of biographical disruption to better understand the experiences of mothers within the sociocultural, economic and political context of Zambia.

This research also contributes to the current scholarship at both methodological and epistemological levels. My position as a male researcher exploring women's experiences of mothering a child with disabilities contrasts with research by female scholars which dominates the field. This study therefore, demonstrates that male scholars can not only develop an awareness of mothers' discrimination and stigmatisation but can also contribute to the feminist body of knowledge using appropriate theoretical and methodological approaches. These should allow for a greater focus on the perspectives of the participants while being reflective of the whole research process.

Findings of this study provided an account of the joys and challenges mothers experienced and provided a nuanced understanding of motherhood within the context of disability. One of the most striking findings in this thesis across economic and urban-rural divide was the ranking of disability. For example, severe cerebral palsy, Down's syndrome and autism were ranked as the worst forms of disabilities that had greater impact on the

carers. This was evidenced as mothers compared the condition of their disabled child to other disabled children as a means of a coping strategy. While this brought relief to some, it had impacted negatively on others. This study furthermore, extends the scholarship on societal perception and attitudes of people with disabilities. It also contributes to the field especially on the importance of the emergence of belief in spiritual healing among mothers of children with disabilities in Zambia.

Findings of this study and a review of literature show that there are things that are common across the developed and developing countries for example, women are taking the major responsibility of caregiving, seeking professional healthcare, reactions of families and impact on relationship amongst others. Much as these things were common across the developing and developed countries, they were mediated by local variations and other structural factors such as culture, religion, views about witchcraft, beliefs in God and beliefs about sources of disabilities. This thesis therefore, acts as a threshold study and makes a bi-fold scholarship contribution at national and global level.

9.9 Areas for Further Research

The study on which the thesis was based was a small scale qualitative enquiry, but it is possible to highlight a number of areas which require to be investigated further. Evidence from this research indicates that there is a tendency by men to divorce their spouses particularly when the first child is diagnosed with a disability that requires lifelong care. It is important to get the perspectives of men on what their understanding of disability is, of having a child with disabilities, and how this contributes to their separation from their partners when there is a child with disabilities in the family. The study findings revealed how young mothers were affected by divorce. In acknowledging the need for young mothers to help them overcome the impacts of divorce, further research is required to investigate the long-term impacts. In view of the findings concerning sexual abuse of children with

disabilities especially girls, further research related to the scourge would help inform policy on how such children can be protected. There is lack of basic data in Zambia about the number of children with disabilities and what kind of disabilities they have. There is need therefore to carry out a study to ascertain the exact number of children with disabilities. This information would help to improve intervention programmes.

Further research could also make use of interviewing men in order to understand their views and attitudes towards their spouses especially when they have a child with severe disabilities. Since the attitudes and views towards caregiving identified in this research were gendered there are evidently differences in the views held by both men and women, and between men of different classes. An investigation of the views and attitudes of men might show a different face of the same coin and reveal whether or not men have patriarchal consciousness. The importance of exploring men's patriarchal consciousness can help us to understand men's role in the reproduction of patriarchy, which will further help in reducing women's oppression especially those with children with disabilities.

9.10   Concluding Comments

This study presented in this thesis attempted to explore the lived experiences of mothers of children with disabilities in Zambia. This research has highlighted the critical role that mothers play and the challenges they go through in raising children with disabilities, as one participant stated in one of the interviews:

> Tandiwe [L]: we hold the key to the future generation yet we remain unsung heroes

This is a group of women whose interests need to be recognised in policy making and support services. Their lives are hidden and their experiences are hidden. They should be *sung not unsung heroes*. In summary,

circumstances of mothers were diverse as evidenced in this study. Based on the findings of this thesis, it can be said that there are a variety of viewpoints on the social construction of motherhood and what it means to these mothers to parent a child with disabilities. These ranged from views of parenting for the first-time to those who already had children prior to having a child with disabilities. Their experiences may be reflected in the way they reacted to news about the child's diagnosis. Even though these mothers were not randomly sampled, their in-depth stories still revealed and highlighted much of what it means becoming and mothering a child with disabilities.

This chapter synthesises the major findings and considers my original contribution to existing literature on disability and parenting children with disabilities both in Zambia and globally. I also present my reflections on the whole research process and how I have developed as a researcher. I discuss the limitations of my study and also highlight the areas that require further research.

Bibliography

Abbott, S. and McConkey, R., 2006. The barriers to social inclusion as perceived by people with intellectual disabilities. *Journal of Intellectual Disabilities,* 10(3), pp.275-287.

Abebe, T. and Skovdal, M., 2010. Livelihoods, care and the familial relations of orphans in eastern africa. *AIDS Care,* 22(5), pp.570-576.

Adam T.,E., 2008. A review of narratives ethics. *Qualitative inquiry,* 14(2), pp.175-194.

Adams, R., 2003. Social work and empowerment. 3rd ed. New York: Palgrave Macmillan.

Adams, R., 2008. *Empowerment, participation and social work.* Hampshire, England: Palgrave Macmillan.

Adato, M. and Bassett, L., 2009. Social protection to support vulnerable children and families: the potential of cash transfers to protect education, health and nutrition. *AIDS Care*, 21(S1), pp.60-75.

Adler, P., Adler, P., 2011. *The tender cut: inside the hidden world of self-injury.* New York: New York University Press.

Adnams, C.M., 2010. Perspectives of intellectual disability in south africa: epidemiology, policy, services for children and adults. *Current Opinion in Psychiatry*, 23(5), pp.436-440.

Albert, B., 2006, Lessons from the Disability, Knowledge and Research (KaR) Programme, Department for International Development, Overseas Development Group and Health link, London.

Aldao, A., Nolen-Hoeksema, S. and Schweizer, S., 2010. Emotion-regulation strategies across psychopathology: a meta-analytic review. *Clinical Psychology Review*, 30(2), pp.217-237.

Aldersey, H. M., 2012. Family perceptions of intellectual disability: understanding and support in Dar es Salaam: original research. *African Journal of Disability,* 1(1), pp. 1-12.

Aldersey, H., Turnbull, A. and Turnbull, R., 2014. Factors contributing to the construction of personhood of individuals with intellectual and developmental disabilities in Kinshasa, Democratic Republic of the Congo. *Canadian Journal of Disability Studies*, 3(2), pp.31-61.

Aldersey, H.M., Turnbull, A.P. and Turnbull, H.R., 2016. Family support in Kinshasa, democratic Republic of the Congo. *Journal of Policy and Practice in Intellectual Disabilities*, 13(1), pp.23-32.

Alheit, P. and Dausien, B., 2007. Lifelong learning and biography: a competitive dynamic between the macro-and the micro level of education. In: L. West, P. Alheit, A. S. Andersen, and B. Merrill, eds.

2007. *Using Biographical and Life History Approaches in the Study of Adult and Lifelong Learning: European Perspectives.* Frankfurt am Main: Peter Lang, pp.57-70.

Alheit, P., 2009. Biographical learning–within the new lifelong learning discourse. In K. Illeris, ed. 2009. *Contemporary Theories of Learning.* London and New York: Routledge. Ch.8.

Aliyu, A. A., Bello, M.U., Kassim, R. and Martin, D., 2014. Positivist and Non-Positivist Paradigm in Social Science Research: Conflicting Paradigms Or Perfect Partners? *Journal of Management and Sustainability*, 4(3), pp.79-95.

Alkass, S., Mazerolle, M., and Harris, F., 1998. Rigour in research and peer-review: a reply. *Construction Management and Economics,* 16(2), pp.139-140.

Amoyaw, J.A., Kuuire, V.Z., Boateng, G.O., Asare-Bediako, Y. and Ung, M., 2015. Conundrum of Sexual Decision Making in Marital Relationships: Safer-Sex Knowledge, Behavior, and Attitudes of Married Women in Zambia. *The Journal of Sex Research*, 52(8), pp.868-877.

Ankeny, E. M., Wilkins, J., and Spain, J., 2009. Mothers' experiences of transition planning for their children with disabilities. *Teaching Exceptional Children,* 41(6), pp.28-36.

Annells, M., 1996. Grounded theory method: philosophical perspectives, paradigm of inquiry, and postmodernism. *Qualitative Health Research,* 6(3), pp.379-393.

Arendell, T., 2000. Conceiving and investigating motherhood: the decade's scholarship. *Journal of Marriage and Family,* 62(4), pp.1192-1207.

Arrow, M., 2016. 'Everyone needs a holiday from work, why not mothers?' Motherhood, feminism and citizenship at the Australian royal commission on human relationships, 1974–1977. *Women's History Review*, 25(2), pp.320-336.

Aterido, R., Beck, T. and Iacovone, L., 2013. Access to finance in Sub-saharan Africa: is there a gender gap? *World Development*, 47, pp.102-120.

Audet, C.M., Hamilton, E., Hughart, L. and Salato, J., 2015. Engagement of traditional healers and birth attendants as a controversial proposal to extend the HIV health workforce. *Current HIV/AIDS Reports*, 12(2), pp.238-245.

Aunos, M., M. Feldman and G. Goupil., 2008. Mothering with Intellectual Disabilities: Relationship Between Social Support, Health and Well-Being, Parenting and Child Behaviour Outcomes. *Journal of Applied Research in Intellectual Disabilities,* 21(4), pp.320-330.

Avdi, E., Griffin, C., and Brough, S., 2000. Parents' constructions of professional knowledge, expertise and authority during assessment and diagnosis of their child for an autistic spectrum disorder. *British Journal of Medical Psychology,* 73(3), pp.327-338.

Azar, M., and Badr, L. K., 2010. Predictors of coping in parents of children with an intellectual disability: comparison between lebanese mothers and fathers. *Journal of Pediatric Nursing,* 25(1), pp.46-56.

Baird, G., Mcconachie H., and Scrutton, D., 2000. Parents' perceptions of disclosure of the diagnosis of cerebral palsy. *Archives of Disease in Childhood*, 83(6), pp.475-480.

Baker, C., Wuest, J., and Stern, P. N., 1992. Method Slurring: the grounded theory/phenomenology example. *Journal of Advanced Nursing,* 17(11), pp.1355-1360.

Baldez, L., 2006. The pros and cons of gender quota laws: what happens when you kick men out and let women in? *Politics and Gender,* 2(1), pp.102-109.

Banda, F., 2006. Blazing a trail: the african protocol on women's rights comes into force. *Journal of African Law,* 50(01), 72-84.

Banda, J., Chuulu, M., Kashoki, M, Chanda, A, W., Malila, M., Zulu, C, L., Chomba, M., F. and Kamuwanga, B., M. 2003. Report on the Review of the Local Courts System. Lusaka: Zambia Law Development Commission.

Banda-Chalwe, M., J. C. Nitz and D. de Jonge., 2012. Globalising accessibility: drawing on the experiences of developed countries to enable the participation of disabled people in Zambia. *Disability & Society,* 27(7), pp.917-934.

Barabasch, A. and Merrill, B., 2014. Cross-cultural approaches to biographical interviews: looking at career transitions and lifelong learning. *Research in Comparative and International Education,* 9(3), pp.287-300.

Barak-Levy, Y., and Atzaba-Poria N. A., 2013. Paternal versus maternal coping styles with child diagnosis of developmental delay. *Research in Developmental Disabilities*, 34(6) pp.2040-2046.

Barker, E.T., Hartley, S.L., Seltzer, M.M., Floyd, F.J., Greenberg, J.S. and Orsmond, G.I., 2011. Trajectories of emotional well-being in mothers of adolescents and adults with autism. *Developmental Psychology, 47*(2), pp.551-561.

Barnes, C. and Mercer, G., 2005. Understanding impairment and disability: towards an international perspective*. The social model of disability: Europe and The Majority World*, pp.1-16.

Barnes, C. and Mercer, G., 2010. *Exploring Disability*. Cambridge: Polity Press.

Barnes, C., Oliver, M., and Barton, L. 2002. *Disability Studies Today,* Cambridge, Blackwell.

Bates, R. H. and Collier, P., 1995. The Politics and economics of policy reform in Zambia. *Journal of African Economies,* 4(1), pp.115-143.

Baylies, C. and Szeftel, M., 1992. The fall and rise of multi-party politics in Zambia. *Review of African Political Economy*, 19(54), pp.75-91.

Beadle-Brown, J., Bigby, C. and Bould, E., 2015. Observing practice leadership in intellectual and developmental disability services. *Journal of Intellectual Disability Research,* 59(12), pp.1081-1093.

Beadle-Brown, J., Leigh, J., Whelton, B., Richardson, L., Beecham, J., Baumker, T. and Bradshaw, J., 2016. Quality of life and quality of support for people with severe intellectual disability and complex needs. *Journal of Applied Research in Intellectual Disabilities*, *29*(5), pp.409-421.

Becker, J., Kovach, A. C. and Gronseth, D. L., 2004. Individual empowerment: how community health workers operationalize self-determination, self-sufficiency, and decision-making abilities of low-income mothers. *Journal of Community Psychology*, 32(3), pp.327-342.

Beckman, L.J., 2014. Training in feminist research methodology: Doing research on the margins. *Women & Therapy*, 37(1-2), pp.164-177.

Bengry-Howell, A. and Griffin, C., 2012. Negotiating access in ethnographic research with 'hard to reach'young people: Establishing common ground or a process of methodological grooming? *International Journal of Social Research Methodology,* 15(5), pp.403-416.

Benschop, M., 2004. *Women's rights to land and property.*[pdf] Contribution from UN-HABITAT to the Commission on Sustainable Development. Available at:<https://www.un.org/ruleoflaw/files/1556_72513_CSD Women.pdf> [Accessed 9 June 2014].

Benson, P.R. and Karlof, K.L., 2009. Anger, stress proliferation, and depressed mood among parents of children with ASD: A longitudinal replication. *Journal Of Autism And Developmental Disorders,* 39(2), pp.350-362.

Berger, R., 2015. Now I see it, now I don't: Researcher's position and reflexivity in qualitative research. *Qualitative Research* 15(2), pp.219-234.

Bergold, J. and Thomas, S., 2012. Participatory research methods: A methodological approach in motion. *Historical Social Research/Historische Sozialforschung,* 37(4), pp.191-222.

Beyer, S. and A. Kaehne., 2008. The transition of young people with learning disabilities to employment: What works? *Journal on Developmental Disabilities,* 14(1), pp.81-90.

Bhattacharjya, M., Birchall, J., Caro, P., Kelleher, D. and Sahasranaman, V., 2013. Why gender matters in activism: Feminism and social justice movements. *Gender and Development*, 21(2), pp.277-293.

Bickenbach, J.E., Chatterji, S., Badley, E.M. and Üstün, T.B., 1999. Models of disablement, universalism and the international classification of impairments, disabilities and handicaps. *Social science & medicine*, *48*(9), pp.1173-1187.

Bigby, C. and Wiesel, I., 2011. Encounter as a dimension of social inclusion for people with intellectual disability: Beyond and between community presence and participation. *Journal of Intellectual and Developmental Disability*, 36(4), pp.263-267.

Bigsten, A. and Kayizzi-Mugerwa, S., 2005. 15 The Political Economy of Policy Failure in Zambia. In: M.Lundahl and M.L.Wyzan, eds. 2005. *The Political Economy of Reform Failure*, Oxon: Routledge. Ch.15.

Birks, M. and Mills, J., 2011. *Grounded Theory : A Practical Guide.* London: SAGE.

Blackburn, C. M., Spencer, N. J. and Read, J. M., 2010. Prevalence of childhood disability and the characteristics and circumstances of disabled children in the UK: secondary analysis of the family resources survey. *BMC Pediatrics,* 10(1), pp.10-21.

Block, S. A., 2002. Political business cycles, democratization, and economic reform: The case of Africa. *Journal of Development Economics,* 67(1), pp.205-228.

Blum, L. M., 2007. Mother-blame in the prozac nation raising kids with invisible disabilities. *Gender and Society*, 21(2), pp.202-226.

Blum, L. M., 2015. *Raising generation rx: mothering kids with invisible disabilities in an age of inequality*. New York: New York University Press.

Bornstein, M. H. and Putnick, D. L., 2012. Cognitive and socioemotional caregiving in developing countries. *Child Development*, 83(1), pp.46-61.

Bourke-Taylor, H., Howie, L. and Law, M., 2010. impact of caring for a school-aged child with a disability: Understanding mothers' perspectives. *Australian Occupational Therapy Journal,* 57(2), pp.127-136.

Boyer, K. and Spinney, J., 2016. Motherhood, mobility and materiality: material entanglements, journey-making and the process of 'becoming

mother'. *Environment and Planning D: Society and Space*, 34(6), pp.1113-1131.

Braddock, D.L. and Parish, S.L., 2001. History of Disability. *Handbook of disability studies*, p.11.

Broach, S., Clements, L. and Read, J., 2016. *Disabled children: a legal handbook*. Legal Action Group.

Bromley, J., Hare, D.J., Davison, K. and Emerson, E., 2004. Mothers supporting children with autistic spectrum disorders: Social support, mental health status and satisfaction with services. *Autism*, 8(4), pp.409-423.

Brown, I. and Schormans, A. F., 2014. Quality of life, children with intellectual and developmental disabilities, and maltreatment. *International Public Health Journal*, 6(2), pp.185-197.

Brown, I., Hatton, C. and Emerson, E., 2013. Quality of life indicators for individuals with intellectual disabilities: Extending current practice. *Intellectual and Developmental Disabilities*, 51(5), pp.316-332.

Brugar, K., 2013. Power of one: Using biographies to investigate an individual's impact on the past and present. *The Ohio Social Studies Review*, 50(2), 8-14.

Bryman, A., 2004. *Social Research Methods*. 2nd ed. Oxford ; New York: Oxford University Press.

Bryman, A., 2012 *Social research methods.* 4th ed. Oxford: Oxford University Press.

Budd, J.L., Draper, E.S., Lotto, R.R., Berry, L.E. and Smith, L.K., 2015. Socioeconomic inequalities in pregnancy outcome associated with Down syndrome: a population-based study. *Archives of Disease in Childhood-Fetal and Neonatal Edition*, *100*(5), pp.F400-F404.

Burns, R. B., 2000. *Introduction to research methods*. 4th ed. London: SAGE.

Bury, M., 1982. Chronic Illness as biographical disruption. *Sociology of Health and Illness*, 4(2), pp.167-182.

Bury, M., 2000. On chronic illness and disability. *Handbook of medical sociology*, *5*, pp.173-183.

Bury, M., 2001. Illness narratives: Fact or fiction?. *Sociology of Health and Illness, 23*(3), pp.263-285.

Cambridge, P. and Ernst, A., 2006. Comparing local and national service systems in social care europe: framework and findings from the steps

anti-discrimination learning disability project. *European Journal of Social Work*, 9(3), pp.279-303.

Campbell, C., Nair, Y., Maimane, S. and Sibiya, Z., 2008. Supporting people with AIDS and their carers in rural South Africa: possibilities and challenges. *Health and Place*, *14*(3), pp.507-518.

Caplan, P., 2013. Don't blame mother: then and now. *Gender and Women's Studies in Canada: Critical Terrain*, pp.99-106.

Carbado, D.W., Crenshaw, K.W., Mays, V.M. and Tomlinson, B., 2013. Intersectionality. *Du Bois Review: Social Science Research on Race*, 10(2), pp.303-312.

Carbin, M. and Edenheim, S., 2013. The intersectional turn in feminist theory: A dream of a common language? *European Journal of Women's Studies*, 20(3), pp.233-248.

Carey, M., 2012. *Qualitative research skills for social work theory and practice*. England: Ashgate Publishing Limited.

Cargo, M. and Mercer, S. L., 2008. The value and challenges of participatory research: strengthening its practice. *Annual Review Public Health,* 29, pp.325-350.

Carlile, P. R., 2004. Transferring, translating, and transforming: an integrative framework for managing knowledge across boundaries. *Organization Science*, 15(5), pp.555-568.

Carricaburu, D. and Pierret, J., 1995. From biographical disruption to biographical reinforcement: the case of HIV-Positive men. *Sociology of Health and Illness*, 17(1), pp.65-88.

Cayless, S., Forbat, L., Illingworth, N., Hubbard, G. and Kearney, N., 2010. Men with prostate cancer over the first year of illness: their experiences as biographical disruption. *Supportive Care in Cancer*, 18(1), pp.11-20.

Cederberg, M., 2014. Public discourses and migrant stories of integration and inequality: Language and power in biographical narratives. *Sociology*, 48(1), pp.133-149.

Chamberlayne, P., Bornat, J. and Wengraf, T. eds., 2000. *The Turn to Biographical Methods in Social Science: Comparative Issues and Examples*. London: Routledge.

Chang, M. Y. and Hsu, L. L., 2007. The perceptions of taiwanese families who have children with learning disability. *Journal of Clinical Nursing*, 16(12), pp.2349-2356.

Chang, R. S. and Culp Jr, J. M., 2002. After intersectionality. *UMKC Law Review,* 71(2), pp.485-491.

Chapman, C., 2011. Resonance, intersectionality, and reflexivity in critical pedagogy (and Research Methodology). *Social Work Education*, 30(7), pp.723-744.

Charmaz, K and Bryant, A., 2011. Grounded Theory and Credibility. In Siolverman and D (editors) Qualitative Research. 3rd ed. London: SAGE.

Charmaz, K., 2006. *Constructing grounded theory : A practical guide through qualitative analysis*. London: SAGE Publications.

Charmaz, K., 2008. Constructionism and the grounded theory method. Handbook of constructionist research 397-412.

Charmaz, K., Bryant, A. and Silverman, D., 2011. Grounded theory and credibility. *Qualitative Research,* 3, pp.291-309.

Chatrakul Na Ayudhya, U., Smithson, J. and Lewis, S., 2014. Focus group methodology in a life course approach–individual accounts within a peer cohort group. *International Journal of Social Research Methodology*, 17(2), pp.157-171.

Chavira, V., López, S.R., Blacher, J. and Shapiro, J., 2000. Latina mothers' attributions, emotions, and reactions to the problem behaviors of their children with developmental disabilities. *Journal of Child Psychology and Psychiatry*, *41*(2), pp.245-252.

Cheru, F., 2002. Debt, adjustment and the politics of effective response to HIV/AIDS in Africa. *Third World Quarterly*, 23(2), pp.299-312.

Chinsembu, K., 2016. Ethnobotanical study of medicinal flora utilised by traditional healers in the management of sexually transmitted infections in Sesheke District, Western Province, Zambia. *Revista Brasileira de Farmacognosia,* 26(2), pp.268-274.

Chiovitti, R. F. and Piran, N., 2003. Rigour and grounded theory research. *Journal of Advanced Nursing*, 44(4), pp.427-435.

Chirwa, M., 2011. Inclusive Education: A Study of Opportunities and Challenges. Saarbrucken: Lambert Academic Publishing.

Chirwa, M., 2016. Perspectives of parenting children with intellectual disabilities: experiences of mothers in Zambia. *Journal of Intellectual Disability Research*, 60(7), pp.648.

Cho, S., Crenshaw, K. W., and Mccall, L., 2013. Toward a field of intersectionality studies: theory, applications, and praxis. *Signs,* 38(4), pp.785-810.

Choo, H.Y. and Ferree, M.M., 2010. Practicing intersectionality in sociological research: A critical analysis of inclusions, interactions, and

institutions in the study of inequalities. *Sociological theory*, *28*(2), pp.129-149.

Cobigo, V., Ouellette-Kuntz, H., Lysaght, R. and Martin, L., 2012. Shifting our conceptualization of social inclusion. *Stigma Research and Action*, 2(2), pp.75-84.

Cohen, L., Manion, L. and Morrison, K. (2011) *Research methods in education.* 7th edition. New York: Routledge.

Cohen, L., Manion, L. and Morrison, K., 2007. *Research Methods in Education.* London: Routledge.

Cole, B. A., 2009. Gender, narratives and intersectionality: can personal experience approaches to research contribute to "undoing gender"? *International Review of Education*, 55(5-6), pp.561-578.

Connors, C. and Stalker, K., 2007. Children's experiences of disability: pointers to a social model of childhood disability. *Disability and Society*, 22(1), pp.19-33.

Corbally, M., 2015. Accounting for intimate partner violence: a biographical analysis of narrative strategies used by men experiencing IPV from their female partners. *Journal of Interpersonal Violence*, 30(17), pp.3112-3132.

Couch, K. A., Tamborini, C. R., and Reznik, G. L., 2015. The long-term health implications of marital disruption: Divorce, work limits, and social security disability benefits among men. *Demography*, 52(5), pp.1487-1512.

Cowdery, R. S. and Knudson-Martin, C., 2005. The construction of motherhood: Tasks, relational connection, and gender equality*. *Family Relations*, 54(3), pp.335-345.

Craig, G. and Mayo, M., 1995. *Community empowerment: a reader in participation and development.* London: Zed Books.

Craig, J., 2001. Putting privatisation into practice: the case of Zambia Consolidated Copper Mines Limited. *The Journal of Modern African Studies*, 39(3), pp.389-410.

Cramer, E.P. and Plummer, S.B., 2009. People of color with disabilities: Intersectionality as a framework for analyzing intimate partner violence in social, historical, and political contexts. *Journal of Aggression, Maltreatment and Trauma*, *18*(2), pp.162-181.

Crenshaw, K. 1991. Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Colour. *Stanford Law Review***,** 1241-1299.

Crenshaw, K., 1989. Demarginalizing the intersection of race and sex: A black feminist critique of antidiscrimination doctrine, feminist theory and antiracist politics.The *University of Chicago Legal Forum,* pp.139-167.

Creswell, J. W., 2007. *Qualitative inquiry and research design : Choosing among five approaches.* 2nd ed. London: SAGE Publications.

Creswell, J. W., 2013. *Qualitative inquiry and research design : Choosing among five approaches.* 3rd ed. Los Angeles: SAGE Publications.

Crotty, M., 1998. *The Foundations of Social Research : Meaning and Perspective in The Research Process.* London: SAGE.

CSO, 2007. *Zambia demographic and health survey.* Lusaka: Central Statistical Office Publication.

CSO, 2011. Selected social economic indicators 2010. Lusaka: Central Statistical Office Publication.

CSO, 2012a. *Living conditions monitoring survey report 2006-2010.* Lusaka: Central Statistical Office Publication.

CSO, 2012b. *Zambia 2010 Census of population and housing: population summary Report.* Lusaka: Central Statistical Office Publication.

CSO, 2012c. *Zambia 2010 Census of population and housing: national analytical report.* Lusaka: Central Statistical Office Publication.

CSO. 2010. Selected Social Economic Indicators 2010. Lusaka: Central Statistical Office Publication.

Cuomo, D. and Massaro, V. A., 2016. Boundary-making in feminist research: new methodologies for 'intimate insiders'. *Gender, Place and Culture*, 23(1), pp.94-106.

Dabrowska, A. and Pisula, E., 2010. Parenting stress and coping styles in mothers and fathers of pre-school children with autism and down syndrome. *Journal of Intellectual Disability Research,* 54(3), pp.266-280.

Dale, E., Jahoda, A. and Knott, F., 2006. Mothers' attributions following their child's diagnosis of autistic spectrum disorder: exploring links with maternal levels of stress, depression and expectations about their child's future. *Autism*, 10(5), pp.463-479.

Danseco, E. R., 1997. Parental beliefs on childhood disability: insights on culture, child development and intervention. *International Journal of Disability, Development and Education*, 44(1), pp.41-52.

Danso, A.K., Owusu-Ansah, F.E. & Alorwu, D., 2012, 'Designed to deter: Barriers to facilities at second cycle institutions in Ghana', African Journal of Disability 1(1) n.p

Dardas, L. A. and Ahmad, M. M. , 2015. For fathers raising children with autism, do coping strategies mediate or moderate the relationship between parenting stress and quality of life? *Research in Developmental Disabilities*, 36, pp.620-629.

Datta K., 2011. 'In the eyes of a child, a father is everything': changing constructions of fatherhood in urban Botswana. *Women's Studies International Forum,* 30 (2), pp.91-113.

Dave, D., et al., 2017. Study of anxiety and depression in caregivers of intellectually disabled children. *Journal of Research in Medical and Dental Science*, 2(1), pp.8-13.

Davis K. and Gavidia-Payne S., 2009. The impact of child, family, and professional support characteristics on the quality of life in families of young children with disabilities. *Journal of Intellectual and Developmental Disability,* 34, pp.153–162.

Davis, K., 2008. Intersectionality as buzzword: a sociology of science perspective on what makes a feminist theory successful. *Feminist Theory*, 9(1), pp.67-85.

Day, C. and Evans, R., 2015. Caring responsibilities, change and transitions in young people's family lives in Zambia. *Journal of Comparative Family Studies*, XLVI(1), pp.137-152.

De Vogli, R. and Birbeck, G.L., 2005. Potential impact of adjustment policies on vulnerability of women and children to HIV/AIDS in sub-Saharan Africa. *Journal of Health, Population and Nutrition*, pp.105-120.

Delius, P. and Glaser, C., 2004. The myths of polygamy: a history of extra-marital and multi-partnership sex in south africa. *South African Historical Journal*, 50(1), pp.84-114.

Denzin, N. K. and Lincoln, Y. S., 2008. *Strategies of qualitative inquiry*. 3rd ed. Los Angeles: SAGE Publications.

Denzin, N. K., 1989. *Interpretive Biography*. Newbury Park ; London: SAGE.

Deshingkor, R. and Farrington, J., 2009. *Circular migration and multilocational livelihood strategies in rural India.* New Dehli: Oxford University Press.

Dickson-Swift, V., James, E. L. and Liamputtong, P., 2008. What is sensitive research. *Undertaking Sensitive Research in The Health and Social Sciences: Managing Boundaries, Emotions and Risks*, 1, pp.1-10.

Dickson-Swift, V., James, E.L., Kippen, S. and Liamputtong, P., 2009. Researching sensitive topics: qualitative research as emotion work. *Qualitative Research*, 9(1), pp.61-79.

Dickson-Swift, V., James, E.L., Kippen, S. and Liamputtong, P., 2007. Doing sensitive research: what challenges do qualitative researchers face? *Qualitative research*, *7*(3), pp.327-353.

Dolan, A., 2007. 'Good luck to them if they can get it': exploring working class men's understandings and experiences of income inequality and material standards. *Sociology of Health and Illness*, 29(5), pp.711-729.

Domma, F. and Giordano, S., 2012. A stress–strength model with dependent variables to measure household financial fragility. *Statistical Methods and Applications,* 21(3), pp.375-389.

Dowling, M. and Dolan, L., 2001. Families with children with disabilities-inequalities and the social model. *Disability and Society*, 16(1), pp.21-35.

Downey, B., 2015. The looking glass self and deliberation bias in qualitative interviews. *Sociological Spectrum*, 35(6), pp.534-551.

Dubois, B. and Miley, K. K., 2014. *Social work : an empowering profession*. 8th ed. London: Pearson.

Dumont, M. and Provost, M. A., 1999. Resilience in adolescents: protective role of social support, coping strategies, self-esteem, and social activities on experience of stress and depression. *Journal of Youth and Adolescence*, 28(3), pp.343-363.

Duncombe, J. and Jessop, J., 2002. *'Doing Rapport' and The Ethics of 'faking Friendship'*. London: SAGE.

Durà-Vilà, G., Dein, S. and Hodes, M., 2010. Children with intellectual disability: a gain not a loss: parental beliefs and family life. *Clinical Child Psychology and Psychiatry*, 15(2), pp.171-184.

Dykens, E.M., Fisher, M.H., Taylor, J.L., Lambert, W. and Miodrag, N., 2014. Reducing distress in mothers of children with autism and other disabilities: a randomized trial. *Pediatrics*, 134(2), pp.e454-e463.

Edwardraj, S., MumtaJ, K., Prasad, J., Kuruvilla, A. and Jacob, K. 2010. Perceptions about Intellectual Disability: A Qualitative Study from Vellore, South India. *Journal of Intellectual Disability Research,* 54**,** 736-748.

EFZ, 2009. *The Voice of The Church on Gender Matters in Zambia*. Lusaka: Evangelical Fellowship of *Zambia*.

Ellis, F., 2012. 'We are all poor here': economic difference, social divisiveness and targeting cash transfers in Sub-Saharan Africa. *Journal of Development Studies,* 48(2), pp.201-214.

Ely, R. and Padavic, I., 2007. A feminist analysis of organizational research on sex differences. *Academy of Management Review*, 32(4), pp.1121-1143.

Emden, C. and Sandelowski, M., 1998. The good, the bad and the relative, part one: conceptions of goodness in qualitative research. *International Journal of Nursing Practice*, 4(4), pp.206-212.

Emerson, E., 2003. Mothers of children and adolescents with intellectual disability: social and economic situation, mental health status, and the self-assessed social and psychological impact of the child's difficulties. *Journal of intellectual Disability Research*, 47(4-5), pp.385-399.

Emerson, E., 2007. Poverty and people with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews,* 13(2), pp.107-11

Emerson, E., Graham, H., McCulloch, A., Blacher, J., Hatton, C. and Llewellyn, G., 2009. The social context of parenting 3-year-old children with developmental delay in the UK. *Child: care, health and development*, *35*(1), pp.63-70.

Emerson, E., Hatton, C., Llewellyn, G., Blacker, J. and Graham, H., 2006. Socio-economic position, household composition, health status and indicators of the well-being of mothers of children with and without intellectual disabilities. *Journal of Intellectual Disability Research*, *50*(12), pp.862-873.

Emmett, T., 2006. Disability, poverty, gender and race. *Disability and social change: a South African Agenda,* pp.207-233.

Enosh, G. and Ben-Ari, A., 2016. Reflexivity: the creation of liminal spaces—researchers, participants, and research encounters. *Qualitative Health Research*, 26(4), pp.578-584.

Ensor, T., Quigley, P., Green, C., Razak Badru, A., Kaluba, D. and Siziya, S., 2013. Knowledgeable antenatal care as a pathway to skilled delivery: modelling the interactions between use of services and knowledge in Zambia. *Health Policy and Planning*, 29(5), pp.580-588.

Erevelles, N. and Minear, A., 2010. Unspeakable offenses: untangling race and disability in discourses of intersectionality. *Journal of Literary and Cultural Disability Studies,* 4(2), pp.127-145.

Esposito, N., 2001. From meaning to meaning: the influence of translation techniques on non-english focus group research. *Qualitative Health Research*, 11(4),pp. 568-579.

Estes, A., Munson, J., Dawson, G., Koehler, E., Zhou, X.H. and Abbott, R., 2009. Parenting stress and psychological functioning among mothers

of preschool children with autism and developmental delay. *Autism*, 13(4), pp.375-387.

Esu-Williams, E., Schenk, K.D., Geibel, S., Motsepe, J., Zulu, A., Bweupe, P. and Weiss, E., 2006. 'We are no longer called club members but caregivers': Involving youth in HIV and AIDS caregiving in rural Zambia. *AIDS care*, *18*(8), pp.888-894.

Etikan, I., Musa, S. A. and Alkassim, R. S., 2016. Comparison of convenience sampling and purposive sampling. *American Journal of Theoretical and Applied Statistics,* 5(1), pp.1-4.

Evans, A., 2014. 'Women can do what men can do': the causes and consequences of growing flexibility in gender divisions of labour in Kitwe, Zambia. *Journal of Southern African Studies*, 40(5), pp.981-998.

Evans, R., 2010. children's caring roles and responsibilities within the family in Africa. *Geography Compass*, 4(10), pp.1477-1496.

Feher-Prout, T., 1996. Stress and coping in families with deaf children. *Journal of Deaf Studies and Deaf Education*, 1(3), pp.155-166.

Feniger-Schaal, R. and Oppenheim, D., 2013. Resolution of the diagnosis and maternal sensitivity among mothers of children with intellectual disability. *Research in Developmental Disabilities*, 34(1), pp.306-313.

Ferguson, P. M., 2002. A place in the family an historical interpretation of research on parental reactions to having a child with a disability. *The Journal of Special Education*, 36(3), pp.124-131.

Fillis, I., 2006. A biographical approach to researching entrepreneurship in the smaller firm. *Management Decision*, 44(2), pp.198-212.

Findlay, A.M. and Stockdale, A., 2016, February. The temporal and social embeddedness of migration: a methodological exploration using biographical analysis. *Geography Research Forum*, 23, pp.4-29.

Finkelstein, V., 1981. Disability and the helper/helped relationship: a historical view. In: A. Brechin, Liddiard, P. and Swain, J. eds. 1981. *Handicap in A Social World.* London: Hodder and Stoughton.

Finkelstein, V., 2001. The social model of disability repossessed. *Manchester Coalition of Disabled People*, 1, pp.1-5.

Fraser, E. D., Dougill, A. J., Mabee, W. E., Reed, M. and McAlpine, P. 2006. Bottom up and top down: analysis of participatory processes for sustainability indicator identification as a pathway to community empowerment and sustainable environmental management. *Journal of Environmental Management,* 78**,** pp.114-127.

Freedman, B. H., Kalb, L. G., Zablotsky, B. and Stuart, E. A. 2012.

Relationship status among parents of children with autism spectrum disorders: a population-based study. *Journal of Autism and Developmental Disorders,* 42**,** 539-548.

Freeland, N., 2007. Superfluous, pernicious, atrocious and abominable? The case against conditional cash transfers. *Institute of Development Studies Bulletin*, 38(3), pp.75-78.

Friedman, M., 2015. Mother blame, fat shame, and moral panic:"obesity" and child welfare. *Fat Studies,* 4(1), pp.14-27.

Friedmann, J. 1992. *Empowerment: the politics of alternative development*, Cambridge: Blackwell.

Gabel, S. and Peters, S., 2004. Presage of a paradigm shift? Beyond the social model of disability toward resistance theories of disability. *Disability and Society*, 19(6), pp.585-600.

Garland-Thomson, R., 2002. Integrating disability, transforming feminist theory. *National Woman Suffrage Association Journal*, 14(3), pp.1-32.

Geere, J., Gona, J., Omondi, F., Kifalu, M., Newton, C. and Hartley, S. 2013. Caring for children with physical disability in Kenya: potential links between caregiving and carers' physical health. *Child: Care, Health and Development,* 39**,** 381-392.

Gentles, S.J., Jack, S.M., Nicholas, D.B. and McKibbon, K., 2014. Critical approach to reflexivity in grounded theory. *The Qualitative Report*, 19(44), pp.1-14.

Geok, C. K., Abdullah K. L. and Kee, L. H., 2013. Quality of life among Malaysian mothers with a child with down syndrome. *International Journal of Nursing Practice*, 19(4), pp. 381-389.

Gewald, J.B., Hinfelaar, M. and Macola, G. eds., 2008. One Zambia, many histories: towards a history of post-colonial Zambia. Leiden: IDC Publishers.

Giddens, A. and Sutton, P. W., 2013. *Sociology*. 7th ed. Cambridge: Polity Press.

Giddens, A., 1991. Modernity and self-identity: self and society in the late modern age. Cambridge: Polity Press.

Gill, M.J., 2014. The Possibilities of Phenomenology for Organizational Research, *Organizational Research Methods*, 17(2), pp.118-137.

Gillborn, D., 2015. Intersectionality, critical race theory, and the primacy of racism: race, class, gender, and disability in education. *Qualitative Inquiry,* 21(3), pp.277-287.

Gimbel, E. W., 2016. Interpretation and objectivity: a gadamerian reevaluation of max weber's social science. *Political Research Quarterly*, 69(1), pp. 72-82.

Glaser, B. and Strauss, A., 1967. Grounded theory: The discovery of grounded theory. *Sociology the Journal of The British Sociological Association*, *12*, pp.27-49.

Glenn, E. N., Chang, G. and Forcey, L. R., 1994. *Mothering : ideology, experience and agency*. London: Routledge.

Goddard, J. A., Lehr, R., and Lapadat, J. C., 2000. Parents of children with disabilities: telling a different story. *Canadian Journal of Counselling*, 34(4), pp.273-289.

Goethals, T., De Schauwer, E. and Van Hove, G., 2015. Weaving intersectionality into disability studies research: inclusion, reflexivity and anti-essentialism. *European Congress of Qualitative Inquiry Proceedings 2017*, pp.228-243

Gona, J.K., Mung'ala-Odera, V., Newton, C.R. and Hartley, S., 2011. Caring for children with disabilities in Kilifi, Kenya: what is the carer's experience?. *Child: Care, Health And Development*, *37*(2), pp.175-183.

Gona, J.K., Newton, C.R., Rimba, K., Mapenzi, R., Kihara, M., Van De Vijver, F.J. and Abu bakar, A., 2015. Parents' and professionals' perceptions on causes and treatment options for Autism Spectrum Disorders (ASD) in a multicultural context on the Kenyan Coast. *PloS one*, 10(8), pp.1-13

Gona, J.K., Xiong, T., Muhit, M.A., Newton, C.R. and Hartley, S., 2010. Identification of people with disabilities using participatory rural appraisal and key informants: a pragmatic approach with action potential promoting validity and low cost. *Disability and Rehabilitation*, *32*(1), pp.79-85.

Gooding, K. and Marriot, A., 2009. Including persons with disabilities in social cash transfer programmes in developing countries. *Journal of International Development*, 21(5), pp.685-698.

Goodley, D. and Runswick C. K., 2015. Critical psychologies of disability: boundaries, borders and bodies in the lives of disabled children. *Emotional and Behavioural Difficulties*, 20(1), pp.51-63.

Goodley, D., 2000. *Self-advocacy in the lives of people with learning difficulties : the politics of resilience*. Buckingham: Open University Press.

Goodley, D., 2001. 'Learning difficulties', the social model of disability and impairment: challenging epistemologies. *Disability and Society*, 16(2), pp.207-231.

Goodley, D., 2004. *Researching life stories : method, theory, and analyses in a biographical age*. London: Routledgefalmer.

Goodley, D., 2017. Dis/Entangling critical disability studies. In: A. Waldschimidt, H. Berressem, M. Ingwersen. eds. 2017. *Culture-theory-disability: encounters between disability studies and cultural studies*. German: Transcript Publisher. pp.81-97.

Goodley, D., Armstrong, D., Sutherland, K. and Laurie, L., 2003. Self-advocacy, "learning difficulties," and the social model of disability. *Mental Retardation*, 41(3), pp.149-160.

Goodson, I., Loveless, A. and Stephens, D. eds. 2012. *Explorations in narrative research*. Rotterdam: Sense Publishers.

Gopaldas, A., 2013. Intersectionality 101. *Journal of Public Policy and Marketing,* 32(Special Issue), pp.90-94.

Goulding, C., 2005. Grounded theory, ethnography and phenomenology: a comparative analysis of three qualitative strategies for marketing research. *European Journal of Marketing*, 39(3/4), pp.294-308.

Grant, S., et al., 2013. Parental social support, coping strategies, resilience factors, stress, anxiety and depression levels in parents of children with MPS III (Sanfilippo Syndrome) Or Children with Intellectual Disabilities (ID). *Journal of Inherited Metabolic Disease*, 36(2), pp.281-291.

Graungaard, A. H. and Skov, L., 2007. Why do we need a diagnosis? a qualitative study of parents' experiences, coping and needs, when the newborn child is severely disabled. *Child: Care, Health and Development*, 33(3), pp.296-307.

Gray, D.E., 2006. Coping Over Time: The Parents of Children with Autism. Journal of Intellectual Disability Research, 50(12), pp.970-976.

Grbich, C., 2009. *Qualitative data analysis: an introduction*. London: SAGE.

Greeff, A. P. and K.-J. Van der Walt., 2010. Resilience in families with an autistic child. *Education and Training in Autism and Developmental Disabilities,* pp.347-355.

Greene, M.J., 2014. On the inside looking in: methodological insights and challenges in conducting qualitative insider Research. *The Qualitative Report, 19*(29), pp.1-13.

Grenade, L. and Boldy, D., 2008. Social Isolation and Loneliness Among Older People: Issues and Future Challenges in Community and Residential Settings. *Australian Health Review,* 32(3), pp.468-478.

Grillo, T., 1995. Anti-essentialism and intersectionality: tools to dismantle the master's House. *Berkeley Journal of Gender, Law and Justice, 10(1)*, pp.16-30

Grinnell, R. M., 1988. *Social Work Research and Evaluation.* 3rd ed. Illinois: F.E. Peacock Publishers.

Grix, J., 2010. *The Foundations of Research.* 2nd ed. Basingstoke: Palgrave Macmillan.

Grobler, M.E., 2012, A paradigm of Namibian families. Paper presented at the national social workers' workshop on parenting, 21–25 May 2012. Windhoek: Namibia.

Groce, N.E., Kembhavi, G., Wirz, S., Lang, R., Trani, J.F. and Kett, M., 2011. *Poverty and Disability: A critical review of the literature in low and middle-income countries.* London: Leonard Cheshire Disability and Inclusive Development Centre.

Grut, L. and B. Ingstad., 2010. Using Qualitative Method in Studying the Link between Disability and Poverty: Developing a Methodology and Pilot Testing in Kenya. SINTEF Health Research.

Guillemin, M. and Gillam, L., 2004. Ethics, reflexivity, and "ethically important moments" in research. *Qualitative inquiry*, 10(2), pp.261-280.

Guthrie, G., 2010*. Basic research methods an entry to social science research.* New Delhi: SAGE Publications.

Halcomb, E.J., Gholizadeh, L., DiGiacomo, M., Phillips, J. and Davidson, P.M., 2007. Literature review: considerations in undertaking focus group research with culturally and linguistically diverse groups. *Journal of clinical nursing*, 16(6), pp.1000-1011.

Hall, E., 2010. Spaces of social inclusion and belonging for people with intellectual disabilities. *Journal of Intellectual Disability Research*, 54(s1), pp.48-57.

Hall, H. R. and Graff, J. C., 2012. Maladaptive behaviors of children with autism: parent support, stress, and coping. *Issues in Comprehensive Pediatric Nursing,* 35(3-4) , pp.194-214.

Hall, J. G., 2013. The role of patient advocacy/parent support groups. *South African Medical Journal* , 3(12), pp.1020-1022.

Hamilton-Giachritsis, C. and Browne, K., 2012. Forgotten children? an update on young children in institutions across europe. *Early Human Development*, 88(12), pp.911-914.

Handa, S., Peterman, Seidenfeld, D. and Tembo, G., 2016. Income transfers and maternal health: evidence from a national randomized social cash transfer program in Zambia. *Health Economics*, 25(2), pp.225-236.

Hansen, A. M. W., M. Siame and J. Van Der Veen (2014). A qualitative study: barriers and support for participation for children with disabilities: original research. *African Journal of Disability*, 3(1), pp.1-9.

Harper, A., Dyches, T.T., Harper, J., Roper, S.O. and South, M., 2013. Respite care, marital quality, and stress in parents of children with autism spectrum disorders. *Journal of autism and developmental disorders*, *43*(11), pp.2604-2616.

Harpur, P., 2012. Embracing the new disability rights paradigm: the importance of the convention on the rights of persons with disabilities. *Disability and Society*, 27(1), pp.1-14.

Harris, A. and Enfield, S., 2003. Disability, Equality and Human Rights. *A training manual for development and humanitarian organisations, Oxfam.*

Hartley, S., Ojwang, P., Baguwemu, A., Ddamulira, M. and Chavuta, A., 2005. How do carers of disabled children cope? The Ugandan perspective. *Child: Care, Health and Development,* 31, pp.167-180.

Hartley, S.L., Barker, E.T., Seltzer, M.M., Greenberg, J.S. and Floyd, F.J., 2011. Marital satisfaction and parenting experiences of mothers and fathers of adolescents and adults with autism. *American Journal of Intellectual and Developmental Disabilities*, 116(1), pp.81-95.

Hasan, M. N., 2016. Positivism: to what extent does it aid our understanding of the contemporary social world? *Quality and Quantity,* 50(1), pp.317-325.

Hastings, R. P., 2003. Child behaviour problems and partner mental health as correlates of stress in mothers and fathers of children with autism. *Journal of Intellectual Disability Research*, 47(4-5), pp 231-237.

Hastings, R.P., Kovshoff, H., Brown, T., Ward, N.J., Espinosa, F.D. and Remington, B., 2005. Coping strategies in mothers and fathers of preschool and school-age children with autism. *Autism, 9*(4), pp.377-391.

Hatton, C. and Emerson, E., 2009. Does socioeconomic position moderate the impact of child behaviour problems on maternal health in south

asian families with a child with intellectual disabilities? *Journal of Intellectual and Developmental Disability*, 34(1), pp.10-16.

Havens, C., 2005. Becoming a resilient family: child disability and the family system. *Access today,* 17(5).

Heath, S., Charles, V., Crow, G. and Wiles, R., 2007. Informed consent, gatekeepers and go-betweens: negotiating consent in child and youth-orientated institutions. *British Educational Research Journal*, 33(3), pp.403-417.

Heiman, T. and Berger, O., 2008. Parents of children with asperger syndrome or with learning disabilities: family environment and social support. *Research in Developmental Disabilities*, 29(4), pp.289-300.

Heiman, T., 2002. Parents of children with disabilities: resilience, coping, and future expectations. *Journal of Developmental and Physical Disabilities*, 14(2), pp.159-171.

Hendricks, A., 2007. UN convention on the rights of persons with disabilities. *European Journal of Health Law,* 14, 273-298.

Hennink, M. M., Hutter, I. and Bailey, A., 2011. *Qualitative Research Methods*. Los Angeles: SAGE.

Hesse-Biber, S., Yaiser, M. and Leavy, P. 2004. Feminist approaches to research as a process: reconceptualising epistemology, methodology and methods. In: Hesse-Biber, S. and Yaiser, M. eds. 2004. *Feminist perspective on social research.* Oxford: Oxford Press.

Hetherington, S.A., Durant-Jones, L., Johnson, K., Nolan, K., Smith, E., Taylor-Brown, S. and Tuttle, J., 2010. The lived experiences of adolescents with disabilities and their parents in transition planning. *Focus on Autism and Other Developmental Disabilities*, 25(3), pp.163-172.

Hill, C. and McPherson, M.F., 2004. *Promoting and Sustaining Economic Reform in Zambia.* Harvard: Harvard University Press.

Hodge, N. and Runswick-Cole, K., 2013. 'They never pass me the ball': exposing ableism through the leisure experiences of disabled children, young people and their families. *Children's Geographies*, 11(3), pp.311-325.

Hodges, L. and Dibb. B., 2010. Social comparison within self-help groups: views of parents of children with duchenne muscular dystrophy. *Journal of Health Psychology*, 15(4), pp.483-492.

Horowitz, C. R., Robinson, M. and Seifer. S. 2009. Community-based participatory research from the margin to the mainstream. *Circulation*, 119(19), pp.2633-2642.

Hudson, B., 2006. Making and missing connections: learning disability services and the transition from adolescenceto adulthood. *Disability and Society*, 21(1). pp,47-60.

Jackson, D. and Mannix, J., 2004. Giving voice to the burden of blame: a feminist study of mothers' experiences of mother blaming. *International Journal of Nursing Practice*, 10(4), pp.150-158.

Johl, S. K. and Renganathan, S., 2010. Strategies for gaining access in doing fieldwork: reflection of two researchers. *The Electronic Journal of Business Research Methods,* 8(1), pp.42-50.

John, A., 2012. Stress among mothers of children with intellectual disabilities in urban India: role of gender and maternal coping. *Journal of Applied Research in Intellectual Disabilities*, 25(4), pp.372-382.

Jones, J. M., 2015. The looking glass lens: self-concept changes due to social media practices. *The Journal of Social Media in Society*, 4(1), pp.100-125.

Jootun, D., McGhee, G. and Marland, G. R., 2009. Reflexivity: promoting rigour in qualitative research. *Nursing Standard*, 23(23), pp.42-46.

Judd, T., 2012. *Neuropsychotherapy and Community integration: Brain Illness, Emotions, and Behavior*. New York: Springer Science and Business Media.

Kale, R., 1995. Traditional Healers in South Africa: A Parallel Health Care System. *British Medical Journal*, 30, pp.1182-1185.

Kanter, A. S., 2008. United Nations convention on the rights of persons with disabilities and its implications for the rights of elderly people under international law. *The Georgia University Law Review,* 25(3), pp.527-573.

Karnieli-Miller, O., Strier R. and Pessach, L. 2009. Power relations in qualitative research. *Qualitative Health Research,* 19(2). pp.279-289.

Karst, J. S. and Van Hecke, A. V., 2012. Parent and family impact of autism spectrum disorders: a review and proposed model for intervention evaluation. *Clinical Child and Family Psychology Review*, 5(3), pp.247-277.

Kashima, Y., 2014. Meaning, grounding, and the construction of social reality. *Asian Journal of Social Psychology*, 17(2), pp.81-95.

Kazmierska, K., 2004. Ethical aspects of biographical interviewing and analysis. *in* P. Chamberlayne, J. Bornat, and U. Apitzsch., eds. 2004. *Biographical Methods and Professional Practice. An International Perspective.* Bristol: The Polity Press. Ch.12.

Keen, D., et al., 2007. A pilot study of the effects of a social-pragmatic intervention on the communication and symbolic play of children with autism. *Autism*, 11(1), pp.63-71.

Keenan, M., Dillenburger, K., Doherty, A., Byrne, T. and Gallagher, S., 2010. The experiences of parents during diagnosis and forward planning for children with autism spectrum disorder. *Journal of Applied Research in Intellectual Disabilities*, 23(4), pp.390-397.

Kees Van Donge, J., 1998. Reflections on donors, opposition and popular will inthe 1996 zambian general elections. *Journal of Modern African Studies.* 36(1), pp.71-99.

Kelly, A., T. Ghalaieny and C. Devitt, 2012. A pilot study of early intervention for families with children with or at risk of an intellectual disability in northern Malawi. *Journal of Policy and Practice in Intellectual Disabilities*, 9(3), pp.195-205.

Kiamba, J.M., 2008. Women and leadership positions: social and cultural barriers to success. *Wagadu: A Journal of Transnational Women's and Gender Studies*, 5, pp.5-24.

Kingston, A., 2007. *Mothering Special Needs: A Different Maternal Journey.* London: Jessica Kingsley Publishers.

Knight, J., 2012. Poverty and disability. *Development in Practice*, 22(1), pp.136-138.

Kolahi, A.A. and Tahmooreszadeh, S., 2009. First febrile convulsions: inquiry about the knowledge, attitudes and concerns of the patients' mothers. *European Journal of Pediatrics*, 168(2), pp.167-171.

Kragelund, P., 2009. Part of the disease or part of the cure? Chinese investments in the Zambian mining and construction sectors. *The European Journal of Development Research*, 21(4), pp.644-661.

Kromberg, J., Zwane, E., Manga, P., Venter, A., Rosen, E. and Christianson, A., 2008. Intellectual disability in the context of a South African population. *Journal of Policy and Practice in Intellectual Disabilities*, 5(2), pp.89-95.

Krumholz, H. M., 2010. Informed Consent to Promote Patient-Centered Care. *JAMA Internal Medicine*, 303(12), pp.1190-1191.

Kruske, S. and Barclay, L., 2004. Effect of shifting policies on traditional birth attendant training. *Journal of Midwifery and Women's Health*, 49(4), pp.306-311.

Kuhn, J. C. and Carter, A. S. , 2006. Maternal self-efficacy and associated parenting cognitions among mothers of children with autism. *American Journal of Orthopsychiatry,* 76(4), pp.564-575.

Kyei, N.N., Campbell, O.M. and Gabrysch, S., 2012. The influence of distance and level of service provision on antenatal care use in rural Zambia. *PloS one,* 7(10) e46475, pp.1-6.

Labie, M., Méon, P.G., Mersland, R. and Szafarz, A., 2015. Discrimination by microcredit officers: Theory and evidence on disability in Uganda. *The Quarterly Review of Economics and Finance*, *58*, pp.44-55.

Lambert, S.D. and Loiselle, C.G., 2008. Combining individual interviews and focus groups to enhance data richness. *Journal of Advanced Nursing*, 62(2), pp.228-237.

Landsman G.H., 2009. Reconstructing motherhood and disability in the age of "perfect" babies. New York: Routledge.

Laney, E.K., Carruthers, L., Hall, M.E.L. and Anderson, T., 2014. Expanding the self: motherhood and identity development in faculty women. *Journal of Family Issues*, *35*(9), pp.1227-1251.

Lapan, S.D., Quartaroli, M.T. and Riemer, F.J., 2012. Qualitative research: an introduction to methods and designs. San Francisco: Jossey-Bass.

Larmer, M., 2005. Reaction and Resistance to Neo-liberalism in Zambia. *Review of African Political Economy*, 32(103), pp.29-45.

Larsson, A.T. and Grassman, E.J., 2012. Bodily changes among people living with physical impairments and chronic illnesses: biographical disruption or normal illness? *Sociology of Health and Illness*, 34(8), pp.1156-1169.

Law, M., King, S., Stewart, D. and King, G., 2002, The perceived effects of parent-led support groups for parents of children with disabilities. *Physical and Occupational Therapy in Pediatrics*, 21(2-3), pp.29-48.

Leary, M. R. and Jongman-Sereno, K., 2010. Social Anxiety As An Early Warning System: A Refinement and Extension of The Self-Presentation Theory of Social Anxiety. *Social Anxiety: Clinical, Developmental, and Social Perspectives*, pp.471-486.

Leclerc-Madlala, S., 2002. On the virgin cleansing myth: gendered bodies, AIDS and ethnomedicine. *African Journal of AIDS Research*, 1(2), pp.87-95.

Leiter, V., Krauss, M. W., Anderson, B. and WellS, N. 2004. The Consequences of Caring Effects of Mothering a Child with Special Needs. *Journal of Family Issues,* 25**,** 379-403.

Levin, M., 2012. Academic integrity in action research. *Action Research,* 10(2), pp.133-149.

Lewis, C., 2004. Microfinance from the point of view of women with disabilities: lessons from Zambia and Zimbabwe. *Gender and Development*, 12(1), pp.28-39.

Lewis, G., 2009. Celebrating intersectionality? Debates on a multi-faceted concept in gender studies: themes from a conference. *European Journal of Women's Studies*, 16(3), pp.203-210.

Llewellyn, A. and Hogan, K., 2000. The use and abuse of models of disability. *Disability and Society*, 15(1), pp.157-165.

Loeb, M.E., Eide, A.H. and Mont, D., 2008. Approaching the measurement of disability prevalence: the case of Zambia. *ALTER-European Journal of Disability Research/Revue Européenne de Recherche sur le Handicap*, 2(1), pp.32-43.

Lukemeyer, A., Meyers. M. K. and Smeeding, T., 2000. Expensive children in poor families: out-of-pocket expenditures for the care of disabled and chronically ill children in welfare families. *Journal of Marriage and Family*, 62(2), pp.399-415.

Luthans, F., Luthans, K. W. and Luthans, B. C., 2004. Positive psychological capital: beyond human and social capital. *Business Horizons*, 47(1), pp.45-50.

Lyons, A.M., Leon, S.C., Phelps, C.E.R. and Dunleavy, A.M., 2010. The impact of child symptom severity on stress among parents of children with ASD: the moderating role of coping styles. *Journal of Child and Family Studies*, *19*(4), pp.516-524.

Mackey, A.P., Park, A.T., Robinson, S.T. and Gabrieli, J.D., 2017. A pilot study of classroom-based cognitive skill instruction: effects on cognition and academic performance. *Mind, Brain, and Education*, *11*(2), pp.85-95.

MacKinnon, C. A., 2013. Intersectionality as method: a note. *Signs*, 38(4), pp.1019-1030.

Maher, J., 2005. A mother by trade: australian women reflecting mothering as activity, not identity. *Australian Feminist Studies*, 20(46), 17-29.

Mahon-Daly, P. and Andrews, G. J., 2002. Liminality and breastfeeding: women negotiating space and two bodies. *Health and Place*, 8(2), pp.61-76.

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.

Mann, M., 2012. *The sources of social power: volume 3, global empires and revolution, 1890-1945.* Cambridge: Cambridge University Press.

Mansell, W. and Morris, K. 2004. A survey of parents' reactions to the diagnosis of an autistic spectrum disorder by a local service access to information and use of services. *Autism*, 8(4), pp.387-407.

Mapoma, C. C. and Masaiti, G., 2012. Perceptions of and attitudes towards ageing in Zambia. *European Journal of Educational Research*, 1(2), pp.107-116.

Marshall, B., Cardon, P., Poddar, A. and Fontenot, R., 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.

Marten, L. and Kula, N.C., 2008. Zambia:'One Zambia, one nation, many languages'. *Language and National Identity In Africa*, pp.291-313.

Marvin, R. S. and Pianta, R. C., 1996. Mothers' reactions to their child's diagnosis: relations with security of attachment. *Journal of Clinical Child Psychology,* 25(4), pp.436-445.

Masasa, T., Irwin-Carruthers, S. and Faure, M., 2005. Knowledge of, Beliefs About and Attitudes to Disability: Implications for Health Professionals: Original Research. *South African Family Practice*, 47(7), pp.40-44.

Maskey, M., Warnell, F., Parr, J.R., Le Couteur, A. and McConachie, H., 2013. Emotional and behavioural problems in children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 43*(4), pp.851-859.

Masulani-Mwale, C., Mathanga, D., Silungwe, D., Kauye, F. and Gladstone, M., 2016. Parenting children with intellectual disabilities in Malawi: the impact that reaches beyond coping? *Child: Care, Health And Development, 42*(6), pp.871-880.

Mathambo, V. and Gibbs, A., 2009. Extended family childcare arrangements in a context of aids: collapse or adaptation? *AIDS Care*, 21(S1), pp.22-27.

McCabe, H., 2007. Parent advocacy in the face of adversity: Autism and families in the People's Republic of China. *Focus on Autism and Other Developmental Disabilities*, 22(1), pp.39-50.

McCabe, H., 2010. Employment experiences, perspectives, and wishes of mothers of children with autism in the people's republic of China. *Journal of Applied Research in Intellectual Disabilities,* 23(2), pp.122-131.

McCabe, J. L., and Holmes, D., 2009. Reflexivity, critical qualitative research and emancipation: a Foucauldian perspective. *Journal of Advanced Nursing*, 65(7), pp.1518–1526.

McCall, L, 2005. The complexity of intersectionality. *Signs: Journal of Women in Culture and Society,* 30(3), pp.1771-1800.

McConkey, R., 2015. Measuring Public Discomfort At Meeting People with Disabilities. *Research in Developmental Disabilittayies*, 45, pp.220-228.

McConkey, R., Kahonde, C. and McKenzie, J., 2016. Tackling Stigma in Developing Countries: The Key Role of Families. *Intellectual Disability and Stigma*, Springer, pp.179-194.

McConkey, R., Kelly, F., Craig, S. and Mannan, H., 2013. A longitudinal study of the intra-country variations in the provision of residential care for adult persons with an intellectual disability. *Journal of Intellectual Disability Research*, *57*(10), pp.969-979.

McConnell, D., Savage, A. and Breitkreuz, R., 2014. Resilience in families raising children with disabilities and behavior problems. *Research in Developmental Disabilities*, 35(4), pp.833-848.

McFerson, H.M., 2010. Poverty among women in Sub-Saharan Africa: a review of selected issues. *Journal of International Women's Studies*, 11(4), pp.50-72

McKenzie, J. A., 2016. An exploration of an ethics of care in relation to people with intellectual disability and their family caregivers in the Cape Town Metropole in South Africa. *ALTER-European Journal of Disability Research/Revue Européenne De Recherche Sur Le Handicap*, 10(1), pp.67-78.

McKenzie, J. A., R. McConkey and Adnams, C., 2013. Intellectual disability in Africa: Implications for research and service development. *Disability and Rehabilitation*, 35(20), pp.1750-1755.

McKenzie, J. and McConkey, R., 2016. Caring for adults with intellectual disability: The perspectives of family carers in South Africa. *Journal of Applied Research in Intellectual Disabilities*, 29(6), pp.531-541.

McLaughlin, M., Nam, Y., Gould, J., Pade, C., Meeske, K.A., Ruccione, K.S. and Fulk, J., 2012. A video sharing social networking intervention for young adult cancer survivors. *Computers in Human Behaviour*, 28(2), pp.631-641.

McNally, A. and Mannan, H., 2013. Perceptions of caring for children with disabilities: experiences from Moshi, Tanzania. *African Journal of Disability*, 2(1), pp.1–10.

Meadan, H., Halle, J. W. and Ebata, A. T., 2010. Families with children who have autism spectrum disorders: stress and support. *Exceptional Children*, 77(1), pp.7-36.

Mehl, M. R. and Conner, T. S., 2012. *Handbook of research methods for studying daily life*. New York: Guilford Pres.

Merrill, B. and West, L., 2009. Using biographical methods in social research. London, SAGE.

Merrill, B., 2012. Learning to become an adult student: Experiences in A UK University. *International Journal of Continuing Education and Lifelong Learning, 5*(1), pp.21-42

Merrill, B., 2015. Determined to stay or determined to leave? A tale of learner identities, biographies and adult students in higher education. *Studies in Higher Education,* 40(10), pp.1859-1871.

Metz, T. and Gaie, J.B., 2010. The African ethic of Ubuntu/Botho: implications for research on morality. *Journal of Moral Education*, 39(3), pp.273-290.

Mhone, G., 2004. Historical trajectories of social policy in post-colonial Africa: The case of Zambia. In: T.Mkandawire, ed. 2004. *Social Policy in A Development Context*. Hampshire: Palgrave Macmillan. Ch.14.

Miles, M.B., Huberman, M.A. and Saldana, J., 2014. Drawing and verifying conclusions. Qualitative data analysis: a methods sourcebook. 3rd ed. London: SAGE Publications.

Milimo, M.C., 2004. *Zambia Strategic Country Gender Assessment: A Report of the World Bank*.

Miller, R. L., 2000. *Researching life stories and family histories*. London: SAGE Publications.

Miller, T., 2005. *Making sense of motherhood : a narrative approach*. New York: Cambridge University Press.

Mills, J., Bonner, A. and Francis, K., 2006. Adopting a constructivist approach to grounded theory: Implications for research design. *International Journal of Nursing Practice*, 12(1), pp.8-13.

Mitra, S., 2006. The capability approach and disability. *Journal of Disability Policy Studies*, 16(4), pp.236-247.

Mkabela, Q., 2005, 'Using the Afrocentric method in researching indigenous African culture', The Qualitative Report 10(1), 178–189.

Moawed, S.A. and Saeed, A.A., 2000. Knowledge and practices of mothers about infants' diarrheal episodes. *Saudi Medical Journal*, *21*(12), pp.1147-1151.

Moodley, J. and Graham, L., 2015. The importance of intersectionality in disability and gender studies. *Agenda*, *29*(2), pp.24-33.

Morgan, D. L., 1997. *Focus Groups As Qualitative Research*. 2nd ed. London: SAGE Publications.

Morgan, H., 2012. The social model of disability as a threshold concept: Troublesome knowledge and liminal spaces in social work education. *Social Work Education*, 31(2), pp.215-226.

Morrow, O., Hawkins, R. and Kern, L., 2015. Feminist research in online spaces. *Gender, Place and Culture*, 22(4), pp.526-543.

Moyer, C.A., Adongo, P.B., Aborigo, R.A., Hodgson, A., Engmann, C.M. and DeVries, R., 2014. "It's up to the woman's people": how social factors influence facility-based delivery in Rural Northern Ghana. *Maternal and Child Health Journal*, *18*(1), pp.109-119.

Mpofu, E. and Harley, D. A., 2002. Disability and rehabilitation in Zimbabwe: lessons and implications for rehabilitation practice in the US. *Journal of Rehabilitation*, 68(4), pp.26-33.

Mpofu, E., 2002, 'Indigenization of the psychology of human intelligence in SubSaharan Africa', in W.J. Lonner, D.L. Dinnel, S.A. Hayes, & D.N. Sattler (eds.), On-line Readings in Psychology and Culture (Unit 5, Chapter 2), (http://www. wwu.edu/~culture), Center for Cross-Cultural Research, Western Washington University, Bellingham, Washington, USA.

Mueller, T.G., Milian, M. and Lopez, M.I., 2009. Latina mothers' views of a parent-to-parent support group in the special education system. *Research and Practice for Persons with Severe Disabilities*, 34(3-4), pp.13-122.

Mullender, A. and Hague, G., 2005. Giving a voice to women survivors of domestic violence through recognition as a service user group. *British Journal of Social Work*, 35(8), pp.1321-1341.

Mullender, A., Ward, D. and Fleming, J., 2013. *Empowerment in Action : Self-Directed Groupwork*. London: Palgrave Macmillan.

Mung'omba, J., 2008. Comparative policy brief: status of intellectual disabilities in the republic of Zambia. *Journal of Policy and Practice in Intellectual Disabilities*, 5(2), pp.142-144.

Munyi, C. W., 2012. Past and present perceptions towards disability: a historical perspective. *Disability Studies Quarterly,* 32(2). [online] Available at: http://dsq-sds.org/article/view/3197. [Accessed 10 July 2014].

Murphy, R.F., Scheer, J., Murphy, Y. and Mack, R., 1988. Physical disability and social liminality: A study in the rituals of adversity. *Social Science & Medicine*, 26(2), pp.235-242.

Mushi, D., Burton, K., Mtuya, C., Gona, J., Walker, R. and Newton, C., 2012. Perceptions, social life, treatment and education gap of Tanzanian Children with epilepsy: a community-based study. *Epilepsy and Behavior*, 23, pp.224-229.

Mvunga, M.P., 1980. *The colonial foundations of Zambia's land tenure system*. Lusaka: NECZAM.

Mwale, N. and Chita, J. C., 2016. Religious pluralism and disability in Zambia: approaches and healing in selected pentecostal churches. *Studia Historiae Ecclesiasticae*, 42(2), pp.54-72.

Nabuzoka, D. and Rønning, J. A. (1997). Social acceptance of children with intellectual disabilities in an integrated school setting in Zambia: A pilot study. International Journal of Disability, Development and Education, 44, 105–115

Nash, J. C., 2008. Re-thinking intersectionality. *Feminist Review*, 89(1), pp.1-15.

Navon, L. and Morag, A., 2004. Liminality as biographical disruption: unclassifiability following hormonal therapy for advanced prostate cancer. *Social Science and Medicine*, *58*(11), pp.2337-2347.

Ndebele, P., Mfutso-Bengo, J. and Mduluza, T., 2008. Compensating clinical trial participants from limited resource settings in internationally sponsored clinical trials: a proposal. *Malawi Medical Journal*, 20(2), pp.42-45.

Ndubani, P. and Höjer, B., 1999. Traditional healers and the treatment of sexually transmitted illnesses in rural Zambia. *Journal of Ethnopharmacology*, 67(1), pp.15-25.

Ndulo, M.B. and Kent, R.B., 1996. Constitutionalism in Zambia: past, present and future. *Journal of African Law*, 40(2), pp.256-278.

Nikander, P., 2008. Working with transcripts and translated data. *Qualitative research in psychology*, 5(3), pp.225-231.

Nixon, S., Cameron, C., Cameron, D., Hanass-Hancock, J., Ibanez-Carrasco, F., Manning, E., Parsons, J., Simwaba, P., Solomon, P. and Yoshida, K., 2011. The intersectionality of HIV and disability in Zambia: results from the Sepo Study. In: 20th Annual *Canadian Conference HIV/AIDS Research.* Toronto, Canda, 14-17 April 2011. Ottawa: Canadian Association for HIV Research.

Njelesani, J., Nixon, S., Cameron, D., Parsons, J. and Menon, A., 2015. Experiences of work among people with disabilities who are HIV-positive in Zambia. *African Journal of AIDS Research*, 14(1), pp.51-56.

Nkomazana, F. and Tabalaka, A., 2009. Aspects of healing practices and methods among pentecostals in Botswana-Part 1. *BOLESWA: Journal of Theology, Religion and Philosophy*, 2(3), pp.137-159.

Noyoo, N., 2000. *Social Welfare in Zambia*. Lusaka: Multimedia.

Nsamenang, A.B., 2006, 'Human ontogenesis: An indigenous African view on development and intelligence', International Journal of Psychology 41(4), 293– 297.

Ntumngia, R.N. 2009, 'Uncovering farmers' ethnobotanical knowledge: A methodology for assessing farmers' perceptions of cassava varieties', African Crop Science Conference Proceedings 9, 467–473.

Nyoni, J. and Serpell, R., 2012. The impact on parents of raising a young child with autism: a phenomenological study of parents in Lusaka, Zambia. *International Journal of Disability, Community and Rehabilitation*, 11(1).

O'Neill, M., Roberts, B. and Sparkes, A., 2014. *Advances in Biographical Methods: Creative Applications.* New York: Routledge.

Oakley, A., 1981. *From Here to Maternity : Becoming A Mother*. Harmondsworth: Penguin.

Oakley, A., 1992. *Social Support and Motherhood : The Natural History of A Research Project*. Oxford: Blackwell.

Odom, S. L., 2007. *Handbook of Developmental Disabilities*. London: Guilford Press.

Oktay, J. S., 2012. *Grounded Theory: Pocket Guides to Social Work Research Methods*. New York: Oxford University Press.

Oliver, D. P., 2011. Rigour in Qualitative Research. *Journal of Research on Aging*, 33(4), pp.359-360.

Oliver, M. and Barnes, C., 2010. Disability studies, disabled people and the struggle for inclusion. *British Journal of Sociology of Education,* 31(5), pp.547-560.

Oliver, M. and Barnes, C., 2012. Back to the future: the World Report on Disability. *Disability & Society*, *27*(4), pp.575-579.

Oliver, M. and Zarb, G., 1989. The politics of disability: a new approach. *Disability, Handicap & Society*, *4*(3), pp.221-239.

Oliver, M., 1991. Disability and participation in the labour market. *Poor Work: disadvantage and the division of labour*, pp.132-146.

Oliver, M., 1993. *Re-defining disability: a challenge to research*(pp. 61-67). Sage, London.

Oliver, M., 1996. *Understanding disability : from theory to practice.* Basingstoke: Macmillan.

Oliver, M., 2013. The social model of disability: thirty years on. *Disability & society, 28*(7), pp.1024-1026.

Olsen, R. and Clarke, H., 2003. *Parenting and Disability : Disabled Parents' Experiences of Raising Children.* Bristol: Policy Press.

O'Reilly, C. and Gordon, A., 1995. *Survival strategies of poor women in Urban Africa: the case of Zambia.* Chatham: Natural Resource Institute.

Oshionebo, E., 2010. Stabilization clauses in natural resource extraction contracts: legal, economic and social implications for developing countries. *Asper Review of International Business and Trade Law,* Volume X, pp.1-34.

Owusu-Ansah, F.E. and Mji, G., 2013. African indigenous knowledge and research. *African Journal of Disability, 2*(1), pp.1-5.

Pandit, N. R., 1996. The creation of theory: a recent application of the grounded theory method. *The Qualitative Report*, 2(4), pp.1-15.

Panitch, M., 2008. *Disability, Mothers, and Organization : Accidental Activists.* London: Routledge.

Parish, S. L. and Cloud. J. M., 2006. Financial well-being of young children with disabilities and their families. *Social Work*, 51(3), pp.223-232.

Parish, S.L., Rose, R.A., Grinstein-Weiss, M., Richman, E.L. and Andrews, M.E., 2008. Material hardship in US families raising children with disabilities. *Exceptional Children, 75*(1), pp.71-92.

Park, J., Turnbull, A. P. and Turnbull, H. R. 2002. Impacts of Poverty on Quality of Life in Families of Children with Disabilities. *Exceptional children,* 68**,** 151-170.

Parsons, J.A., Bond, V.A. and Nixon, S.A., 2015. 'Are we not human?' Stories of Stigma, Disability and HIV from Lusaka, Zambia and their Implications for Access to Health Services. *PloS one*, 10(6), pp.1-20.

Pasana, M., 2011. *Adjustment mechanism of parents of children with autism spectrum disorder: basis for an intervention scheme.* Eulogio Amang: Rodriguez Institute of Science and Technology.

Pearson, H., 2010. Complicating intersectionality through the identities of a hard of hearing Korean adoptee: An autoethnography. *Equity & Excellence in Education*, 43(3), pp.341-356.

Perez-Milans, M., 2016. Reflexivity and social change in applied linguistics. *AILA Review*, 29(1), pp. 1-14.

Peta, C., McKenzie, J. and Kathard, H., 2015. Voices from the periphery: a narrative study of the experiences of sexuality of disabled women in Zimbabwe. *Agenda,* 29(2), pp.66-76.

Phillips, R.E. and Stein, C.H., 2007. God's Will, God's Punishment, Or God's Limitations? Religious coping strategies reported by young adults living with serious mental illness. *Journal of Clinical Psychology*, 63(6), pp.529-540.

Phiri, B. J., 2006. A political history of Zambia: from colonial rule to the third republic, 1890-2001. Trenton: Africa World Press.

Phiri, S., 2016. Political dis-empowerment of women By ICTS: The case of the Zambian elections. *Overcoming Gender inequalities Through Technology integration.* IGI Global., pp.54-67.

Phiri, S.N.A., Fylkesnes, K., Moland, K.M., Byskov, J. and Kiserud, T., 2016. Rural-urban inequity in unmet obstetric needs and functionality of emergency obstetric care services in a Zambian district. *PloS one, 11*(1), p.e0145196.

Plummer, K., 2001. *Documents of Life 2 : An invitation to A Critical Humanism.* 2nd ed. London: SAGE.

Polit, D. F. and Beck, C. T., 2010. *Study guide for essentials of nursing research: appraising evidence for nursing practice.* Wolters Kluwer Health/Lippincott Williams & Wilkins.

Pool, I.A., Poell, R.F., Berings, M.G. and ten Cate, O., 2015. Strategies for continuing professional development among younger, middle-aged, and older nurses: A biographical approach. *International journal of nursing studies, 52*(5), pp.939-950.

Posner, D.N., 2004. The political salience of cultural difference: why chewas and tumbukas are allies in Zambia and adversaries in Malawi. *American Political Science Review,* 98(4), pp.529-545.

Priestley, M. ed., 2001. *Disability and the life course: Global perspectives.* Cambridge: Cambridge University Press.

Priestley, M., 1998. Constructions and creations: idealism, materialism and disability theory. *Disability & Society, 13*(1), pp.75-94.

Probst, B., 2015. the eye regards itself: benefits and challenges of reflexivity in qualitative social work research. *social Work Research*, 39(1),pp. 37-48.

Punch, K.F., 2013. *Introduction to social research: Quantitative and qualitative approaches.* London: SAGE.

Raskin, P. M., 2006. Women, Work, and Family Three Studies of Roles and Identity Among Working Mothers. *American Behavioral Scientist*, 49(10), pp.1354-1381.

Ravindran, N. and B. J. Myers, 2012. Cultural influences on perceptions of health, illness, and disability: a review and focus on autism. *Journal of Child and Family Studies*, 21(2), pp.311-319.

Read, J. and Harrison, C., 2002. Disabled Children Living Away From Home in The UK Recognizing Hazards and Promoting Good Practice. *Journal of Social Work* 2(2), pp.211-231.

Read, J., 2000. *Disability, The Family and Society : Listening to Mothers*. Buckingham: Open University Press.

Read, J., Blackburn, C. and Spencer, N., 2010. Disabled children in The UK: A Quality assessment of quantitative data Sources. *Child: Care, Health and Development,* 36**,** pp.130-141.

Reeve, J., Lloyd-Williams, M., Payne, S. and Dowrick, C., 2010. Revisiting biographical disruption: exploring individual embodied illness experience in people with terminal cancer. *Health: An Interdiscipkinary Journal for the Social Study of Health, Illness and Medicine*, 14(2), pp.178-195.

Reeves, C. L., 2010. A difficult negotiation: fieldwork relations with gatekeepers. *Qualitative Research*, 10(3), pp. 315-331.

Reichman, N. E., Corman, H., and Noonan, K., 2008. Impact of child disability on the family. *Maternal and Child Health Journal*, 12(6), pp.679-683.

Reid-Cunningham, A.R., 2009. Anthropological theories of disability. *Journal of Human Behavior in The Social Environment*, 19(1), pp.99-111.

Reinharz, S. and Davidman, L., 1992. *Feminist Methods in Social Research*. Oxford: Oxford University Press.

Reinharz, S., 1997. Who am I? The need for a variety of selves in the field. *Reflexivity and Voice*, pp.3-20.

Richardson, A.M., 2004. Women's inheritance rights in Africa: the need to integrate cultural understanding and legal reform. *Human Rights Brief*, 11, pp.19-67.

Richter, L.M., Sherr, L., Adato, M., Belsey, M., Chandan, U., Desmond, C., Drimie, S., Haour-Knipe, M., Hosegood, V., Kimou, J. and Madhavan, S., 2009. Strengthening families to support children affected by HIV and AIDS. *AIDS Care*, 21(S1), pp.3-12.

Riessman, C. K., 2008. *Narrative Methods for The Human Sciences*. Los Angeles: SAGE Publications.

Ripley, E., Macrina, F., Markowitz, M. and Gennings, C., 2010. Who's doing the math? Are we rea lly compensating research participants? *Journal of Empirical Research on Human Research Ethics*, 5(3), pp.57-65.

Risdal, D. and Singer, G.H., 2004. Marital adjustment in parents of children with disabilities: a historical review and meta-analysis. *Research and Practice for Persons with Severe Disabilities*, 29(2), pp.95-103.

Roberts, B., 2002. *Biographical Research*. Buckingham: Open University Press.

Roberts, H. ed. 2013. *Doing Feminist Research*. London: Routledge.

Robeyns, I., 2005. The Capability Approach: A Theoretical Survey. *Journal of Human Development, 6*(1), pp.93-117.

Robinson, O.C., 2014. Sampling in interview-based qualitative research: A theoretical and practical guide. *Qualitative Research in Psychology*, 11(1), pp.25-41.

Rolfe, G., 2006. Validity, Trustworthiness and Rigour: Quality and The Idea of Qualitative Research. *Journal of Advanced Nursing*, 53(3), pp.304-310.

Rosenthal, G., 1993. Reconstruction of Life Stories: Principles of Selection in Generating Stories for Narrative Biographical Interviews. *The Narrative Study of Lives*, 1(1), pp.59-91.

Rubin, H. J. and I. Rubin, 1995. *Qualitative interviewing : the art of hearing data*. London: SAGE.

Russell, G. and Norwich, B., 2012. Dilemmas, Diagnosis and De-Stigmatization: Parental Perspectives on The Diagnosis of Autism Spectrum Disorders. *Clinical Child Psychology and Psychiatry*, 17(2), pp.229-245.

Rustin, M., 2000. Reflections on the biographical turn in social science. In: P. Chamberlayne, J. Bornat and T. Wengraf. Eds. 2000. *The Turn to Biographical Methods in Social Science: Comparative Issues and Examples*. Ch.1.

Ryan, S. and Rumswick-Cole, K. 2009. From advocate to activist? mapping the experiences of mothers of children on the autism spectrum. *Journal of Applied Research in Intellectual Disabilitie,* 22(1), pp.43-53.

Sadie, Y., 2005. Women in political decision-making in the SADC Region. *Agenda: Empowering Women for Gender Equity*, 19(65), pp.17-31

Sadler, G.R., Lee, H.C., Lim, R.S.H. and Fullerton, J., 2010. Recruitment of hard-to-reach population subgroups via adaptations of the snowball sampling strategy. *Nursing and Health Sciences*, *12*(3), pp.369-374.

Sakala, M. and Korpinen, M. 2013. *Inclusion of People with Disabilities in Zambia* [Online]. Available at< http://www.ilo.org/wcmsp5/groups/public/---ed_emp/---ifp_skills/documents/publications/wcms_115100.pdf> [Accessed 29/12/2013].

Sakala, M., J. Frantz and A. Rhoda, 2012. The challenges experienced by people with disabilities as a result of cultural beliefs: a systematic review. *Journal of Community and Health Sciences*, 7(2), pp.24-31.

Salmela, M., Salanterä, S., Ruotsalainen, T. and Aronen, E.T., 2010. Coping Strategies for Hospital-Related Fears in Pre-School-Aged Children. Journal of Paediatrics and Child Health, 46(3), pp.108-114.

Sarantakos, S. (1998). *Social Research*. 2nd ed. Basingstoke: Macmillan.

Schatz, E. and Ogunmefun, C., 2007. Caring and contributing: the role of older women in rural South African multi-generational households in the HIV/AIDS era. *World Development*, 35(8), pp.1390-1403.

Schilling, R. F., Gilchrist, L. D. and Schinke, S.P., 1984. Coping and Social Support in Families of Developmentally Disabled Children. *Family Relations*, pp.47-54.

Schippers, A., N. Zuna and I. Brown, 2015. A proposed framework for an integrated process of improving quality of life. *Journal of Policy and Practice in Intellectual Disabilities*, 12(3), pp.151-161.

Schischka, J., Dalziel, P. and Saunders, C., 2008. Applying sen's capability approach to poverty alleviation programs: two case studies. *Journal of Human Development*, *9*(2), pp.229-246.

Schubert, B. and Slater, R., 2006. Social cash transfers in low-income african countries: conditional or unconditional? *Development Policy Review,* 24(5), pp.571-578.

Schuengel, C., Rentinck, I.C.M., Stolk, J., Voorman, J.M., Loots, G.M.P., Ketelaar, M., Gorter, J.W. and Becher, J.G., 2009. Parents' reactions to the diagnosis of cerebral palsy: associations between resolution, age and severity of disability. *Child: Care, Health and Development*, 35(5), pp.673-680.

Schütze, F., 2008 biography analysis on the empirical base of autobiographical narratives: how to analyse autobiographical narrative interviews–Part I. *European Studies on inequalities and Social Cohesion*, 1(2), pp. 153-242.

Scior, K., Hamid, A., Hastings, R., Werner, S., Belton, C., Laniyan, A., Patel, M., and Kett, M. (2015). Intellectual Disabilities: Raising Awareness and Combating Stigma- a Global Review. Executive Summary and Recommendations. London: University College London. Available at: https://www.ucl.ac.uk/ciddr/publications [Accessed 13 November 2015].

Scott, K.W., 2004. Relating the categories in grounded theory analysis: using a conditional relationship guide and reflective coding matrix. *The Qualitative Report*, *9*(1), pp.112-126.

Seebohm, P., Chaudhary, S., Boyce, M., Elkan, R., Avis, M. and Munn-Giddings, C., 2013. The contribution of self-help/mutual aid groups to mental well-being. *Health & social care in the community*, *21*(4), pp.391-401.

Semenya, S. S. and Potgieter, M. J. 2014. Bapedi Traditional Healers in The Limpopo Province, South Africa: Their Socio-Cultural Profile and Traditional Healing Practice. *Journal of Ethnobiology and Ethnomedicine*, 10(1), 4.

Sen, A., 2005. Human rights and capabilities. *Journal of Human Development*, 6(2), pp.151-166.

Sen, E. and Yurtsever, S., 2007. Difficulties experienced by families with disabled children. *Journal for Specialists in Paediatric Nursing*, 12(4), pp.238-252.

Shabo, F. H., Mohamed, A. A. R. and Tahir, M. O., 2011. Psychosocial impacts of mentally retarded children on parents in Sudan. *Sudan Journal of Medical Sciences*, 6(1), pp.7-16.

Shafer, D. M., 1990. Sectors, states, and social forces: Korea and Zambia confront economic restructuring. *Comparative Politics*, 22(2), pp.127-150.

Shakespeare, T. and Watson, N., 2002. The Social Model of Disability: An Outdated Ideology? *Research in Social Science and Disability*, 2, pp.9–28.

Shakespeare, T., 2006. The Social Model of Disability. *The Disability Studies Reader* 2, pp.197-204.

Shakespeare, T., Watson, N. and Alghaib, O. A., 2017. Blaming the victim, all over again: waddell and aylward's Biopsychosocial (BPS) model of disability. *Critical Social Policy*, 37(1), pp.22-41.

Shakespeare, T., Watson, N. and Alghaib, O.A., 2017. Blaming the victim, all over again: Waddell and Aylward's biopsychosocial (BPS) model of disability. *Critical Social Policy*, 37(1), pp.22-41.

Shankar, A., Hamer, M., McMunn, A. and Steptoe, A., 2013. Social isolation and loneliness: relationships with cognitive function during 4 years of follow-up in the english longitudinal study of ageing. *Psychosomatic medicine*, 75(2), pp.161-170.

Shaw, L. R., Chan F. and Mcmahon, B. T., 2012. Intersectionality and disability harassment: the interactive effects of disability, race, age, and gender. *Rehabilitation Counseling Bulletin*, 55(2), pp.82-91.

Shearn, J. and Todd, S., 2000. Maternal employment and family responsibilities: the perspectives of mothers of children with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 13(3), pp.109-131.

Shefer, G., Rose, D., Nellums, L., Thornicroft, G., Henderson, C. and Evans-Lacko, S., 2013. 'Our community is the worst': The influence of cultural beliefs on stigma, relationships with family and help-seeking in three ethnic communities in London. *International Journal of Social Psychiatry*, 59(6), pp.535-544.

Shields, S. A., 2008. Gender: an intersectionality perspective. *Sex Roles*, 59(5-6), 301-311.

Shih,Y., 2012. *The journey of becoming and being a mother raising a disabled child. the transformations between and across social positions.* Ph.D. Newcastle University.

Shilling, V., Morris, C., Thompson-Coon, J., Ukoumunne, O., Rogers, M. and Logan, S., 2013. Peer support for parents of children with chronic disabling conditions: a systematic review of quantitative and qualitative studies. *Developmental Medicine & Child Neurology*, 55(7), pp.602-609.

Sialubanje, C., Massar, K., Hamer, D.H. and Ruiter, R.A., 2015. Reasons for home delivery and use of traditional birth attendants in rural Zambia: a qualitative study. *BMC Pregnancy and Childbirth*, 15:216, pp.1-12.

Simkiss, D., Blackburn, C., Mukoro, O., F., Read, J. and Spencer, J., N. 2011. Childhood Disability and Socio-economic Circumstances in Low and Middle Income Countries: Systematic Review. *BMC Pediatrics,* 11**,** 1-15.

Simons, H. (2009). *Case Study Research in Practice.* London: SAGE.

Singh, I., 2004. Doing their jobs: Mothering with Ritalin in a culture of mother-blame. *Social Science & Medicine*, 59(6), pp.1193-1205.

Sipal, R. F. and Sayin. U., 2013. Impact of perceived social support and depression on the parental attitudes of mothers of children who are deaf. *Journal of Child and Family Studies*, 22(8), pp. 1103-1111.

Skjelmerud, A., Halvorsen, V., Hamuwele, D., Tawanda, M. and Simumba, C., 2008. Gender reviews: mainstreaming gender and AIDS in the department *portfolio of the Norwegian Embassy in Zambia*. Oslo: Norwegian Agency for Development Cooperation.

Slater, R., 2011. Cash transfers, social protection and poverty reduction. *International Journal of Social Welfare*, 20(3), pp.250-259.

Sloan, A. and Bowe, B., 2014. Phenomenology and hermeneutic phenomenology: the philosophy, the methodologies, and using hermeneutic phenomenology to investigate lecturers' experiences of curriculum design. *Quality and Quantity*, 48(3), pp.1291-1303.

Sloper, P., 1999. Models of service support for parents of disabled children. What do we know? What do we need to know? Child: *Care, Health and Development*, 25(2), pp.85-99.

Slorach, R., 2014. Out of the shadows: disability movements. *Critical and Radical Social Work*, 2(2), pp.159-174.

Smith, E., Murray, S.F., Yousafzai, A.K. and Kasonka, L., 2004. Barriers to accessing safe motherhood and reproductive health services: the situation of women with disabilities in Lusaka, Zambia. *Disability and rehabilitation*, *26*(2), pp.121-127.

Smith, L.K., Budd, Field, J.L., Draper, D.J., 2011. Socioeconomic inequalities in Outcome of pregnancy and neonatal mortality associated with congenital anomalies: population based study. *BMJ*, 343, d4306, pp.1-9.

Smyth, L., 2012. *The demands of motherhood : agents, roles and recognition*. Basingstoke: Palgrave Macmillan.

Spector-Mersel, G., 2010. Narrative research: time for a paradigm. *Narrative inquiry*, 20(1), pp.204-224.

Spencer, N., Blackburn, C. and Read, J., 2010. Prevalence and social patterning of limiting long-term illness/disability in children and young people under the age of 20 years in 2001: UK census-based cross-sectional study. *Child: Care, Health and Development*, 36(4), pp. 566-573.

Squires, A., 2008. Language barriers and qualitative nursing research: methodological considerations. *International Nursing Review*, 55(3), pp.265-273.

Standing, G., 2008. How cash transfers promote the case for basic income. *Basic income Studies*, 3(1), pp. 1-30.

Staub-Bernascon S., 2010. *Social action, empowerment and social work- an integrative theoretical framework for social work and social work with groups*. London: Routledge.

Stekelenburg, J., Jager, B.E., Kolk, P.R., Westen, E.H., van der Kwaak, A. and Wolffers, I.N., 2005. Health care seeking behaviour and utilisation of traditional healers in Kalabo, Zambia. *Health policy*, *71*(1), pp.67-81.

Steptoe, A., Shankar, A., Demakakos, P. and Wardle, J., 2013. Social isolation, loneliness, and all-cause mortality in older men and women. *Proceedings of the National Academy of Sciences*, *110*(15), pp.5797-5801.

Stevens, R., Bressler, M. and Silver, L., 2016. Challenges in marketing academic conferences: a pilot study. *Services Marketing Quarterly*, 37(3), pp.200-207.

Stewart, D. (2009). Transition to adult services for young people with disabilities: current evidence to guide future research. *Developmental Medicine and Child Neurology*, 51(S4), pp.169-173.

Stoltz, P., 2014. Book Review: The politics of belonging: intersectional contestations. *European Journal of Women's Studies*, 21(1), pp.122-125.

Strauss, A. L. and Corbin, J. M., 1998. *Basics of qualitative research: techniques and procedures for developing grounded theory*. 2nd edition. London: Sage.

Strega, S., Et Al. (2008). Connecting father absence and mother blame in child welfare policies and practice. *Children and Youth Services Review,* 30(7), pp.705-716.

Stronach, I., Garratt, D., Pearce, C. and Piper, H., 2007. Reflexivity, the picturing of selves, the forging of method. *Qualitative Inquiry*, *13*(2), pp.179-203.

Strydom, H. and Delport, C., 2011. Sampling and pilot study in qualitative research. *Research at Grass Roots: for The Social Sciences and Human Service Professions,* 4, pp.390-396.

Stuttard, L., Beresford, B., Clarke, S., Beecham, J., Todd, S. and Bromley, J., 2014. Riding the Rapids: Living with autism or disability—An evaluation of a parenting support intervention for parents of disabled children. *Research in Developmental Disabilities*, 35(10), pp.2371-2383.

Suárez-Ortega, M., 2013. Performance, reflexivity, and learning through biographical-narrative research. *Qualitative Inquiry*, *19*(3), pp.189-200.

Taanila, A., Syrjälä, L., Kokkonen, J. and Järvelin, M. R., 2002. Coping of parents with physically and/or intellectually disabled children. *Child: Care, Health and Development,* 28**,** pp.73-86.

Tanyanyiwa, V.I. & Chikwanha, M., 2011, 'The role of indigenous knowledge systems in the management of forest resources in Mugabe area, Masvingo, Zimbabwe', Journal of Sustainable Development in Africa 3(3), n.p.

Taylor, B. J. and Francis, K. 2013. Qualitative research in the health sciences : methodologies, methods and processes. Abingdon: Routledge.

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.

Theule, J., Wiener, J., Tannock, R. and Jenkins, J.M., 2013. Parenting stress in families of children with ADHD: a meta-analysis. *Journal of Emotional and Behavioral Disorders*, 21(1), pp.3-17.

Thiara, R. K., Hague, G. and Mullender, A., 2011. Losing out on both counts: disabled women and domestic violence. *Disability and Society*, 26(6), pp.757-771.

Thill, C., 2015. Listening for policy change: how the voices of disabled people shaped australia's national disability insurance scheme. *Disability and Society*, 30(1), pp.15-28.

Thomas and C., 2002. Disability Theory: Key Ideas, Issues and Thoughts. In C. Barnes, L. Barton. And M. Oliver, eds. 2002. *Disability Studies Today*. Cambridge: Polity Press.

Thomas, C., 1999. *Female forms: Experiencing and Understanding Disability*. Buckingham: Open University Press.

Thomas, C., 2004. How is disability understood? An examination of sociological approaches. *Disability and Society*, 19(6), pp.569-583.

Thomas, C., 2012. Theorising disability and chronic illness: Where next for perspectives in medical sociology?. *Social Theory & Health*, *10*(3), pp.209-228.

Thompson, N., 2007. *Power and Empowerment*. Lyme Regis, Dorset: Russell House Publishing.

Thwala, S.K., Ntinda, K. and Hlanze, B., 2015. lived experiences of parents of children with disabilities in Swaziland, *Journal of Education and Training Studies*, 3(4), pp.206–215.

Tobin, G. A. and Begley, C. M., 2004. Methodological rigour within a qualitative framework. *Journal of Advanced Nursing* , 8(4), pp.388-396.

Tomaka, J., Thompson, S. and Palacios, R., 2006. The relation of social isolation, loneliness, and social support to disease outcomes among the elderly. *Journal of Aging and Health*, *18*(3), pp.359-384.

Totsika, V., Hastings, R. P. and Vagenas, D., 2017. Informal caregivers of people with an intellectual disability in england: health, quality of life and impact of caring. *Health and Social Care in The Community,* 25(3), pp.951-961.

Totsika, V., Hastings, R.P., Emerson, E., Lancaster, G.A. and Berridge, D.M., 2011. A population-based investigation of behavioural and emotional problems and maternal mental health: Associations with autism spectrum disorder and intellectual disability. *Journal of Child Psychology and Psychiatry*, 52(1), pp.91-99.

Traini, F., J. and Leob, M., 2012. Poverty and disability: a vicious circle? Evidence from Afghanistan and Zambia. *Journal of International Development,* 24**(**S1), S19-S52.

TREMAINS, S. 2013. Introducing Feminist Philosophy of Disability. *Disability Studies Quarterly,* 33**,** 10-20.

Trute, B., Benzies, K.M., Worthington, C., Reddon, J.R. and Moore, M., 2010. Accentuate the positive to mitigate the negative: mother psychological coping resources and family adjustment in childhood disability. *Journal of Intellectual and Developmental Disability*, *35*(1), pp.36-43.

Tsouroufli, M., Rees, C.E., Monrouxe, L.V. and Sundaram, V., 2011. Gender, identities and intersectionality in medical education research. *Medical Education*, *45*(3), pp.213-216.

Turnbull, R. and Turnbull, A., 2015. Looking backward and framing the future for parents' aspirations for their children with disabilities. *Remedial and Special Education, 36*(1), pp.52-57.

Turner and B. S., eds., 2003. Biology, vulnerability and politics. In: S.J. Williams, L. Birke, and G.A. Bendelow, eds. 2003. *Debating Biology: sociological reflections on health, medicine and society*. London: Routledge.

UNICEF 2008. Situation Analysis of Children and Women 2008. Lusaka: New Horizon Printing Press.

UPIAS, 1976. *Fundamental Principles of Disability*. London: Union of The Physically Impaired Against Segregation.

Urquhart, C., 2013. *Grounded theory for qualitative research : a practical guide*. London: SAGE.

Valentine, G., 2007. Theorizing and researching intersectionality: a challenge for feminist geography*. *The Professional Geographer*, 59(1), pp.10-21.

Van Der Mark, E.J. and Verrest, H., 2014. Fighting The Odds: Strategies of Female Caregivers of Disabled Children in Zimbabwe. *Disability and Society*, 29(9), pp.1412–1427

Vincent, K. and Cull, T., 2009. Impacts of Social Cash Transfers: Case Study Evidence From Across Southern Africa. In: II Conferência IESE "Dinâmicas da Pobreza e Padrões de Acumulação Económicaem Moçambique", 22-23 April 2009. Maputo: Instituto De Estudos Sociais Económicos.

Walby, S., Armstrong, J. and Strid, S., 2012a. Intersectionality and the quality of the gender equality architecture. *Social Politics: International Studies in Gender, State and Society*, 19(4), pp.446-481.

Walby, S., Armstrong, J. and Strid, S., 2012b. Intersectionality: multiple inequalities in social theory. *Sociology*, 46(2), pp.224-240.

Walker, C., 1995. Conceptualising motherhood in twentieth century south africa. *Journal of Southern African Studies*, 21(3), pp.417-437.

Warner, L.M., Ziegelmann, J.P., Schüz, B., Wurm, S., Tesch-Römer, C. and Schwarzer, R., 2011. Maintaining autonomy despite multimorbidity: self-efficacy and the two faces of social support. *European Journal of Ageing*, 8(1), pp.3-12.

Watt, D., 2007. On becoming a qualitative researcher: the value of Reflexivity. *The Qualitative Report*, 12(1), pp.82-101.

Watts, J. H., 2008. Emotion, empathy and exit: reflections on doing ethnographic qualitative research on sensitive topics. *Medical Sociology Online,* 3(2), pp.3-14.

Welch, V., Hatton, C., Emerson, E., Collins, M., Robertson, J., Langer, S. and Wells, E., 2012. Using direct payments to fund short breaks for families with a disabled child. *Child: Care, Health and Development*, *38*(6), pp.900-909.

Wengraf, T., 2001. *Qualitative Research Interviewing : Biographic Narrative and Semi-Structured Methods.* London: SAGE.

White, N. and Hastings, R. P., 2004. Social and professional support for parents of adolescents with severe intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 17(3), pp.181-190.

WHO-WB, 2011. World Disability Report 2011. Malta, World Health Organisation and World Bank.

Wickenden, A., Nixon, S. and Yoshida, K. K., 2013. Disabling Sexualities: Exploring The Impact of The Intersection of HIV, Disability and Gender on The Sexualities of Women in Zambia. *African Journal of Disability*, 2(1), pp.1-8.

Wiles, R., Heath, S., Crow, G. and Charles, V., 2005. Informed consent in social research: A literature review. *National Centre for Research Methods Review Papers,* NCRM/001.

Willett, J. and Deegan, M., 2001. Liminality and disability: rites of passage and community in hypermodern society. *Disability Studies Quarterly*, 21(3), pp.137-152.

Williams, S., 2000. Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept. *Sociology of Health and Illness*, 22(1), pp.40-67.

Wills, A.J., 1985. An introduction to the history of central Africa: Zambia, Malawi, and Zimbabwe. Oxford: Oxford University Press.

Wilson, A. R., 2013. *Situating Intersectionality : Politics, Policy, and Power*. Basingstoke: Palgrave Macmillan.

Wilson, C., 2011. The impact on mothers raising a child and significant disabilies in the developing world. Master thesis.

Wilson, S. (2007). 'When you have children, you're obliged to live': motherhood, chronic illness and biographical disruption. *Sociology of Health and Illness*, 29(4), pp.610-626.

Winker, G. and Degele, N., 2011. Intersectionality as multi-level analysis: dealing with social inequality. *European Journal of Women's Studies*, 18(1), pp.51-66.

Woodman, A. C., 2014. Trajectories of stress among parents of children with disabilities: a dyadic analysis. *Family Relations*, 63(1), pp.39-54.

Woodman, A.C. and Hauser-Cram, P., 2013. The role of coping strategies in predicting change in parenting efficacy and depressive symptoms among mothers of adolescents with developmental disabilities. *Journal of Intellectual Disability Research*, 57(6), pp.513-530.

World Health Organization. WHO Traditional Medicine Strategy 2002-2005.

Yoshida, K., Hanass-Hancock, J., Nixon, S. and Bond, V., 2014. Using intersectionality to explore experiences of disability and HIV among women and men in Zambia. *Disability and Rehabilitation*, 36(25), pp.2161-2168.

Yuval-Davis, N., 2006. Intersectionality and feminist politics. *European Journal of Women's Studies*, 3(3), pp.193-209.

Zambian Government, 2012. *Persons with Disabilities Act of 2012*. Lusaka: Government Printers.

Zimmerman, M. A. and Warschausky, S., 1998. Empowerment theory for rehabilitation research: conceptual and methodological issues. *Rehabilitation Psychology*, 43(1), pp.3-16.

Zimmerman, M. A., 2000. Empowerment Theory. *Handbook of Community Psychology*. Springer US, pp.43-63.

Zulu, E., 2016. "Watipa Leza": a critical re-engagement of nsenga (African) religious values and disability. *Journal of Disability and Religion*, 20(1-2), pp.84-92.

Zuna, N. I., Brown, I. and Brown, R. I., 2014. Family quality of life in intellectual and developmental disabilities: a support-based framework. *International Public Health Journal,* 6(2), pp.161-184.

Appendices
APPENDIX A: Ethical Approval Form

THE UNIVERSITY OF
WARWICK

Humanities and Social Sciences

Research Ethics Committee
Kirby Corner Road
Coventry
CV4 8UW

23 February 2015

Dr Christine Harrison
Centre for Lifelong Learning
University of Warwick
Coventry
CV4 8UW

Dear Dr Harrison,

Ethical Application Reference: 58/14-15

Title: The Impact on Mothers Raising a Child with Mild to Severe Disabilities in a Developing Country. A case Study of Lusaka and Kaoma, Zambia

Thank you for submitting your application to the Humanities and Social Sciences Research Ethics Sub-Committee for Chair's approval.

We are pleased to advise you that, under the authority delegated to us by the University of Warwick Research Ethics Committee, full approval for your project is hereby granted for the period of 42 months effective from the date of this letter.

Any material changes to any aspect of the project will require further consideration by the Committee and the PI is required to notify the Committee as early as possible should they wish to make any such changes.

May I take this opportunity to wish you the very best of luck with this study.

Yours sincerely

Dr Friederike Schlaghecken
Chair, Humanities and Social Sciences Research Ethics Sub-Committee

APPENDIX B: Introduction Letter

THE UNIVERSITY OF

WARWICK

LIFELONG LEARNING

31 March 2015

To whom it may concern
Re: Masauso Chirwa

I am writing to respectfully confirm that Masauso Chirwa is currently a PhD student in the Centre for Lifelong Learning in the University of Warwick in the United Kingdom. His research title is:
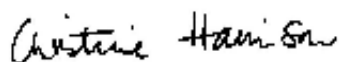
The impact of poverty on gender roles: the perspectives of women in Zambia caring for disabled children

As you can see, his research will be conducted in Zambia. Masauso's proposal has been the subject of full ethical scrutiny in the University and he has received ethical clearance to begin his fieldwork. As part of this, he will be approaching a number of individuals and organisations in order to brief them in full about his research and, in some instances, to seek advice and assistance in accessing research participants or disseminating his findings.

A main objective of Masauso's research is to improve the lives of disabled children and their mothers in terms of their health, education and wellbeing. He will gladly provide any organisations with which he has contact with a detailed report of his findings and their policy implications, and a shorter summary for ease of access. We very much hope that these will benefit agencies in this field.

As one of Masauso's supervisors, I wanted to introduce him to you, to support the authenticiy of his work and, on his behalf, to say how grateful we will be for any co-operation you can give him. My contact details are below if you need to contact me at anytime in connection with Masauso's research.

Many thanks in anticipation.

Yours fathfully
Dr Christine Harrison
Associate Professor
Centre for Lifelong Learning
University of Warwick
Coventry CV4 7AL
UK +44 2476 523541   c.harrison@warwick.ac.uk

APPENDIX C: Information Sheet

Information Sheet for Mothers

Research Title

The Impact on Poverty on Gender Roles: the Perspectives of Women in Zambia caring for Disabled Children

Research Supervisors

Christine Harrison and Barbara Merrill

You are invited to participate in this study. However, it is important to understand the rationale for doing this research before making a decision. Kindly, read through the information provided below. Whatever decision you will make will be respected.

Who Am I?

My name is Masauso Chirwa. I am a PhD researcher at the Centre for Lifelong Learning, University of Warwick in the United Kingdom. I have previously undertaken research involving women, children and the disabled.

Purpose of the study

This research is about the experiences of parenting a child with moderate to severe disabilities. I believe that mothers hold the key to the future as they have the responsibility of teaching societal values and socially acceptable behaviours to their children. They also play an important role in uplifting the living standards of their children. The study's aim is therefore, to get your views with regard to among other things:

➢ What it is like to become a mother and raise a child with moderate to severe disabilities

➢ How parenting a disabled child affects the socio-economic wellbeing of the family

➢ What are the joys and challenges associated with parenting a disabled child

➢ Your, and society's perceptions and attitudes towards disabilities, and how these affect power dynamics at individual, household and societal level, and how disability and motherhood combined impact on these relations

➢ Socio-cultural factors that perpetuate the erroneous notion that mothers of disabled children are somehow of lesser value than their counterparts who do not have disabled children

➢ The support and services available/needed to help you overcome challenges you face

Do I have to Participate?

Participation is voluntary. If you decide to take part, I will give you the information sheet which you will keep. I will also request you to consent by way of signing a form. Kindly note, that you have the right to withdraw from the study anytime without even giving reasons. You are also free not to answer some of the questions.

Interview Process

Should you decide to take part, among other issues, the interview will cover your experience of becoming and being a mother of a child with disabilities. I would also like us to discuss the joys and challenges, if any, that come with parenting such a child. With

your permission, I intend to audio-record and transcribe the interview. You will decide where and when you would like us to have the interview.

Confidentiality and Anonymity

Everything that will be discussed during the interview will be kept strictly confidential. You do are obliged to provide your name, village or township. All your identifiers will be sufficiently removed from the transcripts. This will ensure that you are protected from being identified. The interview will not be discussed with other people, except my two supervisors who are in the United Kingdom are the only ones who will see the anonymised transcripts. The reason for them seeing the transcripts will be to ensure quality of data being collected.

Findings

The findings of this study will be presented at academic conferences and in journals. However, despite this, anonymity and confidentiality will be strictly adhered to. It is also hoped that the findings will be presented to relevant government institutions and non-governmental organisations.

For any further information, you may contact the University of Warwick:

Christine Harrison   Barbara Merrill
C.Harrison@warwick.ac.uk   Barbara.Merrill@warwick.ac.uk
Tel: +44 (0) 2476523541   Tel: +44 (0) 2476523787

Thank you!

Demographic Data

1. Tell me a little about yourself and your family?
   a) How old is (mention the child's name)?

   b) Do you have other children apart from him/her?

   c) How old are other children?

   d) What are other children doing? Are they at school?

2. What is your level of education?

3. And what is your occupation?

4. Who is the breadwinner in your family? Do you live with your spouse?

5. How many people live in your household? How many of these help in providing for the family?

6. How many are at school? What grades are they doing?

7. Taking a range of ages 15-19, 20-25, 26-30, 31-35 and so on and so forth, which age brackets do you fall under?

Understanding of Disability

1. What type of impairment does your child have?

2. When was it diagnosed?

3. What were the concerns about your child that led you to get him evaluated for (name of impairment)?

4. What were your initial thoughts when (mention the child's name) was diagnosed with an impairment?

5. What was the first thing you did when you found out?

6. How did your other children react and what has been the impact on their lives?

7. How does this affect your child's life? Brothers and sisters?

8. How did your spouse, the extended family and your friends react to you and your child?

9. What could be the causes of disabilities/impairments? How do you know this is the cause?

Joys and Challenges of Parenting a Disabled Child

1. What was life like before you had (mention the child's name)?

2. As a parent of a child with disabilities, have any of your dreams changed?

3. Has having a child with disabilities affected your working life? How would you describe your relationship with your spouse, other family members and the community (neighbours)?

4. Beyond the day-day business of extra doctor appointments, school..etc…in what other ways is the family life a challenge by having a child with disabilities?

5. What has been the most difficult moments or conversations for you as a parent of a disabled child?

6. What challenges do you and your family experience in supporting your child in our country, Zambia, in this age of economic challenges? How has the child affected your life and your family's life?

7. How do you handle the financial difficulties associated with raising a disabled child?

8. What is the greatest moment to date that you have had with your child? What are couple of the great moments with your child?

9. What is the best thing about your child that the world doesn't see?

10. What have you learnt from raising (mention child's name)?

11. What in your opinion is the most important thing to know about how a child with disabilities affects family relations?

Emotional, Social Support and Coping Strategies

1. How do you perceive stress?

2. Think specifically about stress on a scale of 1 and 10, with 1 being less stressed, please tell me the level of stress that you experience from your child giving role?

3. What level of stress would you want to be at?

4. What do you think should be done to get you to less stress levels?

5. How much control do you have over stress, can you do something about it?

6. Do you take time away from your care giving role/duty? How easy is it for you to do other things?

7. How important is support in your life with your child?

8. Where do you get your help in caring for (mention the name of the child)?

9. What kind of support has been most helpful to you?

10. Did you receive early intervention services? If so, how did they help or not help your child?

11. Do you have support group or any type of support system to help you?

12. Have you made any contact with other families/parents who have children with disabilities? Have you shared experiences from your daily life with them?

13. What has been your experience with professionals such as health personnel, social workers or teachers?

14. What kind of services do you think are absolute necessity for children like (mention the child's name)? Are there available in Kaoma/Lusaka?

Future Expectations

1. What fears do you have as a parent of a child with disabilities? And how do you address them?

2. What concerns do you have now that he/she is closer to being an adult?

3. Where do you see your child 10 years from now? And where do you see yourself 10 years from now?

4. What tips would you give new parents dealing with disabilities? Other mothers like yourself?

5. If you were giving advice to a professional who needed to explain to parents that their child has a special need, what would that advice be?

6. Is there one thing that you would love for people not familiar with raising children with disabilities to know?

7. What other information would you like me to know about working with children with disabilities?

8. What advice do you have for the government?

9. Finally, what has (child's name) meant to you?

Thank You!

APPENDIX E: Consent Form

Research Topic: Impact on Mothers raising children with moderate to severe disabilities in a developing world. A case study of Zambia

Research Supervisors: Christine Harrison and Barbara Merrill

	Kindly tick the appropriate one
I hereby agree to voluntarily take part in the study.	**Yes/No**

I hereby agree to voluntarily take part in the study.   **Yes/No**

The researcher has given me the information sheet.   **Yes/No**

The researcher has explained to me in writing the purpose of the study. **Yes/No**

I agree that he can audio-record the interview.   **Yes/No**

I understand that the information will be held in confidential and that all personal information will be removed to protect my identity.   **Yes/No**

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.   **Yes/No**

……………………………………………….   Date:………………………….
Signature

………………………………………………
Name

APPENDIX F: Coded Transcript

Except from an Interview

Masauso: Before you were told at hospital about cerebral palsy, what was on your mind?

[handwritten: Initial symptoms]
[handwritten: Beliefs about the child's condition]

Emma [L]:   What was in my mind was that suddenly the child has changed I was thinking that maybe it could be related to bad omens from other people, so we even started going to traditional healers but his condition was not improving.

[handwritten: Treatment options]

Masauso: Did you take the child to the traditional healer?

[handwritten: Response to treatment]

Emma [L]:   No. I first started taking him to the hospital but it was very strange that he wasn't getting better. Then with time I thought of trying traditional healers.

[handwritten: Accessing healthcare s]
[handwritten: Alternative treatment]

Masauso: Did you go alone to see the traditional healer?

[handwritten: Decision making]

Emma [L]:   I used to go with Albert's grandmother. Because his condition was not improving, she suggested that we consult the traditional healer. It wasn't an ordinary illness, she was also sure that there was someone behind it.

[handwritten: Response to treatment]
[handwritten: Mothers belief of child's condition]

[handwritten: Family's belief about condition]

Masauso: Ok, so his grandmother thought that there was someone behind Albert's condition. What do you think could have caused his condition?

Emma [L]:   He was bewitched. *[handwritten: – Belief]*

Masauso: So you went to the traditional healer, what did the healer say?

[handwritten: Treatment options]

Emma [L]:   I have actually been to three tradition healers, the first one we saw told us that this child is about to be used for business rituals, some people want to

[handwritten: Myths and beliefs]

[handwritten: Myths & beliefs]

use him for debt recovery. He said that there are two people who are fighting for him, it is not from your family when one of them takes him that will be the end of him, and he will die. This is what the first tradition healer told us. She was very sure about that. *[handwritten: Myths a beliefs]*

Masauso: According to her those two people fighting over him when one of them wins that will mean the child will die, would he? What did you think of the traditional healer said?

Emma [L]:   Yes the child will die. The traditional healer was right. *[handwritten: – Beliefs]*

1

320

Masauso: When you were told that, what came to you mind?

Emma [L]:   I asked her why they were fighting over him how about if no one wins — *Belief*
him. She said that until one of them wins that is when they will stop fighting. She
even give us some herbal medicine that we should be bathing him with it. → *Treatment*

Masauso: Did you see any change?

Response to treatment   *Treatment option*

Emma [L]:   No we didn't see any change so we decided to go and consult another
traditional healer.

Masauso: Who suggested that you seek the services of another traditional
healer?

Role of family (Decision making)

Emma [L]:   Albert's grandmother.

Masauso: What did you think of the idea of seeing another traditional healer?

Emma [L]:   I was totally for the idea. My son wasn't getting better. I needed him
to recover and I was prepared to do anything just to see him get better. ← *Mother's reaction*

Masauso: What did the second traditional healer say?

Belief

Emma [L]:   The second one said that Albert's paternal grandfather was the one
who had done this to him, and I immediately believed him. ← *Mother's reaction*

Masauso: Even the grandmother was there?

Emma [L]:   Yes, she was.

Masauso: What did she say?

Mother's reaction

Emma [L]:   There was nothing that she said. Then I thought why didn't they
bewitch me and leave Albert alone. I went and shouted and insulted Albert's
grandfather. It was a very big fight. I told him to reverse the illness or I was going to

Mother's reaction

revenge. Then he went and reported the matter to police. It was a very tense
situation. But in the end the matter was settled outside the court of law. The two

Revenge

families sat down and discussed. It was agreed that we give him a goat for him not to
take the case to court, and we gave him a goat.

Compensation

APPENDIX G: Coding Frame
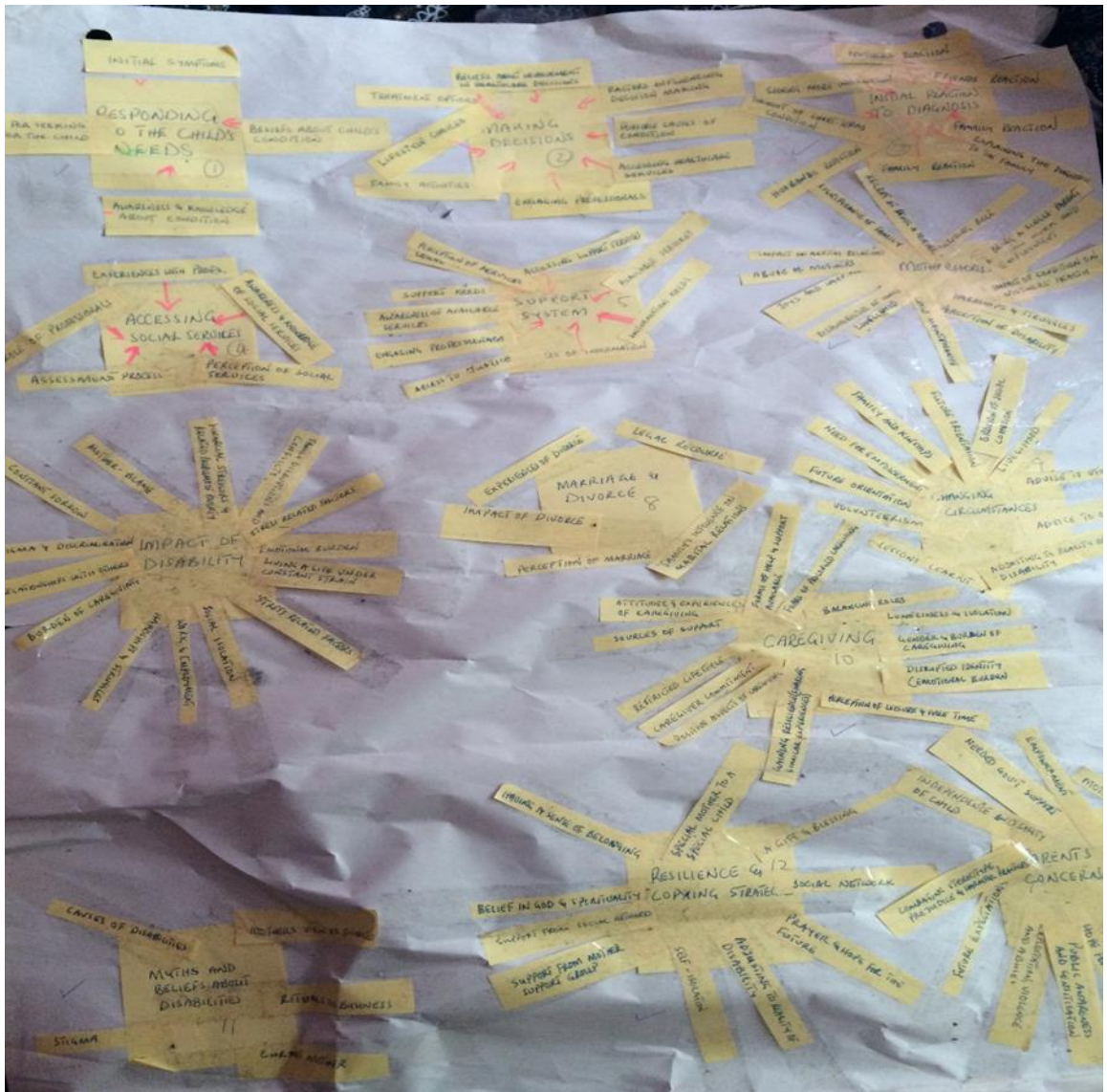
APPENDIX H: Timeline for Data Activities

	Year	2015																																
	Months	MAY				JUNE				JULY				AUGUST				SEPT				OCT				NOV				DEC			
	Weeks	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4
	Pre-defined fieldwork																																
1.	Meeting gatekeepers-Lusaka	▓	▓	▓	▓	▓																											
2.	Meeting gatekeepers-Kaoma																	▓	▓														
3.	Meeting gov't/NGOs officials-Lusaka		▓	▓																													
4.	Meeting gov't/NGOs officials-Kaoma																		▓	▓													
5.	Focus group meetings- Lusaka					▓																											
6.	Focus group meetings- Kaoma																		▓														
	Fieldwork phase																																
1.	Biographical interviews in Lusaka						▓	▓	▓	▓	▓	▓	▓	▓	▓	▓	▓																
2.	Biographical interview in Kaoma																					▓	▓	▓	▓	▓	▓	▓	▓	▓	▓	▓	
3.	Transcribing						▓	▓	▓	▓	▓	▓	▓	▓	▓	▓	▓	▓	▓	▓	▓	▓	▓	▓	▓	▓	▓	▓	▓	▓	▓	▓	
4.	Data analysis						▓	▓	▓	▓	▓	▓	▓	▓	▓	▓	▓	▓	▓	▓	▓	▓	▓	▓	▓	▓	▓	▓	▓	▓	▓	▓	
5.	Exit meeting- Lusaka																▓																
6.	Exit meeting- Kaoma																																▓