

The family-support needs of Zimbabwean asylum-seeking families living with their disabled children in the Western Cape Province of South Africa

By

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ABSTRACT

There is much evidence indicating that asylum-seeking families living with a child with disability experience poverty to a greater degree than those living without one. In the South African context, Zimbabwean asylum-seeking families that are driven into the country by poverty, lack of health facilities for their disabled children and discrimination are seriously disadvantaged by their lack of citizenship. This study on the family-support needs, perspectives and experiences of Zimbabwean asylum-seeking families living with children with disabilities explores the accumulation of impacts when these families attempt to access assistance, education and health care in South Africa. I begin with these families' background in Zimbabwe, a background on immigration into South Africa and a discussion of the effects of the country's immigration policy on immigrant families with disabled children.

I then present a study carried out in Cape Town, South Africa, where 10 interviews were conducted with families of disabled children and 2 interviews with key informants from People Against Suffering, Oppression and Poverty (PASSOP), a local non-governmental organisation that deals with Cape Town-based refugees and asylum seekers from all over the world. The respondents were all Zimbabweans with children with disabilities. The findings indicate that Zimbabwean asylum families living with disabled children like any other asylum seeking families gain access to health care and education in Cape Town- South Africa. Though they are able to access health and education, the findings suggest that they face serious challenges, such as discrimination and stigmatisation. Zimbabwean asylum seeking families living with their disabled children are discriminated on the basis of their nationality, and they are more seriously disadvantaged by their lack of access to financial support, in the form of care-dependency grants, and by their limited access to disability support networks. The study concludes by recommending that the status of disabled immigrants and their families be revised with regard to the support that these families require and are able to access.

DECLARATION

I know that plagiarism is wrong. Plagiarism is to use another's work and pretend that it is one's own. All citations used that are not mine have been referenced accordingly.

I, Willson Tarusarira, declare that the thesis "The family-support needs of Zimbabwean asylum-seeking families living with their disabled children in the Western Cape Province of South Africa" is my own work. Every quotation from the work(s) of other people used in this dissertation is cited and accordingly referenced. This dissertation has never been submitted to any university before with the intention of awarding a degree.

W. Tarusarira

29.02.2016

Date

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LIST OF ACRONYMS

AIDS	:	Acquired Immune Deficiency Syndrome
CTRC	:	Cape Town Refugee Centre
DHA	:	Department of Home Affairs
HIV	:	Human Immune Deficiency Syndrome
PASSOP	:	People Against Suffering Oppression and Poverty
PWD	:	People Living with Disabilities
SADC	:	Southern African Development Committee
SASSA	:	The South African Social Security Agency
SAMP	:	Southern African Migration Programme
UNHCR	:	United Nations Human Rights council
ZDP	:	Zimbabwe Dispensation Permit
ZSDP	:	Zimbabwe Special Dispensation Permit

1. CHAPTER ONE: FRAMING THE STUDY

This chapter will give a brief background of Zimbabwean asylum-seeking families living with disabled children in Cape Town. A brief background description of Zimbabwean migration to South Africa post-Zimbabwe's independence in 1980 to the present day will also be provided. The problem statement, research question and focus, rationale and context of the study will be laid out. The chapter also presents the research aim, objectives, purpose and theoretical framing of the study. Finally, a brief summary of each chapter in the study is included.

1.1 Introduction

Family support for children living with disabilities is one of the South African government's central concerns in ensuring the well-being of children with disabilities (Western Cape Government, 2014). Support is provided by the government to legalised refugees, permanent residents and South African children living with disabilities through the care-dependency grant for people living with disabilities. However, asylum-seeking families (in this case Zimbabwean asylum-seeking families) living with children with disabilities in South Africa do not receive any income from the government to aid in the well-being of their children (SASSA, 2010). This exposes these families to the different challenges that stem from barriers to access, such as cost of care and societal stigma. I carried out this research to find out about their way of life, experiences, and voice and resilience strategies.

1.2 Background to the Study

In general, asylum seekers and refugees encounter numerous challenges and disadvantages in the countries in which they are hosted. Among these challenges are the languages they speak, which may make it difficult for host countries to find appropriate interpreters (SAMP, 2008). This language barrier means that, even if there is available support for this population, communication can hinder the provision of this support. Apart from the language issue, asylum seekers have no existing social networks to rely on for informal support. Social networks are very

important for families, especially families living with a disabled member (Sarason, et al, 1990). Some of these asylum-seeking families may have arrived alone in a foreign country with a child with a disability, and in many cases they settle away from available support. Some families may decide to settle in informal-settlement communities, where they pay less rent. This decision makes these families much more vulnerable to isolation (Lawyers of Human Rights, 2009). Asylum-seeking families are likely to be faced with the challenge of income restriction and are likely to find themselves working as cheap labour, with disabled children left at home (SAMP, 2011).

Lastly, but possibly most significantly, immigration status—and the actual and perceived impact of immigration status on an asylum-seeking family (SAMP, 2011) caring for a disabled child and trying to access benefits and entitlements—still stands as a barrier to the equal treatment of Zimbabwe’s asylum-seeking families living with disabled children in South Africa.

This study is therefore concerned with the family-support needs of displaced asylum-seeking families from Zimbabwe living with disabled children in Cape Town. It seeks to investigate the accumulation of impacts when Zimbabwean asylum-seeking families attempt to access assistance for their children’s welfare, including education, care giving and health care in South Africa. It must be noted that the challenges that these families encounter are mainly due to a lack of financial support. Leaving a child with a disability alone or with a stranger at home in order to search for employment likely puts the child in danger. On the other hand, taking care of a child with a disability without having a household income means nothing but widespread suffering for the child and the family. In order for the child to have a normal, active life like other able-bodied children, a family member must be working to bring in income or the family has to receive a certain form of support, hence, the importance of social-support needs for these families.

The emphasis of this study will be on family support systems. However, putting emphasis on family support systems does not mean that attention is not given to the disabled child: it only means that it is important that the parents or any family member looking after the child be well supported, in order to keep him or her

physically and emotionally healthy and ensure his or her well-being and upkeep. This care can only be given if the caregiver or family member is supported with the resources that are essential for the child. It is for this reason that I directed my research towards the family members who care for the child.

The challenges faced by Zimbabwean asylum seekers as a group, and by Zimbabwean families living with disabled children in particular, will be highlighted. Examples of research implemented in developed countries will be discussed in this study, in a bid to explore the essential support needs of a family living with a child with a disability. This chapter will stream down to focus on the family support needs required by asylum seekers from Zimbabwe who are living with their disabled children in Cape Town, South Africa.

1.2.1 Rationale/Problem Statement

This study on the needs and supports of Zimbabwean asylum-seeking families living with children with disabilities in South Africa is significant, given the current situation that refugees are facing globally. The existing refugee calamity in Europe brings to light the legal challenges and humanitarian crisis that asylum seekers face. The complications of the international laws governing asylum seekers seem to be highlighted by the present invasion of refugees into Europe. This invasion has exposed not only the seemingly outdated international laws governing migrants but also the interpretation of such laws. The 1976 protocol (Noll, 2005) does not encompass the current challenges that people face in their countries that may contribute to their migration. Problems such as the economy, the climate and terrorism are not covered in the protocol as possible contributors to the migration of people. In addition, there is silence surrounding disability, and especially child disability, as a reason for migration.

Refugees and asylum seekers in Europe are reported to be facing health problems. The World Health Organisation (2015) reported that newly arrived migrants in Europe face health problems that include accidental injuries, pregnancy and delivery-related complications. In the current European refugee crisis, female migrants are facing challenges related to sexual and reproductive health and violence (WHO, 2015).

Though the refugee crisis in South Africa has been in the limelight for the past few years, attention has shifted to the recent European refugee crisis. Less attention is given now to asylum-seeking families in Africa, and especially to Zimbabwean asylum seekers migrating to South Africa. Research that leads to an understanding of the factors affecting Zimbabwean asylum seekers living with children with disabilities in South Africa is of interest both from a theoretical perspective, in order to understand better how various factors influence these families' functioning, and from a practical perspective, in order to develop more effective ways of providing services. I selected this issue because it is both an area of individual interest and an area that has been ignored. I was once a Zimbabwean asylum seeker in South Africa and have gone through some of the challenges that asylum seekers from Zimbabwe with disabled children are going through. By carrying out research that focuses on the family support needs of Zimbabwean asylum seekers living with their disabled children in South Africa, we can begin to make some of the essential alterations to the support already in place, which may be in need of reassessment and remodelling in order to provide the best holistic support for asylum-seeking families. This research is especially essential in its attempt to hear the voices of these Zimbabwean asylum seekers as they express their views and experiences.

1.2.2 Aim of the Study

This study aims to explore the perceptions and experiences of Zimbabwean asylum-seeking families living with children with disabilities regarding the provision of family support in Cape Town. This exploration is effected in order to identify areas of support that can be improved or developed to enhance the quality of their lives while they are not yet accorded refugee or permanent-residence status. This research also seeks to give these families a voice and, thereby, to better understand their life experiences.

1.2.3 Research Questions

This study centres on the following research questions:

- What are the perspectives and experiences of a Zimbabwean asylum-seeking family living with a disabled child in Cape Town, South Africa?

- What are the family support needs of Zimbabwean asylum-seeking families living with a disabled child in Cape Town, South Africa?
- What are the resilience strategies employed by Zimbabwean asylum-seeking families living with children with disabilities in Cape Town, South Africa?

1.2.4 Objectives

This study sets out to:

- Explore the impact of disability on the family in Zimbabwe and South Africa;
- Identify barriers to accessing care and education for disabled family members;
- Identify existing support structures for families living with disabled children.

1.3 Overview of Chapters

The following summary of the chapters gives an overview of the entire study on the family support, experiences and perspectives of Zimbabwean asylum seekers living with children with disabilities in Cape Town. It highlights the focus of each chapter and the key points raised in each chapter.

1.3.1 Chapter One Overview

This chapter introduced the thesis. It highlighted the nature of the South African government's policy on children living with disabilities within its borders. In showing why this study is vital, a brief discussion of the refugee crisis in Europe was raised with a focus on the health challenges faced by migrants in Europe. In light of the challenges faced by immigrants in Europe, this chapter managed to justify why a study of Zimbabwean asylum-seeking families with disabled children is important in South Africa. The research question and objectives of the study were also dealt with in this chapter.

1.3.2 Chapter Two Overview

In this chapter, the literature on family support and its definition is reviewed. The literature on family support for asylum seekers in Africa is scarce. Literature is

available from developed countries, where family support is revealed as being key to the well-being of a child living with a disability. This literature will be employed in this study in a bid to establish whether family support for Zimbabwean asylum seekers living with disabled children in Cape Town exists and what the families' views are on such social support. From the literature available, it seems that constant advocacy has changed the conceptual boundaries from a medical model to a social- and rights-based approach to disability. However, little attention has been devoted to whether this paradigm shift has taken place for those outside the citizenship community. The present study seeks to address this gap, investigating the South African government's approach to family support for Zimbabwean asylum seekers living with disabled children in Cape Town.

1.3.3 Chapter Three Overview

This chapter presents the methodology and design of the study. The motivation for employing a qualitative, descriptive methodology is also given. The chapter deliberates on data-collection methods, analysis and data management. Lastly this chapter discusses the ethical considerations of the study and the steps taken to ensure rigour.

1.3.4 Chapter Four Overview

The study's findings will be presented in this chapter. The viewpoints of the participants regarding the study's interest are recorded. Important quotes are used as support.

1.3.5 Chapter Five Overview

This is the discussion chapter. It discusses the results of the study, connecting it to current literature and practices. The most important areas of discussion focused on the findings related to the family support of asylum-seeking families with children with disabilities in Cape Town, South Africa.

1.3.6 Chapter Six Overview

This chapter is the conclusion chapter. It gives a summary of all the chapters of the thesis and reintroduces the main findings. The researcher's limitations, recommendations and reflections will be covered in this chapter.

2. CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction and Overview

The overall aim of this research is to produce an understanding of the perceptions and experiences of Zimbabwean asylum-seeking families living with disabled children in Cape Town with regard to the provision of family support, in order to identify areas of support that can be improved or developed to boost the quality of their lives while they are not yet accorded refugee or permanent residence status. The researcher therefore seeks to explore the accumulation of impacts when Zimbabwean asylum seeker families with disabled children attempt to access assistance, education and health care in South Africa.

This chapter will give a brief background description of Zimbabwean migration to South Africa, from independence in 1980 to the present day. A discussion on the challenges faced by Zimbabwean asylum seekers as a group, and the challenges of asylum seekers living with disabled children, will be presented. Examples of research implemented in developed countries will be discussed in a bid to explore the support needs of families living with disabled children. The research will discuss not only the range of support systems required by asylum-seeking families living with disabled children but also their support needs in general terms.

Furthermore, the research will employ “ecological theory” to bring to light the interconnectedness of the levels of support that affect Zimbabwean asylum families living with disabled children, away from their home country.

2.2 Background of Zimbabwean Migration to South Africa

The migration of Zimbabweans to South Africa dates back to the 1980s, when white people staying in Zimbabwe migrated to South Africa soon after the Lancaster House agreement ended the Rhodesian government (SAMP, 2008). The early 1990s witnessed another phase that was characterised by young men migrating to South Africa due to the drought that year in Zimbabwe (Hassim, 2008). In 2000, a greater number of Zimbabweans migrated to South Africa due to the downturn in the political and economic situation (Monson, 2009).

As the political and economic situation degenerated in 2005, the sizeable number of Zimbabweans entering and staying in South Africa as asylum seekers increased (Lawyers of Human Rights, 2009). Contributing to the debate on Zimbabweans migrating to South Africa, Monson (2009) found out that in the year 2000, a great number of Zimbabweans migrated to South Africa due to the downturn in the political and economic situation. Monson's assertion is also congruent with that of the Lawyers for Human Rights (2009) reported that, as the political and economic situation worsened in 2005, the large number of Zimbabweans entering and staying in South Africa as asylum seekers increased.

Demonstrating the influx of Zimbabwean asylum seekers in South Africa, Lawyers for Human Rights (2009) reported that South Africa has the world's largest number of registered asylum seekers, most of them Zimbabwean. The numbers have risen steadily over the past six years. There were 20,000 new applications in 2005; 50,000 in 2007; and 264,000 in 2008, with similar numbers in 2010 (Lawyers of Human Rights, 2009).

But what are the pushing factors that compel Zimbabwean asylum-seeking families with disabled children to enter into a foreign country? Examining these factors will offer an understanding of why these asylum seekers hoped for a better life when crossing the border, despite not knowing the situation in South Africa.

According to the Leonard Cheshire Disability Zimbabwe Trust (2010), the migration of Zimbabweans is premised on the fact that disabled people are among the most marginalised, socially excluded and poorest groups in Zimbabwe. Leonard Cheshire Disability Zimbabwe Trust (2010) reported that increasing poverty levels, the HIV/AIDS pandemic and other prevalent health conditions, the economic hardships and a prevailing negative culture toward people living with disabilities are some of the factors that contributed to Zimbabweans living with children with disabilities migrating to South Africa.

2.2.1 Legal Status

In order to understand the legal challenges that asylum-seeking Zimbabwean families living with their disabled children face in Cape Town South Africa, it is vital

to distinguish between a refugee and an asylum seeker, as these terms are often confused. According to the United Nations Convention of 1951 (UNHCR), “a refugee is any person, owing to well-founded fear of being persecuted for reasons of race, religion, and nationality, membership of a particular group or political opinion, is outside the country of his nationality and is unable to or owing to such fear, is unwilling to avail himself of protection of that country.”

On the other hand, an asylum seeker is a person seeking international protection, whose claim has not yet been decided by UNHCR or the relevant authorities of the country in which he/she has requested refugee status (UNHCR, 2002). In the South African context, not all Zimbabwean asylum seekers will ultimately be accorded refugee status, but every Zimbabwean refugee was initially an asylum seeker. What this therefore entails is that those remaining in the category of asylum seeker will find themselves further limited in their access to certain basic needs that may assist them in the upkeep and welfare of their disabled child. For example, asylum seekers are not eligible to receive a social grant, even if they are disabled. This is, however, different in the case of a refugee. Although a refugee still has limited problems when accessing certain needs, he or she is in a position of relative advantage when compared to the asylum seeker.

Though the above-cited reasons have contributed to a greater incidence of Zimbabweans migrating to South Africa, the migration of Zimbabweans to South Africa is not a new phenomenon. The increased flow in asylum seekers in recent years has turned attention to the manner in which South Africa deals with the provision of services to asylum seekers, especially those from Zimbabwe. In addition, South Africa’s immigration laws are steadily becoming restrictive. The number of Zimbabwean asylum seekers and refugees in South Africa has been estimated at 1.5 million, but determining how many of these might be undocumented is extremely complicated as some have a 90-day visa “at the moment” or are moving through the asylum-seeker process (Polzer, 2010)

Although the number of asylum applications is high at the Department of Home Affairs in South Africa, only a minority of applicants receive refugee status or exceptional leave to remain in South Africa. A total of 44,423 Zimbabweans claimed

asylum in South Africa between 2005 and 2007. However, in 2004, 2005, and 2006, only 241 Zimbabweans were recognised as refugees (UNHCR, 2007).

Adding to the woes of asylum seekers in South Africa, the director of the refugee rights organisation People Against Suffering Oppression And Poverty (PASSOP) estimates that over 95% of asylum applications from Zimbabweans get rejected (PASSOP, 2011). In the face of a high number of applicants, the asylum process is completely overburdened and incapable of accommodating the many asylum seekers. The general inefficiency and corruption that has been widely documented at Home Affairs' Refugee Reception Offices across the country exacerbate these delays (PASSOP, 2011). As a result, it is common for an asylum seeker to have to wait for years for his or her status to be decided. When a decision is eventually reached, the outcome is negative for the vast majority of asylum seekers (PASSOP, 2011).

The high volume of asylum seekers and refugees flocking to South Africa in the past years in general, and of asylum seekers and children in particular, has attracted considerable attention in the press, and in the political, academic and public domain (CORMSA, 2009). Recent legislation has tightened the control over those entering South Africa and receiving refugee status, also adding more restrictions to the entitlements of asylum seekers and refugees and their access to different social services.

Polzer (2010) and Lawyers for Human Rights (LHR, 2006) are prominent in the literature that deals with the challenges of Zimbabwean migrants. They have carried out research to establish the total population and the challenges and experiences of Zimbabwean asylum seekers in South Africa, particularly with regard to their attempts to access employment, education and health services. They found out that Zimbabwean asylum seekers face serious challenges when looking for employment, at health centres, and when enrolling their children at schools. This was largely associated with their nationality (LHR, 2006). While neither of these studies address the disability burden for asylum-seeking families living with a disabled child, it is likely that asylum-seeking families have less access than local people to the basic services that are needed for the development and well-being of their disabled

children, despite having the same challenges that the local families living with disabled children face.

2.3 Disability and Migration

Disabled people and migrants represent significant minorities all over the globe (IOM, 2012; WHO, 2011). Migration is a worldwide phenomenon with a rough estimation of 216 million migrants across the world. The number of migrants who are disabled is not known, but using the current approximation of the prevalence of disability, it is reasonable to assume that between 10-15% of migrants are disabled (WHO, 2011).

The connection between disability and migration is difficult and to a degree unknown (WHO, 2011). The two groups encounter structural and systemic obstacles to affirming and realising their right to take part in society. Whereas disabled people have seen a growing respect with regard to their right to contribute fully in society, migrants encounter rising limitations in this regard. A key for migrants and the disabled is the problem of citizenship (WHO, 2011). While people living with disabilities have achieved an official recognition of their rights to take part wholly in society, in a number of countries migrants face various restrictions in this regard (Castles, 2010). Both encounter difficulties in their ability to realise citizenship rights, however these are defined. Migrants answer to a variety of drive and pull issues in their choice to leave their countries: war and economic challenges are principal among others.

Migration can be seen as a key aspect of social transformation in society today (Castles, 2010). However, for numerous countries, migration and certain types of migrants are still a problem. Immigration policies are, by their very nature, normative, seeking to ensure that migrants will “integrate” into their host society and be “productive”. Kostakopoulou (2010) argues that the notion of integration has shifted from being one concerned with equality and social inclusion to one that is principally concerned with the preservation of national norms and values, with such values being conditional on socio-political membership. Disabled people symbolise one such group who, through official policies, are seen as a “problem

migrant”. The rights of people living with disabilities to benefit from the same rights as those living without disabilities are ratified by a number of countries through the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

The immigration laws of host countries suggest that people living with disabilities are unable to productively contribute to the host country. Recently, the UK changed its immigration law, calling for migrants to be in receipt of a minimum income of £18,600 (Disability Rights Now, 2012). This will impact on people living with disabilities and their families, as families with a disabled member frequently have a lower household income. Similarly, the health requirement for visa applicants seeking to reside in Australia is such that many disabled people will fail to meet the requirement (Disability Rights Now, 2012). Such policies deny not only individuals but also families and communities the right to seek a better life. Not only do these policies entail a material impact on disabled people, but they also constitute a form of psycho-emotional disability, undermining the worth of individuals (Reeve, 2012).

While we can point to the ways in which migration policy seeks to forbid disabled people from full participation, disabled migrants are an unseen population (SCOPE, 2012), with their views, and the structural forces that shape their experiences of the migration process and their lives in their new countries, remaining unclear. Does the migration process itself create injury and disability? Does the interaction of migration policy with health or employment policy result in increasing impairment among groups? For example, the increasing criminalisation of undocumented migration denies individuals access to healthcare systems, which may result in illness and impairment (SCOPE, 2012). Disability rights activists and scholars all have a role to play in revealing and challenging the many, intersecting forms of repression experienced by disabled migrants, and stressing the capability and rights of all to meaningfully contribute to society.

2.4 Challenges for Parents Living with Disabled Children

The birth of a child in a family is an eagerly awaited experience and a time of rejoicing. The Shona tradition in Zimbabwe sees the arrival of a healthy child as a

blessing to the family. The Shona tradition, which is my tradition, asks many questions about whether the child will be similar to the mother or the father occupy all family members before the birth of a child. When the child is a boy, he is expected to resemble his father, and likewise, if the child is girl, she is expected to be like the mother, hence the Shona idiom "*akatodza baba vake or amai vake*" (he is like his father or her mother) is pronounced after the birth of a child by the elders. This is common in Zimbabwean cultures especially my Shona tradition where certain features must be likened to the biological parent or with somebody in the lineage of the child's father. Some families in the Shona traditions will go to the extent of giving names to children before they are even born, indicating how happy the family is to receive the baby. Because of this excitement, no parent is prepared to receive a child with a disability. This is mainly the reason why in my culture (Shona tradition) the child is not like the father when he or she is born with a disability or very ill. To show how a person living with a disability is a bad sign in Zimbabwean communities, pregnant women are instructed to not look at or associate with people living with disabilities or they may give birth themselves to a child with disabilities (Chimedza, 1999). This is the reason a child born with a disability is always the mother's fault (Addison, 1986). It is mainly on account of this unexpectedness of giving birth to a disabled child that African parents do not celebrate before the arrival of a child until they are sure that the baby is healthy and will live on (Addison, 1986).

Learning that one's child has a disability represents a major loss for all concerned (Bernier, 1990). With the loss of the ideal healthy child, family members move through the process of transitioning to the reality of having a child with a disability (Clarke, 2002). From the moment that parents begin to suspect that there is something "different" about their child, their journey of "family life" begins to depart from that of the norm (Cowie, Quinn, Gunning, and Gunning, 1998). With the birth of a disabled child, considered in the African worldview, existing relationships in the households, especially that between the spouses, may be negatively affected. The husband may start to spend more time with his mother and sisters, neglecting the mother of the disabled child. Apart from the strain on the relationship, parents of a disabled child may change their daily timetable. The time

to wake up automatically changes. With lack of support from the in-laws due to the disability of the child, the days of a family with a disabled child may start early and end late, as a great deal of responsibility is involved in caring for a disabled child (Chimedza, Peters, 1999).

Having adjusted to starting the day early and finishing late, the family is likely to cut some of its spending on other necessities so as to accommodate the therapies essential for raising a disabled child. The lifestyle of a family living with a disabled child is likely to be different from a family living with a typically developing child. For instance, a family living with a disabled child may require a specialised mode of transport for their child (for example, a wheel chair), an expense and responsibility that does not obtain in the case of a typically developing child. Beresford (2007) argues that parenting a disabled child goes beyond “ordinary” parenting. This is why one could argue that the situation of a family living with a disabled child is analogous to that of a migrant in a foreign land (Cowie et al., 1998). The journey that lies before such a person is indeed long and fraught with unexpected challenges and disappointments. It is during this moment that formal and informal support is vital to ease the burden of care.

With regard to further challenges associated with having a disabled child, Barnibill (2000) reports that families living with disabled children are economically marginalised on a number of accounts, such as parental ability to access to work (for example, the availability of appropriate and affordable childcare), difficulties when employers fail to recognise the parental responsibilities of parents living with disabled children, and impairment and disability-related costs. The failure by employees to recognise the parental responsibilities of such parents may work against Zimbabwean asylum-seeking families with disabled children, as they may opt to do away with their jobs in order to give maximum care to their children. However, losing employment may invite extra challenges, as these families do not receive the care dependency grant from the South African government, while still facing the challenges of having to provide for a disabled child.

For Zimbabwean asylum-seeking families living with disabled children in Cape Town, the inability to speak the local language adds to some of the existing challenges.

Language can lead to community marginalisation of these asylum-seeking families with disabled children. Having a child with a disability in a foreign community and not being able to speak the local language may be reason enough for their rejection by the communities at service centres such as clinics (SAMP, 2011).

As a result of these challenges, it is likely that families raising disabled children are confronted with doubts about their own capacities in nurturing their children's development, and therefore may experience serious crises of confidence in their parenting abilities (Bernier, 1990).

Though the above is relevant to the burden that families living with disabled children face, it is essential to note that some families may have a positive approach in having a disabled child. Some parents have different interpretations and views toward the condition of disabled children. Some families may receive a child with a disability as a blessing from God. When trying to understand the circumstances or meaning behind having a disabled child, researchers report that many parents take comfort in their spirituality, which helps them to view their child as a blessing or a test of their faith, as opposed to a burden (Blacher et al, 2005).

Kelly and McGilloway (2007) found that most participants with disabled children were satisfied with their lives and had realistic expectations for their children and their future, as well as positive coping methods. In a study of hope as a psychological resilience factor in parents of disabled children, Lloyd & Hastings (2009) established that hope offered an increase in the positive wellbeing of families and a decrease in their psychological distress. A positive perception by parents of disabled children may lead to a positive outcome in caring for a disabled child. Hence, Weinger (1999) discovered that mothers with a more positive perception of the disabled child gave a higher rating to the perceived functioning of their family.

Scholars studying the social support needs of families living with disabilities members state that there are many ways in which parents can reframe the disability experience into a positive one (Scorgie & Sobsey, 2000). In reframing the experience of disability, some families reported a sense of personal growth through their disabled child (Stainton & Besser, 1998). Apart from personal growth, Scorgie

and Sobsey (2000) wrote that families living with a disabled child reported that their child's disability has given them an increased sense of purpose. Improvement in relationships and social networks are some of the positive aspects that some families experience through their disabled child (Scorgie & Sobsey, 2000). For Ylven et al. (2006), a positive outlook on childhood disability correlates with decreased feelings of stress and burden.

In this section I have outlined the negative and positive perceptions of having a disabled child as reported by a selection of different families, and I have also explored the resilience that these families use in dealing with their circumstances. My research will now turn to a discussion on the support needs of a family living with a disabled child, regardless of whether the family views the child as a burden or a blessing.

2.5 Family Support

Family-support services are essential services that would enable disabled individuals of any age to live with their families and contribute to their communities (IASSIDD, 2013). The family support system is more than just a matter of financial services.

As highlighted before, this study acknowledges the problems associated with the definition of family support (Kagan, et al., 1987). Adding to the problems of this definition is the lack of literature in the field of family support on asylum-seeking families living with disabled children in South Africa and Africa at large.

The problems associated with the definition of family support maybe associated with its origins, where many interpretations have been offered. "Family support" (Kagan, et al., 1987) has taken on a variety of definitions since its inception in the late 1970s. The term was used in reference to friendly local programmes that were meant to support the parents of young children with "whatever it takes" (Kagan, et al., 1987). These local programmes, or the "family resource programs," as they were initially called, were voluntary and provided resources for all families, most of them on a "drop-in" basis where parents did not need to sign up or pay for the opportunity to participate (Kagan, et al., 1987). Family support is also seen as a style of work and encompasses a wide range of activities that strengthen positive

informal social networks through community-based programmes and services (Rizzolo et al., 2009). The main focus of these services is on early intervention, aiming to promote and protect the health, well-being and rights of all children, young people and their families. At the same time, particular attention is given to those who are vulnerable or at risk.

However, the need to agree on a meaningful definition of family support is reinforced in the literature. Penn and Gough (2002) contend that family support is a phrase that has been used frequently, and that its meaning has nearly vanished as it encompasses so many meanings that it becomes difficult to disentangle. Frost et al. (2001) have described family support as a “slippery concept” and in need of a consensual definition. Contributing to the debate on the meaning of what family support is, Dolan and Holt (2002) noted that an absence of an agreed definition weakens policy advocacy and makes it difficult to deliver coherent services and effective practice methods. The literature and debate on family support (Devaney, 2011) focuses on definitions, principles and categories, in an effort to conceptualise family support as an approach to working with children and families.

In searching for an appropriate definition of family support, one that can adequately account for the needs of Zimbabwean asylum-seeking families with disabled children, this study finds the definition offered by the Irish government to be the most suitable. The definition used in an Irish context, from a theoretical, practical and policy perspective of family support, seems to do justice to this current study as it holds true with the findings of this study. Here, family support is defined as:

[b]oth a style of work and a set of activities which reinforce positive informal social networks through integrated programmes. These programmes combine statutory, voluntary and community and private services and are generally provided to families in their own homes and communities. The primary focus is on promoting and protecting the health, well-being and rights of all children, young people and their families, paying particular attention to those who are vulnerable or at risk (Pinkerton et al., 2004, p.22).

The definition above covers both forms of support: in other words, the formal and informal support services that are essential for Zimbabwean asylum-seeking families living with disabled children. For asylum-seeking Zimbabwean families living with disabled children, life is not easy. Life events for these families, ranging from depression to illness, are likely to put stress and strain on family life and relationships with the disabled child.

The family-support programme helps ensure that all available resources are accessed creatively and leveraged to the greatest possible benefit of the child and family (Baker, 2011). These will include, among others, relief services, home health care, family education and training, family counselling, and support groups designed (Agosta, 1989) to enable and empower family members to make informed decisions for the good of the disabled child. These services are vital for the upbringing of a child who is disabled. On the same subject, Ojeda (2000) argued that services should be responsive to the needs of the entire family, and that services should not address one particular problem but must be flexible enough to accommodate other needs. These services can be in the form of cash subsidies, vouchers that families use for their bills, medication and other necessities. This form of cash services (Agosta, 1998) empowers families to select and purchase services tailored to their own unique needs.

To illustrate the significance of family-support needs for families living with disabled children, Herman used the Michigan Family Support Subsidy Program (MFSSP) as an example. Herman (1994) noted that of the families that were involved in that support subsidy programme, the majority were more satisfied than dissatisfied with cash assistance, and felt that the amount provided by the subsidy was helpful in assisting the family to pay for basic necessities. This subsidy programme reduced families' financial burdens, improved families' ability to care for their children, and reduced families' levels of stress (Herman, 1991). As noted above, apart from cash subsidies, relief services, home health care, and family education and training, family counselling and support groups are some of the support needs vital for asylum-seeking families living with disabled children.

In order to understand the importance and value of family support, especially for Zimbabwean asylum seekers living disabled children in Cape Town, it is important for one to understand the meaning of a family in an African context.

2.6 Family in an African Context

The most salient features of the African family institution include, among other features, strong patriarchal traditions, albeit with large-scale polygamy, institutionalised age cohorts, major cultural weight given to fertility and lineage, and pervasive politico-economic, social and cultural patterning through kinship (Therborn, 2006). Adding to the perceived value of a family in Africa, Chataika and McKenzie (2015) stated that a family is a very strong cultural institution in most African countries, with responsibilities between family members taken seriously.

In the African Synod Comes Home, seeing 'the Church as the Family of God in Africa', the Church Fathers (1995: 20) define the African family as follows:

The family is the place where the deep African value of life comes to be, is protected and nourished, a place of belonging where sharing and solidarity are at the heart of daily life and where each one feels himself or herself to be truly at home.

This definition explains the ethical system that undergirds African beliefs, along with human dignity, a respect of life, and the responsibility of taking good care of others. These definitions present a cultural understanding of the African family, and one can therefore infer that an African family means more than a biological father and mother. It extends outside the biological parents. All these members from the extended family are part of the family and add value to its functioning. They are equally important as the members of the immediate family.

The centrality of the family in relation to the current study is located in its capacities to meet the welfare and needs of a disabled child, as the familial space is the primary setting where children's needs can be best met (Pringle, 1975). It is the responsibility of family members to offer social support for a family member that is in need. In this case, family members and friends of the Zimbabwean asylum-

seeking family living with a disabled child are expected to provide social support essential for the well-being of the child in question.

The urgency of social support for a family in need, in this case that of a Zimbabwean asylum-seeking-family with a disabled child in Cape Town, cannot be over emphasised. As highlighted before, studies on family support for asylum-seeking families living with disabled children is scarce in Africa. However, studies undertaken in developed countries indicate how crucial this support is for families in need. Though the importance of social support as shown in these developed countries may not be entirely applicable to the African scenario, in this case in the South African situation, the literature can still supply relevant information, which could prove useful in the present study.

It is therefore critical to have an understanding of what social support is in relation to the Zimbabwean asylum-seeking family living with a disabled child in Cape Town.

2.7 Social Support

Most observers conclude that rearing a disabled child is likely to be accompanied by challenges that involve stress, alienation and frustration. Because of these challenges, families rearing disabled children are likely to be in need of social support. Social support is defined here as individual groups or institutions that provide assistance of varying degrees to help another individual combat stress that tax her or his personal resources (Barth et. al, 1984). With regard to the current study, it is clear that a lack of social support will accrue disadvantages among a Zimbabwean family living with a disabled child. On the other hand, the availability of social support meaningfully ameliorates the family of a disabled child's capacity to manage stress. Social support both improves a person's well-being and, it is believed, has positive effects on the immune system. Thus, it is also a major factor in preventing the development of negative symptoms such as depression and anxiety (Cutrona, Russell, & Rose, 1986).

A social support system has been described as a set of personal contacts through which the family living with a disabled child maintains its social identity and obtains emotional support, material aid and services, information and new social contacts

(Walker et al., 1977, in Malson, 1983). Social support has also been defined as information or social/environmental conditions that enable an individual to feel loved and cared for, affirmed, or belonging to a group of persons with common goals and beliefs (Schaefer, Coyne, & Lazarus, 2002). Social support can be categorised in three levels: “emotional support”, “informational support” and “instrumental support”. The “emotional support” is based on the individual’s relationships with others, especially spouses, friends and family members that can help individuals maintain emotional health during stressful life events and ongoing life strains (Blankfeld & Holahan, 1996; Cohen & Wills, 1985). The emotional support is vital as parents of disabled children often rely on others to help meet the environment child care demands. “Informational support” is defined by materials providing educational aid and resources that empower individuals and increase the knowledge with which they might improve their current condition (Thoits, 1986). It is not uncommon for parents with a disabled child to request additional information from healthcare professionals regarding their child’s condition. However, with the dawn of new technologies, health care information can be passed to the families in need through the use of the Internet and digital media, which frees the process from being overly cumbersome. With the idea of “instrumental support”, Dunst et al. (2000) defined social support within the context of a family-systems approach in which the family’s social network system is instrumental in providing the resources needed for everyday living; carrying out parenting responsibilities; and supporting the learning development of the child. These members of the family’s social network provided a range of environmental experiences that ultimately influence the development and behaviour of the child and the entire family (Dunst et al., 2000). Social support is thus connected with the functional properties of a social network, which can act as a buffer between parents and the stresses associated with poverty, both by providing access to scarce and necessary resources through mutual aid (Stack, 1974), and by generating opportunities for sharing frustrations and problem-solving, and otherwise helping people to cope with daily life.

Empirically, social support has reduced the negative consequences of poverty on parenting (Benin and Keith, 1995; McLoyd, 1990; Webster-Stratton, 1997; Zigler,

1994), and has worked as a relative safeguard against the possibility of the ill treatment of the child (Garbarino, 1987).

Moreover, Ceballo and McLoyd (2002) demonstrated that emotional support and instrumental support are very important for a family in need. Ceballo and McLoyd's (2002) studies provide support for previous findings that parents' experiences of social support are integral to understanding how they cope with parenting in poverty. In the same vein, Horton & Wallander (2001) argue that the availability of social support from others, especially family members, helps the affected mothers to adjust to their environmental demands.

In order to understand what social support is, it is worth looking at the two forms of social support proposed by Findler (2010): formal vs. informal social support. These forms of social support are largely differentiated by the type of people that are involved in the network and the family's relationship with that individual.

2.7.1 Informal Support

Informal support networks are comprised of individuals such as family members and friends, as well as social groups such as church affiliations and social organisations. Findler (2000) states that the above-mentioned institutions typically assist in offering social support for the routines of daily life. Informal supporters offer unpaid support and provide the most immediately desired support at times of difficulty or in a crisis (Cutrona, 2000; Gilligan, 2000; Dolan and Holt, 2002; Dolan et al., 2006; Families Matter, 2009). Therefore, Whittaker and Garbarino (1983) describe the support within families (informal support) as the "bread and butter" source of help. In their study on parenting, Ghate and Hazel (2002) found that 74 percent of the sample had their primary source of support living in the same house or in very close proximity.

Recent studies on support networks argue that social networks, and the support that they provide, act as a buffer against the challenges that face families with disabled children, and are instrumental to the well-being of the family (Espelage, Hale, & Hannum, 2005). Even research carried out in the late 1980s, like that of Weissbourd et al. (1989), regarded peer support as a particularly important resource

in family support programmes, and highlighted that “informal supports increase a family’s ability to cope and foster independence and mutual interdependence in contrast to dependence”. As Gardner (2003) proposed in her research on parents’ support needs, the greater the informal support network, the lower the degree of difficulty perceived by parents regarding their vulnerability, stress and ill-health. Conversely, the weaker their informal network the greater their degree of difficulty.

2.7.2 Semi-formal Support

Together with informal support, semi-formal support is seen as a vital source of social support. Semi-formal sources of support are described as organised support received from community or neighbourhood-based services, which are normally voluntary associations and do not have paid staff (Ghate et al., 2002). Understood in its relational context, a community is a local environment that provides a set of endangering and protective factors, elements that influence the overall well-being of community members (Chaskin, 2008). Semi-formal support services may be thought of as the assistance to informal supports. This interface between what happens within a family with a disabled member and the outside community is critical for a family raising a disabled child. The importance of the community in assisting a family with a disabled child is acknowledged by McKeown (2000), who noted how a community-development focus addresses the contextual factors that impinge on, and often exacerbate the problems of vulnerable families.

As a form of informal support, religion is believed to be a significant factor for a family of a disabled child. Religious support, among others elements, will include the provision of a place where parents could pray and renew their faith; socio-emotional support and practical aid (for example, transportation) provided by members of the congregation; as well as the meeting of needs pertaining to the child’s medical and therapeutic treatment (Smith, et al. 1994). Religion and spirituality have been studied as psychosocial constructs that have several effects on physical and mental health (Ellison, 2006). Religions have been acknowledged as significant and valuable sources of social support, especially because of their capacity to shield against stress (Smith, et al. 1994).

Apart from the informal and the semi-informal support, formal support is also a crucial source of support for a family living with a disabled child (Dolan et al., 2006). However, it must be understood that the informal, semi-formal and the formal supports can be used simultaneously by a family in need.

2.7.3 Formal Support

While the informal support network comprises individuals such as family members, and the semi-informal network with the community and neighbourhood, formal support networks are composed of professionals (i.e., physicians and social workers), and agencies (i.e., hospitals, health departments, and early intervention programmes) formally organised to provide assistance and aid to individuals with specific needs (Dunst et. al, 1988). Formal support refers to the services provided by professional agencies with paid employees, including state-run agencies and those headed by voluntary organisations and offering both universal and targeted interventions.

Having dealt with the importance of social support for families living a disabled child, it will be instructive to examine the family support services that an asylum-seeking family needs in order to ensure the wellbeing of the disabled child. However, it is argued that those families with greater social support systems, whether composed of relatives or friends, have a greater chance of resolving the problems with which they are faced (Sarason, et al. 1990). The process of coping is helped by the presence of someone with whom the subject can discuss problems, or from whom they may obtain unconditional love and support (Gardner, 2003).

2.8 Family-Support Services

Family-support services are based on the belief that all children have the right to a stable family relationship in the community (Clarke, 2006). The available research is grounded in the knowledge that families are the greatest resource open to children. Ideally, family-support services are proactive, and are intended to help prevent families from going into crisis (Freedman and Boyer, 2000). These services provide families with the assistance they need to remain healthy, independent and safe (IASSID, 2013). In addition to supporting families, they strive to help children with

developmental disabilities access community resources and participate as active members of their communities since children with disabilities often need additional services or assistance in order to take part in community recreational or cultural activities (Hek, 2005). The family-support programme helps families find the tools to provide children with this support.

The family-support needs of asylum-seeking families with disabled children is an area that scholars have not dealt with in detail, especially with regard to Africa. There is a paucity of data available regarding the needs of disabled refugees and asylum seekers, and this holds true whether the target group is composed of adults, children or young people. Data collected from these studies can be problematic because of its inaccuracy (Hek, 2005).

However, Harris & Roberts (2004) revealed a lack of inter-agency communication, confusion over the legal obligations regarding the provision of services to disabled refugees and asylum seekers and, in particular, a lack of willingness in social services departments to provide assessments and care packages for this group. There is also a lack of financial support for disabled children, as asylum seekers are not entitled to care dependency grants (SASSA, 2010). Despite challenges that arise from their status as asylum seekers, the experiences of family members of disabled children remains unexplored in the literature on family support needs. This is true of Zimbabwean asylum-seeking families living with disabled children in South Africa's Cape Town. The literature is nearly non-existent, and similar literatures relating to the continentally more broadly are equally sparse.

As highlighted above, researches and programmes in the field of family-support needs for a family with a disabled child have been done in developed countries (Emmerson et al. 2010). Lessons can be drawn from these researches and programs, as positive signs in the family support of families living with disabled children were identified, especially on the growth and decision making of parents living with a disabled child.

Having examined the family needs of a family with a disabled child, I may move to inquire: what is the South African family system like in relation to families living with disabled children? In trying to understand the nature of the family support

system in South Africa, this study will aim to reveal whether Zimbabwean asylum seekers living with disabled children in Cape Town are eligible to receive these family support services for their disabled children.

2.9 South Africa's Family-Support Programme(s)

While the implementation of family support programmes for families with disabled children is believed to be better coordinated in developed countries, the opposite scenario holds true for developing countries, especially in Africa. South Africa is portrayed as a country that has made great strides in providing support for families living with disabled children through the care dependency grant, although this is limited to members within its borders who have been deemed eligible. The Care Dependency Grant is key for a family living with a disabled member. The South African Social Security Agency (SASSA) website (the department responsible for Care Dependency Grants in South Africa) outlines the requisite criteria for qualification for this service. The criteria state that a person must be a South African citizen, permanent resident or refugee, and must submit a medical /assessment report confirming permanent, severe disability in order to qualify for this service (SASSA, 2010). This criterion, therefore, excludes asylum seekers as a group that qualifies to benefit from the social grant scheme. Due to this exclusion from the South African family support programmes, some families face the additional challenge of being excluded by their family members in South Africa. This exclusion by other family members is largely attributable to the trying economic situation that the majority of asylum seekers endure. It is difficult for an asylum seeker to contribute and support the extended family, as he or she is not likely to be employed in well-paying jobs. This leaves the family living with a disabled child in a difficult situation.

In a bid to understand how a Zimbabwean asylum-seeking family living with a disabled child is impacted upon by the fact of the child's being disabled in a foreign country and dependent on its institutions for assistance, the study will now turn to an elaboration of the ecological systems theory pioneered by Urie Bronfenbrenner.

2.10 Ecological-Systems Theory

Bronfenbrenner described the ecological environment as a set of nested systems or as “...the scientific study of the progressive, mutual accommodation between an active, growing human being and the changing properties of the immediate settings in which the developing person lives, as this process is affected by relations between those settings, and by the larger contexts in which the settings are embedded” (Bronfenbrenner, 1993, p. 7).

The principles of family support are strongly embedded in the ecological standpoint, which recognises that the family is a system within itself, and constitutes a space where the care, protection and development of children, along with other tasks, are facilitated (Jack, 2000). Nevertheless, families do not live in seclusion, and they are equally affected by the environment that surrounds them. Fundamentally, the ecological theory recommends that there is a mutually supporting connection between the person and the environment (Bronfenbrenner, 1979; Garbarino, 1992; Kempet al., 1997; Jack, 2000), which must be considered when supporting children and their families. Each family and person in the family lives in relation to those around her or him, and must relate and acclimatise to the environment.

The ecological model presents a framework for understanding how essential aspects in a child’s environment are interrelated. Employing a social ecology framework Bronfenbrenner’s work and that of Whittaker and Garbarino (1983; 1992) has provided the basis for an increased focus on community and family-level interventions with children and families through.

Interventions with children and families do not take place in a void, however, and implementing an ecological approach to meeting their needs through family support provides an awareness of the overall context of the family, community and environment of which they are part. In Bronfenbrenner’s ecological model (1979), the individual is viewed as dynamic and growing, and there is reciprocal interaction between the individual and his or her environment (see the diagram in chapter 5). In agreement with Bronfenbrenner’s hypotheses, Germain suggested that, "people and their environments are viewed as interdependent, complementary parts of a

whole in which the person and the environment are constantly changing and shaping each other” (in Kemp et al., 1997, p. 42).

In describing the ecological environment of a given individual, Bronfenbrenner outlined five levels: the microsystem; the mesosystem; the exosystem; the macrosystem; and the chronosystem (Bronfenbrenner, 1979). However, this study will only use three levels, namely the macrosystem, the exosystem and the microsystem, as these levels speaks directly to the life-experiences of Zimbabwean asylum-seeking families living with disabled children from migration up until their point of settlement in Cape Town. These levels will be elaborated in detail in my subsequent discussion chapter.

2.11 Frameworks for Understanding Disability: the Medical, Social and Human Rights Approach

There are a number of available disability models with which to understand disability more broadly. However, I will restrict my discussion to the two most commonly discussed models: the medical model and the social model.

2.11.1 The Medical Model

The medical model, initially proclaimed in a World Health Organisation definition from 1980, comprehends disability as the result of an “abnormality “that stops persons from doing certain actions (WHO, 2015). Disability is rooted within the individual’s deviance from a healthy norm and is closely linked to the idea of assistance: charity, welfarism, and the perception of persons with disabilities as “patients,” constitute the conceptual cornerstones of this model (Thomas, 2007; Freedman; 2005:202).

This view is inevitably dehumanising in its overall perception of individual ability and independence. However, the medical model was heavily challenged in the 1980s, when supporters of the social model called for disability to be acknowledged as a form of structural oppression (Abberley 1987, Oliver; 1989).

2.11.2 The Social Model

Under this model, disability came to be understood as a result of disability barriers imposed on persons with impairments by an exclusionary society (Oliver; 2002:21). The emphasis was no longer on individual deviance from a medical norm as observed in a given society, but on the social perceptions attached to that difference. Only the oppressive attitudes of society and the environmental barriers one encounters, it is argued, render impairment a disability.

However, to conceive of disability solely as a social status that renders certain people vulnerable to discrimination can result in denial of the assistance needs that persons with disabilities may have due to their impairment (French, 1993, William, 1999). Furthermore, in ignoring the differences and the diversity resulting from the variety of impairment and degrees thereof, the social model risked becoming “an outdated ideology” (Shakespeare and Watson 2001).

The first international treaty specifically addressing the human rights of Persons with Disabilities, the United Nations Convention on the rights of persons with disabilities (UNCRPD), therefore adopted a holistic approach that seeks to understand all human rights as indivisible and interdependent (Rehman, 2003). The UNCRPD obliges signatories to provide protection, recognise the equality and capabilities of persons with disabilities, and provide reasonable accommodation for disability-specific needs.

In the context of Zimbabwean asylum-seeking families living with disabled children in Cape Town, a social model and human rights-based approach is best equipped for this study, since the asylum seekers rely heavily on the normative framework of human rights for the guarantee of their protection

Although there is no commonly agreed definition of disability, community law is believed to protect persons with disabilities under the principles of non-discrimination and equality. The South African government, in this case, recognises that persons with disabilities are likely to experience discrimination, and therefore promotes their protection against such treatment. Taken together, these provisions in community law and policy demonstrate a strong commitment to safeguarding the rights of persons with disabilities.

In practice, however, the South African government discriminates between the rights of nationals and non-nationals, enacting their sovereignty not only at their borders but, increasingly, within them (McAdam, 2005; Guild, 2007). Zimbabwean asylum-seeking families living with their disabled children are therefore likely to find themselves in a legal purgatory until a decision on their claim is made.

Given the above disability frameworks in relation to asylum seekers from Zimbabwe and their disabled children, I now move to the following question: what is the situation of asylum seekers from Zimbabwe in South Africa?

2.12 Zimbabwean Asylum Seekers with Disabled Children in South Africa

Though the present research is chiefly concerned with Zimbabwean asylum seekers living with disabled children in the Western Cape province of South Africa, it is significant for this research to briefly assess the situation of disabled people in Zimbabwe. This could have an immense contribution to explaining why a family with disabled children might make the arduous and embattled migration to South Africa. As highlighted above, Leonard Cheshire and other organisations in Zimbabwe estimated that 1.4 million disabled people in Zimbabwe are poor and regarded as a burden on society. Women who give birth to a disabled child are often physically abused or even divorced by their husbands who hold them culpable for the condition of the child. Their in-laws also add other challenges. Instead of offering much-needed support, the in-laws shun the family and claim they are harbingers of bad luck. The immediate result is that these children are hidden away, and do not get the treatment and care they need because the family's sense of shame is too great to cope with these social pressures (Leonard Cheshire, 2011).

The challenges presented above are most likely part of the reason that Zimbabwean families with disabled children migrate to South Africa.

In South Africa, the available literature on refugees and asylum seekers confirms that this group of people face many challenges. Immigrants and refugees experience complex issues affecting their access and utilisation of services, as well as their experiences of care. They face issues of poverty, single parenthood,

stressors associated with resettlement, social exclusion, and under- and unemployment (SAMP, 2011).

Having fled their home countries due to the socio-political and economic challenges they face, many migrants remain in marginalised positions once in South Africa (CORMSA, 2009). Most newcomers lack local support structures such as friends and families to act as safety nets. They encounter adversity in finding employment, principally because many lack appropriate education/training and have little or no resources to obtain these, or to cover the costs involved in job-searching (CORMSA, 2009). Refugees and asylum seekers with disabilities are among the most socially and economically disadvantaged members of society (Harris, 2003). According to a survey by CORMSA (2008), 48% of refugees and asylum seekers reported being rejected as job applicants because they were not South African, although they had the right to work. This is not to mention the issues of xenophobic tension and discrimination they face because they are foreigners (SAMP, 2008). Many are forced to accept lower wages, higher rent, or are abused by verbal and physical harassment and threats (CORMSA, 2009).

The above challenges are a living reality for asylum families especially those with disabled children despite the fact that the South African law allows for the provision of basic education, employment and access to free emergency care, regardless of one's nationality or immigration status.

Though many believe that only undocumented immigrants face discrimination from public services, asylum seekers still encounter numerous challenges such as a lack of access to grants and social support structures to assist them with the high costs involved in the proper care, education and treatment for their disabled children. For example, the only service provider that has a budget to give financial assistance to vulnerable refugees in the Western Cape, the Cape Town Refugee Centre (CTRC) (an implementing partner of the UNHCR), up until recently only assisted people with refugee status. At present the CTRC is also assisting those with asylum seeker documents when funds are available, but are not making the grants available to people with work or study permits.

Families living with disabled children who have asylum-seeker documents also do not qualify for the so-called Care Dependency Grant. This care dependency grant is administered by the South African Social Security Agency (SASSA) to parents with disabled children. Only in September 2011 did the Department of Social Development, after a legal challenge brought by the Legal Resource Centre and the Scalabrini Centre, change the regulations for the Care Dependency Grant to allow migrants with refugee status to qualify. Although this is a step in the right direction, this policy change only benefits a small portion of migrants (those with refugee status), while excluding the much larger number of asylum seekers and undocumented migrants.

Due to the above-mentioned factors, Zimbabwean asylum-seeking families with their disabled children who come to South Africa in search of peace, security, greater economic opportunity, or proper care for their children, often find conditions not much better than those they left in their home countries. Using data and insights compiled through in-depth interviews with Zimbabwean asylum-seeking families with disabled children living in Cape Town, this paper seeks to expose the family support needs of these families, and their perspectives on the disability of their children.

Being asylum seekers and accompanied by disabled children, these families are likely to be accompanied by extra challenges. Their disabled children form the most marginalised of the population and are forgotten both by people in the wider disability community and by those supposed to render service to refugees (Bailey et.al, 1999). Having a child with a disability creates a potentially wide set of challenges for families (Blacher, 1984), with subsequent needs for information and services that could assist with coping and adaptation. Based on Blacher's assertion, the scenario is most likely to be the same with Zimbabwean asylum seeker families living with their disabled children in Cape Town South Africa. Like other families living with disabled children and young people, Zimbabwean asylum-seeking families living with disabled children in Cape Town are likely to find themselves in the situation of living with parents who are unable to respond to them adequately due to their own emotional turmoil (Levenson & Sharma, 1999; McCallin, 1996).

This leads to the viewpoint that these disabled young Zimbabwean asylum seekers have a wide range of needs, both emotional and physical. In this case, therefore, one can infer that it is vital to understand the experiences of asylum-seeking families living with their disabled children, in an effort to assist these families and their children to settle comfortably and achieve a sense of belonging.

Extra work, costs and time are needed to take care of a child who is disabled (Shelton and Stephanek, 1994). Striking a balance between time to care for their disabled children and time for work is a challenge, since parents have to work and take extra care for the child (Shisheva, 2010). In the same vein, it has been argued (Landry, Smith, & Swank, 2003; Shonkoff & Phillips, 2000) that a child who has been diagnosed with developmental disabilities is often referred to as having “special needs”, which is a term that implies a level of attention, care, and treatment above and beyond that which might be expected in the raising and cultivation of a typically developing child.

Further, Freedman et al (2000), states that families living with a disabled child are more likely to require extra financial support to pay for therapies, medications, and adaptive equipment, and this becomes a challenge for asylum seekers when an individual works fewer days due to extra care needed for the child. For those children who can't use public transport, a special mode of transport is needed and this requires additional finances (Roberts, 2009). Lack of support for parents living with disabled children makes them focus solely on negative expectations –in other words, what the child will not do, or will not be (Cunningham & Sloper, 1977). This can also apply in the case of asylum-seeker parents who are staying with their disabled children.

It appears that the financial circumstances of Zimbabwean asylum seekers living with disabled children can be likened to Clarke's (2006) argument about the situation of disabled asylum seekers in Australia: such asylum seekers are relatively marginal to policy debate about their social exclusion and inclusion, with financial responses to exclusion subsumed under responses to child poverty, which tend to stress parental work as a route to inclusion. This may also be likened to the situation of Zimbabwean asylum seekers living with disabled children, in the sense

that the relationship between their needs and concerns is not discussed in policy documents. Because of this lack of policy articulating their needs, the families are negatively affected, since nothing is extended to them in order to keep their children healthy and socially active. It seems likely that Zimbabwean asylum-seeking families living with a disabled child are more likely to be marginalised economically. This may be for a number of reasons including, parental ability to access to work (e.g. availability of appropriate and affordable childcare); difficulties when employers fail to recognise parental responsibilities; impairment and disability-related costs; and information on, access to, and the stability and adequacy of benefits (IASSID, 2013).

Despite the extraordinary challenges that Zimbabwean asylum seekers encounter (in this case, specifically asylum seekers living with disabled children), these families still emerge victorious in relation to their myriad struggles. They invent new strategies to confront these challenges.

Overall, the cumulative weight and interplay of all of these challenges are responsible for the experiences that asylum families living with disabled children undergo. These apparent challenges for Zimbabwean asylum seekers provide the impetus for the present research, which aims to comprehensively describe the needs that obtain in these families. This research therefore aims to answer the following questions:

Main Research question: What are the main challenges that Zimbabwean asylum seeking families living with disabled children face in Cape Town

Sub research questions:

- What are the perspectives and experiences of Zimbabwean asylum-seeking families when living with their disabled child in the Western Cape Province in South Africa?
- What are the family-support needs of an asylum-seeking family from Zimbabwe living with a disabled child in the Western Cape Province in South Africa?

- What are the strategies of resilience used by Zimbabwean asylum-seeking families living with children with disabilities in Cape Town?

2.13 Chapter Summary

This chapter dealt with a number of issues, among them the definition between the asylum seeker and the refugee. I then proceeded to give the definition of social support and the Irish definition was selected for this research, based on the view that it captures all forms of support that a disabled family living in the Western Cape Province may require. The definition of a family and the constitution of a family were also touched on. Furthermore, the chapter discussed the forms of social support, mainly using Findler's two dimensions of formal and informal systems. From there, I went on to describe the individuals who constitute these two forms of systems. The importance of these forms of support was discussed in relation to a family in need. It was through the discussion on the formal and informal support for the family living with a disabled child that the value of family support came to light. The link with the challenges that the Zimbabwean disabled families face in Cape Town was dealt with in comparison to the challenges that surfaced from the literature in the developed countries. The models of disability and the ecology theory were subsequently elaborated. I concluded the chapter by arguing that families caring for disabled children are faced with numerous challenges, but that they emerge as "winners", in the sense that they are resilient to the challenges that affect them.

During my search for literature on this subject, it became apparent that there were few publications on the family support needs of asylum-seeking families living with disabled children in Africa, in particular.

The next chapter introduces the methodology and study design going forward. I will justify both the preferred design and offer an exploration of the approach with which the study was accomplished.

3. CHAPTER THREE: METHODOLOGY AND DESIGN

3.1 Introduction

This study aims to explore the perceptions and experiences of Zimbabwean asylum-seeking families living with children with disabilities regarding the provision of family support in Cape Town. This exploration is effected in order to identify areas of support that can be improved or developed to enhance the quality of their lives while they are not yet accorded refugee or permanent-residence status. This research also seeks to give these families a voice and, thereby, to better understand their life experiences.

This study centres on the following research questions:

- What are the perspectives and experiences of a Zimbabwean asylum-seeking family living with a disabled child in Cape Town, South Africa?
- What are the family support needs of Zimbabwean asylum-seeking families living with a disabled child in Cape Town, South Africa?
- What are the resilience strategies employed by Zimbabwean asylum-seeking families living with children with disabilities in Cape Town, South Africa?

This chapter outlines a methodology, designed and implemented in order to address the overarching aim and objectives of my study. This chapter is divided into three sections. Section one provides the background of the Western Cape Province, the province in which the study was carried out. It also provides an account of the sampling process and data collection, and a section on the analysis used. The research design, including considerations on theoretical perspectives and reflexivity, is discussed in section two. In the last section, the process of implementing the study will be outlined in detail, including the ethical issues that arise in relation to the research.

3.2 Brief Background of the Western Cape

This research is concerned with Zimbabwean asylum seekers living with disabled children in the Western Cape province of South Africa. Since the study is carried out in this province, a brief description of the Western Cape Province is given below.

In 1993, the Cape Province was divided into three smaller provinces. The Western Cape was the first place in which European travellers settled. The Europeans brought slaves from Malay to serve them, and the Malay culture became a part of South Africa's own heritage. In the Cape, the many languages that were spoken, among them Dutch, French, German and Malay, were mixed to form a new language called Afrikaans that is unique to South Africa. The word "Afrikaans" means "African" in Dutch. Today, Afrikaans is the third most widely spoken home language in South Africa, after isiZulu and isiXhosa. Perhaps it is because of South Africa's history and experience of immigration that Zimbabwean asylum seekers find Cape Town a better province in which to settle. It is not as difficult to find employment on the wine farms and as a result, Cape Town becomes an attractive destination.

3.3 Settlement and Location for Asylum Seekers in South Africa

Zimbabwean immigrants are widely located throughout South Africa. The socio-economic situation of immigrants has been cited as one of the principal motivators for their resettlement and relocation to Cape Town. Sibanda (2011) states that educational and religious beliefs play a major role in determining where one chooses to settle. The educational and religious factors are not likely to be as persuasive in the case of Zimbabwean migrants coming to the Western Cape. One of the more compelling reasons influencing their choice of settlement would be the dense population and large concentration of immigrants from other parts of Africa in Cape Town

In order to understand the life experiences of Zimbabwean asylum families living with their disabled children, it is vital to understand the method that was employed by the study, in the present case, the qualitative method.

3.4 The Qualitative Methodology

3.4.1 Research Design

For this study, I have used a qualitative descriptive approach. My study is basically a phenomenological research, which involves trying to understand the essence of asylum seeking families from Zimbabwe living with their disabled children in Cape Town by examining the views and experiences in living with a disabled child in a foreign country. Phenomenology is interested in the individual experiences of people. It usually involves long, in-depth interviews with subjects, and sometimes researchers will interview the same subject several times to get a full picture of their experience with the phenomenon. The method of data collection consisted of in-depth interviews with Zimbabwean asylum-seeker families living with disabled children in Cape Town. A qualitative approach was deemed necessary because it gathers non-numerical information that would help in understanding the family support structures for Zimbabwean asylum seekers with disabled children in Cape Town. Strauss & Corbin (1990) argue that undertaking qualitative research is a helpful manner in which to deal with variables that are complex to quantify. I agree with this argument and have selected this methodology for my own study. The qualitative descriptive approach is more appropriate for this study as it allows for an in-depth questioning of the participants' responses.

The study of the family-support needs of Zimbabwean asylum-seeking families' living with their disabled children in the Western Cape Province in South Africa is an area about which little is known. Because the area remains under-researched, qualitative design seems an appropriate way to respond to the absence of information. This is in line with Strauss and Corbin (1990), who recommended that qualitative studies be used when one needs to understand a phenomenon about which little is known. In the literature review chapter, it has been confirmed that in South Africa, and even in Africa at large, the family-support needs of asylum-seeker

families remain obscure and understudied. The use of this kind of methodology was therefore necessary in this study, since it aims towards gaining a better understanding of Zimbabwean asylum families with their disabled children in Cape Town.

Qualitative descriptive studies are viewed as comprehensive summaries of events where researchers stay close to the data, and to the surface of words and events (Sandelowski, 2000). In seeking to determine the family-support needs of Zimbabwean asylum seekers living with disabled children in Cape Town, a descriptive study will prove to be a crucial component of my argument.

Hoepfl (1997) supported qualitative inquiry as a source of data that reflects an acceptance of the intricate and ever-changing social world. The use of in-depth interviews to obtain and describe data from Zimbabwean asylum-seeking parents living with disabled children is informed by these views.

Kaplan & Maxwell (1994) are of the opinion that the aim of understanding a phenomenon from the participants' views, and that of understanding its particular social and institutional context, is mostly lost when the textual data is quantified. This research methodology was designed to assist the researcher in understanding the family-support needs of Zimbabwean asylum-seeking families with their disabled children in relation to the social, economic and cultural contexts in which they are immersed. In this regard, I had access to more valid and reliable data in relation to the phenomenon under review.

3.4.2 Reflexivity in Practice

My nationality as a Zimbabwean, and the past experiences I have accumulated, will influence my research design and the execution of my argument. I am a Zimbabwean who came to South Africa as an asylum seeker in 2009 and I now hold a work permit from the South African Home Affairs Department. In line with my experiences as an asylum seeker, Creswell (2007) stated that the influence of personal experiences, culture and history shapes the paradigm held by an individual researcher, thereby highlighting the unique stamp each researcher will bring to his or her study. My understanding of the nature of the subject under investigation,

especially my understanding of the challenges facing asylum seekers in South Africa, and also my knowledge on the Shona and Ndebele cultural beliefs, contributed immensely to the choice of the study methodology and its interpretation. In this study, I am closely linked with the object of my investigation. My stance is reflective of the connection between myself and the research I have undertaken. I was exceptionally mindful of not introducing my own views and opinions indirectly through a prepared interview schedule. The link that exists between me and my research subjects in this study required attention throughout. According to Patton (2002), the researcher must be attentive to, and conscious of, the cultural, political, social and ideological origins of one's own perspective and voice, as well as the perspective and voice of those one interviews and those to whom one reports.

3.4.3 Participant Sampling

I did a purposive sampling by recruiting only Zimbabwean asylum seekers living in Cape Town with disabled children. The sample consists of 10 participants and 2 key informants. Cormack (2000) suggests that qualitative researchers use a small selective sample, because of the in-depth nature of the study, and the amount of data that will have to be analysed. The decision to have 10 participants and 2 key informants was influenced by the repetition of certain data that was consistently generated by the participants. I realised that the information was saturated with enough substantive content to answer my research questions. Purposive sampling allowed me to recruit knowledgeable participants who were willing to provide the information and experiences that I sought as a researcher (Bernard, 2002). In line with Bernard, Creswell describes the purposive sampling approach as "intentionally choosing participants who have experience with the key concept being explored" (2007, p.112).

The ten participants were all Zimbabwean asylum-seeking families caring for children with disabilities. Two key informants were interviewed. The first key informant was a Zimbabwean working as a community worker at the refugee disability desk at a local Non-Governmental Organisation (PASOP). She is also a mother of a child with a disability. These Zimbabwean asylum caregivers were actively involved in the raising of their children and were aware of the needs and

challenges they faced. This enabled me to capture the experiences and gain access to authentic data. The second key informant is a Congolese national and works for the same organisation (PASSOP), and was interviewed in his capacity as an expert in the laws and policies that govern refugees and conditions of asylum in South Africa. The Mountain States Group, Inc. (1999) stated that interviewing key informants from a wide range of sectors allows the researcher to look at varying perspectives and underlying issues or problems. The second key informant, though from the same organisation as the other key informant, is from a different country and this may give a different perspective on the impact of child disability.

The study has done a purposive sample and the inclusion and exclusion of participants is highlighted below.

3.4.4 Inclusion Criteria

The participants must:

1. be a Zimbabwean living with a disabled child;
2. be above 18 years of age (in order to obtain informed consent);
3. have been living in Cape Town for a minimum of one and a half years (so as to obtain the opinions of those most experienced and most exposed to the needs of an asylum-seeking family living with a disabled child);
4. be the main family caregiver and/or provider for the disabled child (a person who knows the child's needs).

3.4.5 Exclusion Criteria

Participants were not considered if they met any of the following criteria:

1. Other nationalities (e.g. South Africans, Somalians);
2. Those with refugee status (refugees are eligible for social grants);
3. Those with less than one and a half years in Cape Town.

Once permission to carry out the study was obtained from the University Of Cape Town Research Ethics Committee (HREC REF: 929/2014), and following a discussion with my supervisor on the piloting of this study, the narrative interview technique

was used in one-on-one interviews with two key informants from PASSOP. This pilot was meant to determine the suitability of the interview questions, logistics of the research and other issues. I include the data obtained through the pilot study in my research. The data that was obtained from the key informants was also used as part of the study. This was easily achieved because of our common interests and the fact that I shared certain similar experiences with the interviewees.

3.4.6 Access and Entry

Access in qualitative research studies is a process that goes beyond initial consent, in order to ensure that the identified individuals are willing to participate throughout the study (Glesne, 1999). The participants must be convinced of the importance and relevance of the study (Glesne, 1999). In an effort to establish personal contact with potential participants, I enlisted the support of a community worker in charge of the Refugee Disability Desk at PASSOP. PASSOP is a not-for-profit human rights organisation devoted to fighting for the rights of asylum seekers, refugees and immigrants in South Africa. They offer free paralegal advice on documentation, labour and other issues, as well as assistance in finding employment (PASSOP, 2014). A letter of invitation and a letter of information were given to the social worker to distribute to all her clients, inviting them to participate in the study (see Appendices B and C).

The community worker from PASSOP was selected to connect the participants and the researcher, as she was personally involved with some responses. Because of her being involved, a trust developed between her and the respondents, thus making it easy for me to gain the trust of the families myself. Since PASSOP is centrally placed, having contact with all relevant parties, it is best identified as the most important link between the researcher and the asylum seekers with disabled children. The social worker asked those who were interested in participating whether she could share their contact details with the researcher. The researcher contacted the participants and identified whether they met the study's inclusion and exclusion criteria. Those who qualified set up an appointment with the researcher to be interviewed at a convenient venue. Before the interview began, the researcher went over the information letter with the participants and requested their informed

consent to participate in the study (see Appendix D). Once I established contact with this network it became fairly easy to identify relevant respondents as other people within the network slowly began to trust me and gave me the details of other people willing to be interviewed. Of the 10 participants only five were members of the PASSOP organisation. The remainder of the participants were referred to the researcher by the other participants.

Table 1: Demographic information

Code	Marital Status Married/Single	Gender and Age of Child	Family Income/R per month	Diagnosis	Ethnicity	Years in Cape Town
Participant I	Married	Boy 9	2 500	Autism	Shona	6
Participant II	Single	Boy 11	3 000	Fredriech’s ataxia	Shona	8
Participant III	Single	Boy 13	1 500	Ehlers-Danlos Syndrome	Shona	9
Participant IV	Married	Boy 11	2 000	Trisomy 21	Ndebele	8
Participant V	Single	Girl 10	2 500	Muscular Dystrophy	Shona	9
Participant VI	Single	Boy14	2 000	Blepharophimosis	Ndebele	8

Participant VII	Single	Girl 13	3 500	Neurofibromatosis	Ndebele	5
Code	Marital Status Married/Single	Gender and Age of Child	Family Income/R per month	Diagnosis	Ethnicity	Years in Cape Town
Participant VIII	Married	Girl 9	1 700	Autism	Shona	6
Participant IX	Single	Boy 14	2 000	Trisomy 21	Shona	7
Participant X	Married	Girl 10	3 000	Fredriech's ataxia	Shona	6
Participant XI	Single	Boy 15	7 500		Ndebele	5
Participant XII	Participant XII is a legal expert not a parent of a child with a disability.				Lingala (Republic of Congo)	5

3.5 Data Collection

3.5.1 In-depth Semi-structured Interviews

I selected interviews as my primary approach in collecting the data for the present study. This was done in line with Bogdan and Biklen (1982), who maintained that interviews can be used as the primary strategy in data collection. The research aims and objectives of the study highly influenced the choice of in-depth semi-structured interviews as the interview medium I would deploy. In-depth interviews are believed to draw responses out in detail with the intent to arrive at an interpretive perspective (Mack et al. 2009). In this study, an in-depth semi-structured interview was mainly employed to elicit Zimbabwean asylum-seeker families living with disabled children's perspectives and experience on their family support needs while in Cape Town.

In-depth semi-structured interviews have been favoured since this method brings out peoples' perspectives and opinions, allowing access to participants' thinking (Luft & Roehrig, 2007). As Janesick (1998) argues, it should nevertheless be noted that in qualitative research, the ability of the researcher to presume the position of an instrument helps capture the deeper meaning of the participants' points-of-view. During the process of this study, the in-depth semi-structured technique helped me to sharpen my skills as I tried to capture a richer analysis of the Zimbabwean asylum-seeker families' perspectives on their family-support needs in Cape Town.

The Interview Process

Interview questions were asked according to three content areas: the participants' perspectives, experiences and resilience strategies with regard to the types of family support available for them and their disabled children in Cape Town. Official interviewees started with warm up questions in a bid to make interviewees feel comfortable with being interviewed. The interview began with simple, common questions, but slowly and surely I began progressing to more in-depth questions and eventually finishing up with direct questions at the end to relax the interviewee. Probing was used to discover the meaning of the questions and

answers alike, and any misunderstandings were instantly double-clarified. Phrases like *“Could you please tell me more?”* were used in order to clarify content.

Berg (2001) and Gray (2004) stated that in semi-structured interviews, researchers have the liberty to explore deeper territory than that allowed by the answers to their pre-prepared questions. In line with Schostack (2006), I made efforts to make the interview proceedings take the shape of a conversation instead of a firm question-and-answer interaction. The interviews were recorded using a digital voice recording device. Mack et al. (2009) suggested that interview information consists of tape recordings, typed transcripts of tape recordings and interviewer’s notes. Further to Mack’s suggestion, Patton (1990:348) put forward that the “tape recorder is indispensable” in an interview. The author adds that recording has an advantage as it captures the data much better than hurriedly written notes. Though the use of a technical device is of paramount importance when doing a study of this nature, one must cautiously guard against the possibility of technical failure (Lincoln and Guba, 1985). In this study, two recording instruments—the tape recorder and my smart phone—were used to make sure backup was available in case of failure on the part of one of these devices.

3.6 Data Analysis

The process of extracting sense from the raw data (Merriam, 1998) started with verbatim transcriptions of the tape recordings. In this study, informal data analysis began following the first incident of data collection, and transcription progressed accordingly with each subsequent incident. The search for patterns involved the breaking down of the data into smaller and more manageable units (Bogdan & Biklen 1982). The analysis focused on the responses of individual participants to each question. Transcribed data was read several times and impressions written down as a way familiarising myself with the text. Powell-Taylor & Renner (2003) recommended that a good understanding of the data can be achieved through reading and re-reading for better analysis. This corresponds to open coding as described by Strauss & Corbin (1990). As Miles and Huberman (1984) suggested, an interim case summary on responses to the research questions was drafted after the first week of data collection and shared with the supervisor. Data from each

question was grouped together into carefully elaborated categories. This is consistent with the idea of “categories in the centre of analysis” described by Mayring (2000:5). Similarly, as Strauss & Corbin (1990) suggested, conceptual categories were developed to allow for easy grouping and identification of data. In this study, descriptive as well as interpretive codes were used to summarise, organise and categorise chunks of data, and to search for deeper meaning as the collection evolved. The interactive cyclical process of data collection proved profitable, as it provided new data to fill up identified gaps (Miles & Huberman, 1984).

As the analysis process evolved, exhaustive and mutually exclusive categories were created that ensured that no data was excluded nor fitted into more than one category. Similar words were grouped into the same category and, where the need arose, the categories were divided into sub-categories, modified, or replaced in the process of analysis. Mayring (2000) suggested working through the material, revising categories and eventually reducing them to main categories, while checking for reliability, while Hoepfl (1997) maintained that categories could be modified or replaced during the subsequent stages of analysis. More inferential codes were developed to illustrate emerging patterns or themes within categories, or cut across categories as data collection and analysis progressed, and continued until no new themes were identified. The process of analysis was inductively conducted to allow for the emergence of the categories and themes from the data (Patton, 1980). This allowed the researcher an opportunity to begin to build a clearer picture of the data (Strauss & Corbin 1990). Category descriptions were used to uncover the expression of key ideas, and similarities and differences in the responses. During the process of breaking down the data into manageable chunks, the researcher colour coded data from each participant differently for easy identification. This corresponds to what Hoepfl (1997:57) terms an “audit trail”, a scheme to identify data according to the speaker.

Themes that appeared to be more significant were revealed through relative importance, while relationships among the themes were uncovered through underpinning data. This is consistent with suggestions made by Miles and

Huberman (1994), Creswell (1998), Powell-Taylor and Renner (2003), and Granehelm and Lundman (2004).

This analysis is expected to direct to a summary that would supply information and understanding of Zimbabwean asylum seekers' perspectives and experiences on their family-support needs in Cape Town, South Africa. In the findings chapter (Chapter 4), analysed data is represented through quotation.

3.7 Rigor and Trustworthiness

This study adheres to the criteria for judging the nature or outcome of a qualitative study as proposed by Guba and Lincoln (1989). The four criteria as suggested by the authors are truth value, applicability, consistency, and neutrality, commonly referred to as credibility, transferability, dependability and confirmability, respectively.

3.7.1 Truth Value/Credibility

To ensure credibility, transcribed data were subjected to a review by the participants, allowing the participants to indicate their satisfaction with the accuracy of the transcripts. The researcher had ample interaction with the participants during the interview process, and constantly referred back to the participants for clarifications. These practices, it is argued, improve the credibility of a qualitative study (Guba & Lincoln, 1989). Credibility was improved through exclusively selecting Zimbabwean asylum-seeker families with disabled children who have enough experience of staying in the Western Cape Province. This was meant to allow for diverse opinions on the phenomenon being investigated (Patton, 1987).

3.7.2 Transferability/Applicability

Transferability is also defined as applicability. A detailed description of the context in which I interviewed disabled Zimbabwean asylum seekers about their family-support needs is provided in this report. This allowed for a better understanding of the makeup of the context, in order to position the findings as representative of similar contexts (Denzin & Lincoln, 1998). Further enhancement of transferability is

offered in this report through the rich presentation of the findings and the use of appropriate quotations (Granehelm & Lundman, 2004).

3.7.3 Dependability/Consistency

I undertook a close examination of the data collection and analysis in order to account for any biases, and to identify any irrelevant information that might have emerged. The transcripts from the audio recordings were shared with the research supervisor to allow for a review of the analytic process. Another way in which dependability was ensured in this study was through the setting up of an audit trail to enable the tracing back of data to the source during the process of data analysis (Guba & Lincoln, 1989).

3.7.4 Conformability/Neutrality

This was observed through the tracking of raw data; checking the transcribed data with the participants; and the interrogation of the data analysis and the logic it used to arrive at interpretations. This attempt to ensure neutrality was done to guarantee that the results were neither biased nor influenced by other biased perspectives (Krefting, 1991).

3.8 Ethical Considerations

Ethics in research is a serious matter and researchers need to adhere to a strict set of principles (Kosslyn & Rosenberg, 2005). The human rights and human dignity of all participants must be treated with respect (Babbie & Mouton, 2003). Carrying out a research on sensitive issues such as those regarding a subject's migration status poses a number of ethical challenges. The researcher is sensitive to the vulnerability of the group involved. This is a group likely to have been exposed to the worst forms of abuse—in their home country, during flight, and in their country of asylum. This group could be traumatised by their experiences, past and present, and therefore it could act with suspicion, or with the incentive of pecuniary gain from those it interacts with. Utmost caution was taken to ensure that the respondents could trust the researcher and that no material gain was expected to result from the interview. Invitations were sent to participants in order to offer them an adequate brief on the research and also to expose them to the consent form. It was

critical for the respondents to feel safe. With respect to the respondents' safety, the researcher left the choice of interview venue(s) and time(s) to the respondents. In this way, the respondent chose a set-up where they felt most comfortable. The advantage of this approach is found in the fact that the more comfortable and secure the respondents felt, the more informative they became. In order to achieve my research results, I adhered to the principles of autonomy, justice, beneficence and non-maleficence. Participants were given a small token of appreciation after the interview session; they were not aware of this prior to the interview. The monetary token of appreciation was given for food and transport costs, as many of the participants were low paid and experiencing financial difficulty.

3.8.1 Autonomy

Before conducting the research, the researcher sought informed consent from each of the participants, and all those who chose to participate did so voluntarily and upheld a right to withdraw from the study without any penalty should this be their wish. The nature of the research and its objectives were explained to participants fully. Confidentiality was strictly maintained. Names of participants and their residential address were not exposed during the course of the research.

3.8.2 Beneficence and Non-maleficence

Any risk of discomfort or harm to the participants was guarded against during the research process. The information obtained will be used for advocacy purposes. Furthermore, information gathered from the research was strictly for academic purposes and would not be identifiable to any third party, particularly the Department of Home Affairs and Zimbabwean government authorities, as this might put the respondents at risk. This research will also be of importance to some asylum families living with disabled children in that those in need of support will be referred to the human rights organisation PASSOP for proper advice and will hence benefit from this research.

3.8.3 Justice

Agreement to participate in this research was reached of the free volition of the candidates and without any coercion or undue influence. Fairness was observed by

adhering to a given set of interview times and demonstrating tolerance towards participants, who at times failed to be punctual in their attendance of the interviews. All potential participants and enrolled participants were treated with respect. PASSOP and each participant received a copy of the research findings as feedback from the research.

3.9 Chapter Summary

This chapter has explored the qualitative methodology of the study. The justification for the use of the case-study approach was given, along with comments on the data-collection process and analysis. I then moved to explain the participants' selection process and elaborated upon the subsequent interview process.

The following chapter presents the findings of the study and will explore the responses and opinions of the interview subjects and of other study participants.

4. CHAPTER FOUR: FINDINGS

4.1 Introduction

It is important to note that all data was coded according to the three major deductive categories articulated below. However, an inductive analysis was done within these categories for three reasons: (1) to explore the impact of disability on disabled Zimbabwean families living in South Africa's Western Cape region; (2) to identify barriers that prevent these families from getting the support they need; and (3) to identify the family-support strategies used by Zimbabwean asylum-seeking families living with disabled children in the Western Cape Province.

Below is a diagram illustrating the impact of disability for Zimbabwean asylum seekers living in Cape Town with their disabled children. The diagram is evidence of the impact of disability upon these families during their time in Zimbabwe, prior to their immigration. These are possible factors that could have pushed them to migrate to South Africa.



Diagram 1: illustrating the impact of disability for Zimbabwean asylum seekers living in Cape Town with their disabled children.

The impact of child disability in these families, both during their time in Zimbabwe and in South Africa, emerged as a chief facet. Under this category, I will discuss major themes like access to health, the impact of traditional beliefs both in Zimbabwe and South Africa, as well as economic factors, as all of these phenomena have had a direct impact on the lives of these families.

The barriers encountered when providing care and education for a disabled family member will be the interest of the second part of this chapter. Major themes that emanate from this category include those of adequate access to education and health, existent legal and policy barriers, and a fear for the future.

The last category of support for families living with disabled children will be discussed in a bid to show the ways in which these families address challenges of caring for a child with a disability in Cape Town. Informal, formal and inner resources will be discussed within this category.

It should be noted that these categories illustrate the challenges faced by families living with a disabled child in Zimbabwe and in South Africa. In this study, the results will be presented by placing quotations from participants' responses within overarching categories and discussing how these relate and interact with one another.

Participants proposed a number of factors that may have forced them to migrate to South Africa, since they found themselves struggling to deal with the challenges of caring for a disabled child, as I will demonstrate below. I will first discuss the impact of disability for these families while in Zimbabwe. This will be followed by the impact of disability experienced upon arrival settlement in South Africa.

4.2 Impact of Disability on the Family in Zimbabwe and South Africa

Like any other families in the world living with a disabled child, the impact of disability can be devastating when access to health is a challenge. Participants revealed that access to health was one serious challenge that forced them to leave Zimbabwe.

4.2.1 Access to Health

The participants' comments revealed that they encountered many challenges in accessing basic health services. This worsened the burden of caring for a disabled child, as their narratives suggest that they did not have enough money to pay for basic clinic and hospitals bills.

Participant 111: "The cheapest medication was R120 and that was too much for me."

Participant IV: "I knew that the operation was good for my child but it was expensive for me. I was to sell 2 cows for that operation."

As if paying expensive hospital fees and specialist surgeries were not enough of a struggle, participants revealed that the cost of medication was very expensive and that they were too poor to afford these necessary but expensive medications for their children.

Participant VIII: "The pharmacies in Zimbabwe are very expensive. If you are to buy two different types of medication, then you must at least sell a goat."

Participant V: "You were to pay consultation fee before your child is examined. You were to pay another \$20-00 (R200) for the prescription for you to go and buy medication at a pharmacy."

One phrase often repeated by participants ("anytime they just hiked the transport money") indicates that the exorbitant transport costs that participants endured when attending appointments at hospitals, clinics and so forth are largely arbitrarily determined and without reference to their means. These transport costs worsened their already-existing financial woes, especially when taking a child to the appointment.

Participant X: "I was to pay same fare transport for myself and my child to the clinic even though my child was four years old. Transport money was really a big problem. Anytime they just hiked the fares."

Participant I: "I missed many appointments for my child because I couldn't afford transport money. You wake to find out that they increased the

transport money by R5. Every time you go the clinic is a different amount of transport money.”

Shortage of Medication

Desperately in need of medication for their disabled children, a common feeling among participants was that they were not happy with the shortages of medication in public and private health institutions in Zimbabwe. This shortage of medication was seen as one of the pushing factors causing migration to South Africa since the unavailability of the medicines was exacerbating the condition or disability of their children.

Participant II: “I went to the main hospital four times in a month but I was told that they don’t have those tablets.”

Participant X: “I used to travel for 10 km to the nearest hospital, only to be told that there were still waiting for medication from the main provincial hospital.”

Not only were the main public or government hospitals running out of medication, but comments by participants also revealed that even the trusted private surgeries in Zimbabwe were running out of important medication and therefore putting the lives of their already disadvantaged children at risk as their health deteriorated.

Participant III: “I was fed up with these nurses’ ‘no medication’ song at a private surgery that everybody trusted. Every time I visited this private surgery it was the same story of no medication for my child.”

Participant VIII: “It was the same song at every clinic and hospital that they were waiting for the medication at the end of the month. Every time I visited the hospital, it was the same story.”

Advice on Better Health in South Africa

Participants’ comments suggested that there were some friends and family members, both in Zimbabwe and South Africa, who encouraged them to look for better services for themselves and their disabled children in South Africa, as

anything associated with child disability was considered much better in South Africa when compared to the prevailing situation in Zimbabwe.

Participant I: “I was told by my mother that the condition of J (my child) was going to be better if I migrate to South Africa because medication was readily available.”

Participant IV: “My friend who was living in South Africa informed me that it was better in South Africa for me and my child, since medication was free at local clinics. I did not waste time [...] packed my bags and migrated to South Africa.”

Apart from the availability of medication and proximity to hospitals and clinics, many reported that they believed that coming to South Africa was the only viable option as they were going to receive the disability grant for their children. Receiving a disability grant was seen as one way to lessen the burden of care for a family living with a disabled child.

Participant IV: “[...] and my brother told me that if I was lucky enough, I was going to get a disability care grant for my child.”

Participant IV: “I thought everybody with a disabled child was able to access the disability grant. No, that’s not true. It’s only for South Africans and refugees.”

4.3 Impact of Traditional Beliefs on Disability in Zimbabwe

Traditional beliefs in Zimbabwe play a crucial role in motivating families living with disabled children to migrate to South Africa. The Shona and Ndebele participants in this study reported that traditionally and culturally there are people in Zimbabwe with negative attitudes and beliefs towards disability and the disabled child and that these attitudes may result in serious challenges to the family of a disabled child.

4.3.1 Child Disability as a Taboo

The participants’ narratives indicated that having a disabled child in Zimbabwe was, by tradition, a taboo. Evil things (such as witchcraft and avenging spirits) were

strongly associated with a disabled child and, as a consequence, nobody would ever want to be associated with a family of a disabled child, and this made their way of living a challenge:

Participant V: “My husband accused my mother of bewitching our child, and claimed that this was why our child was disabled. It was for that reason that he divorced me.”

Participant VII: “Since I gave birth to a disabled child, my father-in-law told me to stop using the family kitchen, since their traditions did not allow for a disabled child to be present in the kitchen where ancestors stay.”

Apart from participants’ close relatives who regarded child disability as a sign of evil spirits, community leaders also believed that child disability was responsible for the absence of rain in their community leading to persistent drought.

Participant I: “The community head believed that we were not getting enough rain because of my child’s disability, so he suggested that I leave my child in the mountain for a night so that the evil spirits that caused this disability could be cleansed by the ancestors at night.”

Participant III: “I was accompanied by a community leader at night to a local traditional healer, because they believed my child’s disability was the cause of hunger in the community.”

4.3.2 Promiscuity

Apart from child disability being a taboo, participants’ comments suggested that the Zimbabwean tradition associated the origin of child disability primarily with promiscuity by the mother during pregnancy, or a sign that the woman’s ancestors were not happy with the mother’s behaviour.

Participant V: “My mother-in-law told me that she wishes that I was not married to her son because I was not faithful and that she does not know whether this problem of giving birth to disabled children was going to come to any end.”

Participant IX: “My husband asked why my ancestors were angry with me and why they decided to punish me with a disabled child.”

It was not only the family members who believed the mother was promiscuous during her pregnancy (and the reason for the child’s condition of disability). Other comments by participants suggested that the community at large also holds the same beliefs and this leads to further isolation imposed by the community.

Participant V: “Many believed that I slept with a lot of men during my pregnancy and that my child was disabled as a result. Nobody wanted me in the community except for my mother, but I felt that I was humiliating her, since people were calling my mother ‘witchcraft’s mother’ .So I thought of leaving the country.”

Participant VII: “Many wanted me out of the community a long time ago because they believed I was having sexual relationships with other men during my pregnancy and that that was why P (my child) was disabled, and that this was the cause of famine in the village. I was to leave the community because many bad things supposedly happened because of my disabled child. So I responded and packed for South Africa.”

4.3.3 Familial Shame about Disability

The expression “My father in-law took my child to the ritual in the early morning but refused to carry her back home” stands as representative of the fact that participants felt their family members were not supportive of a disabled child but, rather, were ashamed of disability since it was a negative thing to have within the family.

Participant I: “The only time I see my in-laws is when the family is having a cleansing ritual, and inform me that my child must attend a cleansing ceremony.”

Participant VI: “My father-in-law took my child to the ritual in the early morning, but refused to carry her back home because he believed that nothing had changed after the ritual.”

4.4 South Africa: Hope for Families with Disabled children

“I thought of going to South Africa with my disabled child”. The preceding sentiment was widely echoed by almost every participant. This suggested that participants felt that staying in Zimbabwe with a disabled child was very difficult and, furthermore, believed that South Africa might be a better place in which to raise a disabled child.

Participant IV: “I was told that the South African culture is tolerant towards people with disabilities and that the South African government gives money to people living with disabilities. I looked at all my suffering with my child and I thought that I’d rather go and stay in South Africa.”

Participant VII: “When I heard that the South African government gives money to people living with disabilities, I just saw South Africa as the destination for my child.”

Apart from the abuse by the community and family in Zimbabwe due to the disability of their children—not to mention the necessity of the dependency care grant available for their children in South Africa—the general understanding and acceptance of a disabled person by community members in South Africa was reported by participants as one of the primary reasons for their migration South.

Participant III: “My sister who was living in Cape Town told me that in the streets of Cape Town, for example at shopping malls, it is common to see parents pushing a disabled child in a wheel chair with no embarrassment. This being such a common sight in Cape Town suggests that disabled children are accepted as part of the normal society. So I thought of coming here to find peace with my child.”

Participant V: “My friend told me that the caring and concern shown by the community towards a disabled child in South Africa was too good to be true, so I asked myself why I kept hanging around in Zimbabwe.”

4.5 Impact of Traditional Beliefs on Disability in South Africa

Some of the participants felt that some of their family members and friends continued to believe that only ancestors in Zimbabwe were able to cure their children of their disability. This presents a further challenge:

Participant X: “My own aunt with whom I stay within the same shack told me to keep the money to take the child to Zimbabwe for ancestral cleansing.”

Participant V: “All the people around me in Cape Town think the best way [to cure my child] is to take me back to Zimbabwe to brew beer that would appease the ancestors and then my child will run like the other kids.”

The participants’ responses revealed not only that their family members and friends in Cape Town believed that the mother of the disabled child must go back to Zimbabwe for the child’s cleansing, but furthermore that the parents of disabled children should stop going against their Zimbabwean culture given that said culture forbids consulting health specialists on child disability.

Participant III: “My uncle told me to respect our Shona tradition of consulting the Sangoma when the child is living with a disability.”

Participant III: “My sister reminded me of the importance of sticking to our traditional ways when addressing child disability, instead of seeking advice from Western doctors.

Apart from being encouraged to seek advice from the Sangomas back home in Zimbabwe, a dominant view among participants was that some of their family and friends in Cape Town regarded consulting health professionals as a form of wasting money.

Participant III: “I just [go] alone to the clinic. I know if I tell them [my family] that they will not approve of my decision. They always say I am wasting money by consulting doctors.

Participant VII: “I always leave the house when my aunt is asleep, because if I tell her that I am going to the hospital because of my disabled child, she will tell me to stop wasting money.”

4.5.1 Mother as the Cause of Disability

Comments by certain participants suggest that some family members and friends in Cape Town continue to uphold the belief that child disability is a result of infidelity by mothers during pregnancy. This is a strong concept that the Zimbabwean tradition upholds back home and impacts negatively on caring for a disabled child.

Participant IV: “My aunt believes that the only way [to properly care for my disabled child] is for me to go back to Zimbabwe and consult the ancestral spirits, because I was not faithful to my husband.”

Participant X: “My friend asked me why I was not faithful to my husband during my pregnancy as this was the cause of P being disabled.”

In trying to affirm the Zimbabwean traditional belief that child disability was a result of maternal infidelity, participants reported that they were asked to admit and confess that they were not faithful to their husbands during their pregnancy.

Participant II: “My uncle told me that I must admit that I was not faithful to my husband and then go back to Zimbabwe to brew beer for the ancestors in pursuit of their forgiveness.”

Participant V: My aunt told me she can't assist me with money before I confess that I was unfaithfully to the father of my child. Once I confess, then she can only give me money to go back to Zimbabwe to see the elders and ask for forgiveness.

4.5.2 Victimization of Disabled Families by the Community in South Africa

Apart from the cultural victimisation or isolation by their own family members, friends and spouses (due to the disabled child), participants stressed that they were subjected to stigmatisation by local people in the communities in which they resided and that this dehumanising of their children was hurting them psychologically and contributing to the stress of raising the disabled child.

Participant IV: “These community people call my child ‘crutch boy’ because he uses crutches. It is not good for my child and, as a result, people don’t respect my child. It hurts and it’s stressful.”

Participant II: “I am always stressed because other community children call him ‘short’ because his leg is a bit short, but I don’t like this at all.”

Linked to the community’s stigmatisation of them, participants’ comments revealed that they started to take charge of their children’s victimisation by speaking out against all negative comments on their children.

Participant VII: “My neighbour refers to my developmentally-delayed son as ‘dumb’. I told her that she must stop calling my child ‘dumb’.”

Participant V: “I went there and confronted that chair lady in our street because every time she calls my child ‘crab’ because my child walks sideways.”

4.5.3 Support Groups and Nationality of Disabled Families

Of the 12 participants, a total of 8 revealed that the disability support groups were of paramount importance to them, as it was there that they learnt many coping strategies to help deal with the challenges of caring for a disabled child.

Participant I: “Our group is comprised of all nationalities as long your child has a disability. It’s a very useful group.”

Participant X: “If you are in this social support group, you feel at home as everybody wants to know about the challenges that you face, in order that they might assist. I love being in this group.”

Though some participants felt that they were being accommodated by the support groups in their communities, comments from another three participants’ signified that they were discriminated by support groups in their communities because of their nationality.

Participant VII: “It is difficult to be a part of this support group because they openly told me that they don’t like foreigners in their group, especially those from Zimbabwe.”

Participant III: “I would love to be a part of that support group, but, it’s only for South Africans. They are clear that no foreigners are allowed.”

4. 6 Economic Factors

Comments by participants revealed that their economic woes were worsened by the lack of present family, spouses’ and friends’ support, since they occupied a lower socio-economic status. They lived in informal settlements, working as domestic workers or gardeners, and were less likely to have enough resources to support them. This affected them tremendously as support from the family is regarded as highly vital to the success of raising a disabled child.

Participant III: “I do not expect my aunt to support me in everything because she also has kids and she is not paid well either. She is a domestic worker.”

Participant V: “My only brother is the one who assists me in difficult times, but the problem is he is a security guard and is lowly paid. He is a security guard.”

The evidence of lower socio-economic status among participants was further revealed by remarks that they sometimes slept on an empty stomach because they could not afford to ask for assistance from their family, friends and spouses every time, since their respective families were also lacking resources.

Participant VIII: “I can’t keep on asking my aunt [for help] when I am short of food in my house because she is also a domestic worker, like me. Sometimes I just eat mayonnaise then go to sleep with my child.”

Participant X: Many times I have made porridge for my child at night and I will just have a cup of tea myself. My friends are also not paid well, so I can’t keep on asking for food every day.”

4.6.1 Improved Economic Situation in South Africa

The interview process revealed that the economic status of Zimbabwean migrants was much better when they were located in South Africa as opposed to Zimbabwe. Many participants echoed the phrase “at least I am working”. Having work and a salary was reported as a reliever of some of the challenges associated with caring for a disabled child since they were able to afford some basic needs requisite to the child’s survival.

Participant I: “I am really happy to be here with my child. I pay nothing at the clinic for my child’s medication and at least I am working so I can afford to pay specialist if I need them.”

Participant IV: “Even if I am asked to pay at the clinic, I can afford it because at least I am working, in spite of the fact that my salary is not enough.

Though participants’ comments above indicate that they were in a position to access certain basic institutions, such as health services, education and also employment, their comments suggest that it is not easy for them to access these support structures as they encountered various barriers.

4.7 Access to Education

Zimbabwean asylum families living with disabled children reported encountering challenges with the schools in their areas. Below I have laid out some of the main challenges that many parents reported encountering.

4.7.1 Schools’ Resistance to Enrolling Asylum Seekers ‘Disabled Children

The phrase “no schools were prepared to offer him a place due to his disability and also because he was a foreign child” captures the frustrations and challenges that participants faced when trying to enrol their disabled children at local schools. Their comments revealed that principals seem to have attitudes that are totally against placing disabled asylum-seeking children in the “regular” school setting, so to speak.

Participant V: “My children stayed out of school for 2 years because schools were not prepared to offer him a place due to his disability and also as

foreigners. My child is very clever but how can he prove that when they schools enrol them last or never.”

Participant VII: “We arrived here in 2009 but my child only got accepted at a local school in 2010 because we are from Zimbabwe and no teacher was able to handle a foreign disabled child.”

The sentiment that “as long as you are a South African child with a disability and receiving a disability social grant, there is always a place for your child in all local schools” was repeated by participants throughout the course of the interview process, indicating that there was a difference in the way foreign children are treated at local schools.

Participant IV: “I was surprised when a South African child with the same condition as my child was successfully enrolled, while my child was denied a place at the school.”

Participant I: “I saw a local disabled child at that school, but the principal told me that they do not enrol children with disabilities at their school since there are no teachers trained for that. It’s only because I am Zimbabwean.”

4.7.2 Teachers’ Lack of Knowledge about Children’s Experiences

“I wish teachers knew what we have gone through” was another sentiment that was echoed by participants. These gestures to a lack of understanding by school authorities/teachers regarding some of the past challenges that disabled asylum children and their families had been forced to endure in their lives. For participants, this may have had an overall detriment on their child’s education.

Participant VIII: “I wish teachers knew what we have gone through. The teacher of my child always asks my child if his disability was because of war. This affects my child terribly.”

Participant III: “My child told me his teacher always asks him whether he was bewitched in Zimbabwe and whether this explains his disability. I wish teachers knew what we have gone through.”

4.7.3 Racism and Bullying of Disabled Children

A common feeling expressed by the majority of participants was that their children suffered bullying at school because they are asylum seeker children with disabilities. This was seen as affecting their children's interest to go to school.

Participant I: "Even when you manage to enrol your child at a local school, some children do not treat your child fairly. It is shocking how other young children at school hate my child because of her being a child of an asylum seeker, or maybe it is because of her disability."

Participant V: My child informed me that he was told to sit on the floor by one child in class because he was dark in complexion and he was a "kwirikwiri" (derogatory term for a foreigner) and can't walk properly."

Though every effort is made by parents to report the bullying of their disabled children to the relevant school authorities, participants felt that ultimately, the teachers were not doing anything to correct this bullying. "Even when teachers are told, they don't care about bullying".

Participant IV: "I don't know why these teachers are not taking measures to address bullying at the school. My child always complained about this and he said he once told his teacher but they are continued to bully him. Even when teachers are told, they don't care about bullying."

Participant VII: "I phoned the headmaster and he told me that he spoke to the girls who were bullying my child, but the child still complains that they are bullying her and it's getting worse. Oh God! Bullying is terrible."

4.7.4 Teachers' Incompetence with Child Disability

The idea captured by the phrase that "teachers at this school seem to know nothing about child disability", as voiced by some participants, expresses how participants felt about the competence of teachers who they saw as not competent enough (not sufficiently trained) to deal with disabled children. Teachers were seen as reluctant to assist their children, or as unaware with regard to the care of disabled children. This state of affairs puts the child's development at a disadvantage.

Participant V: “I wrote some information about my child’s condition in order for his teacher to better understand his condition...especially his symptoms. Teachers at this school seem to know nothing about child disability.”

Participant III: “I told the principal that if my child’s eyes turned yellowish, they must give her two glasses of water to avoid her from fainting.”

Adding to the challenges that disabled asylum seeker children face due teacher incompetence, a key informant (K.I.) from PASSOP revealed that there are a number of special schools in Cape Town where parents can send their children for access to better education and better teachers. It is the high cost that prevents them from applying at these schools. Their economic status forces them into a situation in which they have to send their children to schools where the quality of education is inferior. In a sense, the quality of their children’s education is determined by their economic status.

Participant XII (K.I.): “These parents’ economic status is the reason why they can’t afford to [send] their children to special schools when they can receive a good education. They end up sending their children to schools without a single teacher qualified to teach special kids, and where school facilities are not friendly.”

4.7. 5 Schools’ Environment and Infrastructure

Further comments from participants indicated that they were concerned with school environments and the infrastructure available for their disabled children. They described the environments as unfriendly to children with disabilities, and suggested that these conditions may do further harm to their education, as accessing classrooms became a challenge.

Participant III: “There are steps all over the school and my child spends the whole day in class because he cannot go out and enjoy [the outdoors] with others.”

Participant VII: “There are no lifts to use at the school, and my child is in C class which is in the second floor. He struggles getting to that level. Oh my Lord.”

4.8 Access to Health

Apart from difficulties in accessing education for their disabled children, Zimbabwean asylum seeker families also reported challenges in accessing adequate health care for their children. The challenges they reported are explored in the following pages.

4.8.1 Xenophobia of Health Professionals

Zimbabweans seeking to access healthcare for their disabled children encounter the double oppressions of both xenophobia and prejudice toward disability.

Participant X: “One female nurse at Nyanga clinic told me that he was getting annoyed, since the clinic was attending to more Zimbabweans than South Africans.”

Participant I: “The nurse told me that this clinic is slowly turning into a Zimbabwean clinic and that Zimbabweans can’t speak IsiXhosa.”

Apart from the xenophobic tendencies on the part of health officials, participants’ comments suggested that health workers have lack of cultural knowledge with regard to foreign nationals. These families felt that nurses make general assumptions about their needs or wants on the basis of myths they are told about the Zimbabwean tradition. The following responses on the state of health reveal this tendency:

Participant X: “You Zimbabweans are known [for] consulting Sangomas on issues of disability. What are you looking for in the clinic?”

Participant V: “One male nurse told me that there is no Sangoma in the clinic. ‘You have good Nangas who can assist you in Zimbabwe...’”

In addition to lack of knowledge on asylum seekers families that led to nurses treating patients insensitively and foreign patients being demeaned in front of local patients because of their nationality, comments by participants revealed that health officials had accused them of coming to South Africa for disability social grants.

Participant III: “The nurse looked at me and frowned his face when I told him I am from Zimbabwe. They think we are looking for sympathy to get disability grants.”

Participant IV: “Dzokerai Zimbabwe, kuno hakuna mari yevana venyu vakaremara’... (The nurse at Gugulethu Clinic asked me to go back to Zimbabwe since no disability grant was available for Zimbabweans, but I was there for my child’s stomach problems.”

Some comments by participants suggested that their humiliation by health officials didn’t bother them at all. These participants were more affected by being sent back home by nurses.

Participant VI: “I don’t feel hurt when these nurses humiliate me in front of people. I am worried when my child is not properly examined or when we are send home for no reason.”

Apart from being sent home for no reason, many expressed concern over the manner in which their children were examined. Participants revealed that their children received maltreatment during every visit to the clinic were badly examined, and on some occasions were simply given Panado tablets or sent home without good reason.

Participant VI: “The nurse just took a packet of Panado tablets and gave it to me before I had even finished explaining my child’s problem.

Participant V: The nurse at Gugulethu told me that she had attended to enough Zimbabweans for the day and instructed me to come back tomorrow if the child was still feeling ill.

Participant XII (K.I): “Many parents are sent back home by health officials just because they are from Zimbabwe. No any other reason.”

4.8.2 Language Problems at Health Centres

A dominant view held by participants leads one to believe that they felt that the use of local languages (Afrikaans and IsiXhosa), combined with health officials’ refusal to use English, was a deliberate attempt to isolate them. They were excluded because they cannot speak the required language.

Participant III: “I did not want to embarrass myself I ended up nodding in agreement with the nurse though she was speaking IsiXhosa – a language I don’t understand it at all.”

Participant IV: “I don’t know whether these were the correct tablets. I agreed so that she would feel happy that I understood her language. I prayed that the tablets do not do further harm to my child.”

Apart from the from service providers’ insistence on communicating in a language that these families cannot understand, a key informant from PASSOP reported that when these asylum families speak in English, the nurses feel unhappy.

Participant XII (K.I): “The other problem is when they fail to express themselves well in the local languages and mix IsiXhosa and English. Some service providers don’t like this and they can reject serving, believing them to be showing off.”

4.9 Legal and Policy Barriers

4.9.1 Processing Time of Asylum Documents

A majority of participants seemed to express agreement with following comment: “You cannot plan [for the future], as you cannot predict the long-awaited outcome of Home Affairs’ decision.” This suggests that while these participants waited for the outcome of their status, their lives are put on hold as their asylum appeals could still be denied or accepted.

Participant II: You can wait for a number of years while nothing is done. It is very stressful and you cannot plan for your future”.

Participant V: “We don’t know how long they are going to keep on saying we must wait. It has been almost 3 years of waiting for their decision. This has affected our plans and the future of my children is slowly turning bleak. They don’t see that they are killing our children slowly because we can’t plan what to do for them.”

4.9.1 Laws and Policies as Blockades to Services

Comments by participants suggest they have a common feeling that certain laws and policies were put in place to actively block them from accessing the child disability grant.

Participant II: “This law that prohibits us Zimbabweans from receiving this disability grant must be removed to give us some extra money to care for our children.”

Participant IX: “This is a serious segregation on the part of the South African Laws. Why is it only South African children with disabilities that are receiving the disability grant? Is my child not disabled? This is not fair.”

Apart from laws and policies that participants believed were crafted just to stop them from receiving access to the disability grant, participants felt that people who were meant to implement the laws that govern asylum seekers aren’t always up to speed on the relevant issues surrounding asylum permits and work permits. Participants report that they always face problems.

Participant V: “These nurses don’t know that a work permit is just the same as asylum permit. I can still use it to get services.”

Participant III: “Workshops are needed to orient service providers on the differences between the Zimbabwe Special Permit and the asylum permit. They really don’t know which is which. This is affecting us tremendously.”

4.9.2 Experts on Legal and Social Experiences of Asylum Seekers in the Cape

Apart from participants’ views on the laws and policies that govern them, a law expert on issues affecting the refugees and asylum seekers at People Against Suffering and Oppression of People (PASSOP) felt that South Africa has generous and relatively progressive laws that govern refugees and asylum seekers, but he argued further that the country lacks proper implementation and interpretation from some public institutions and thus adversely affects disabled families.

Participant XII (K.I): “Many asylum-seekers are turned away at some local communities because the nurses do not understand what an asylum permit is, and this affects children with disabilities.”

Participant XII (K.I): “It takes time for an asylum seeker to be accorded a refugee status. This actually prevents families living [with] a disabled child to qualify for a social grant.”

In the same vein, comments by a social worker working with asylum seekers and parents of disabled children at PASSOP suggested a concern regarding the lack of knowledge on the part service providers when it came to the subject of asylum seeker documents.

Participant XI (K.I): “There is nothing we can do. It’s frustrating because some of the nurses do not understand what an asylum permit is all about. They can send you home because they think it’s a receipt.”

Participant XI (K.I): “My child has an asylum permit and the school always wants to know what will happen when it expires and whether it is a genuine government document.”

Similar to participants’ concerns regarding the time spent waiting for their refugee status to be recognised, the social worker’s comments further suggest that the time it takes to accord refugee status in South African law is too long. As a result, this prevents families with disabled children from access to relevant social grants.

Participant XI (K.I): “It takes time for one to be recognised as a refugee and, in the end; the result is that it is the parent with a disabled child who suffers.”

Participant XI (K.I): “The disability grant was going to assist us, but because we are not [recognised as] refugees, we can’t receive this assistance from the government.”

4.9.3 School Policies Governing Foreign Disabled Children

Comments by participants reveal that they felt that some school policies negatively affected the enrolment of their disabled children.

Participant I: “Once they realise that you are not South African and your child is disabled, they start talking about school policies governing foreign children. It’s very difficult for them to accept your child in any class.”

Participant III: “The combination of being an asylum seeker and having a child with a disability is painful. This combination is the reason why my child took two years to be enrolled .They told me about new policies regarding asylum seekers. It’s only that schools are not comfortable accepting a disabled child.”

4.10 Fear for the Future

“Who will take charge of my child?” was a recurrent phrase that encapsulates some of the anxieties of parents living with disabled children. This suggested that participants lived in fear for the future of their children, especially worrying about who would look after their children when they die.

Participant X: “My child will suffer if I die here. Who will take over from me? Nobody! I know what it means to look after him.”

Participant XI (K.I): “The problem is when a parent of a disabled child dies it’s difficult to find a person who can endure the challenges. I always tell parents to go back to Zimbabwe if their health conditions are deteriorating.”

Apart from the question of responsibility toward the disabled child, comments by participants suggested that they were worried as they uncertain whether the South African government will deport their children to Zimbabwe, or accept the responsibility of taking care for them.

Participant III: “I don’t want to be buried here in South Africa if I die before my child. But, what will happen to my child when I die? Will the South African government deport him or take care of him?”

Participant II: “It’s a problem for me every day, thinking what will happen to my child after my death. I am not sure whether the government will take her back to Zimbabwe or will look after her.”

Zimbabwean families reported that accessing services for their disabled children, and for themselves as parents of disabled children, was a real struggle. These struggles were due to the hostilities that emanated from their own family members, friends, and the communities in which they resided, and the segregation of their children at schools and the concomitant stigmatisation that they faced on a daily basis at hospitals and clinics. Though they reported all these challenges, participants, nevertheless acknowledged a number of family support needs that were satisfied by the health professionals and some of their family and friends, as well as churches and nongovernmental organisations.

4.11 Support for Families

Asylum families living with disabled children reported two main support sources as vital to their day to day living. The two forms of support are the informal and the formal support.

4.11.1 Informal Support

Family and Friends

Although the traditional Zimbabwean views about a disabled child were reported to be negative, and therefore one of the main reasons compelling migration to South Africa, some participants commented in positive terms regarding the assistance they received from their family members and friends in South Africa.

Participant III: “We discuss with my aunt, together in my hokkie [shack house] talking about challenges that I face with my child, it relieves me to have somebody with whom to share my problems.”

Participant V: “My aunt always comes and spends the weekend with me just talking about our lives here in Cape Town, and also about my child. This is relieving.”

Apart from family members’ support, the instrumental and informational support from friends was also acknowledged by participants as pivotal sources of support in dealing with the challenges associated with caring for their disabled children:

Participant X: “She is my close friend. That’s why she sometimes pays the transport for my child to school.”

Participant I: “She is the only person who always pays for my transport to all my doctor’s appointments. She is a real friend.”

Apart from the above-mentioned forms of support, spouses were also acknowledged as vital in supporting a family with a disabled child.

Spouses

Of the ten families in the study, only three reported that their spouses were of importance. Those who perceived the assistance of their spouses in Cape Town as key summarised it in the following statement: “we are one, and we do it together in this journey.”

Participant X: “I don’t know how caring for my child would be if I was alone without my husband. He is the best support I have. He takes charge on transport issues for me to take H [my child] to the doctors’ appointments every month. We are one and we do it together in this journey.”

Apart from acknowledging the beauty of having a disabled child, participants suggested that there was love to be found in raising disabled child.

Social and Emotional Bond among Spouses

Comments by some participants were indicative of the fact that disability in their children was a platform which creates further possibilities of social and emotional bonds between the mother and the father.

Participant X: “I am happy that the condition of our child has taught us how to relate better as a husband and a wife. Instead of fighting, our communication skills have improved tremendously. We learnt to love each other with respect the same way we love our child.”

Participant II: “We only started to be close and understand each when we were blessed with T [my child] who is disabled. Our love started blossoming.”

No Support from Spouses

On the other hand, while some acknowledged their spouses as vital in caring for their disabled child, others stated that their spouses were not at all taking responsibility for the caring of a child.

Participant IX: “He is the father of my only child and he does not care about his child. He is working and is paid better, but he is out of touch.”

Apart from family, spouses and friends’ support, participants acknowledged the importance of non-governmental organisations in caring for a child with a disability.

Non-Governmental Organisations

Comments by participants about non-governmental organisations, especially PASSOP, suggested that they were pivotal in the provision of informational and instrumental support.

Participant IV: “I am very happy with the help I received from PAASOP. They helped my child to obtain her Section 22 permit from the Department of Home Affairs. It was really a struggle.”

Participant II: “The Muslim Agency always gives me some money when I am going to meet the doctor for my child.”

Religion

The idea that “God always sees his children through and never give us more than we can bear” was repeated by the majority of participants, acting as a clear indication that they believed that God was in charge of their challenges, as he is the creator and provider of a child born with a disability.

Participant VI: “It’s God’s plan for me to have a child with a disability.”

Participant IX: “...and God gave me a child with a disability because he knew I am up to the task, and I am not – I was not – surprised to have a child like M. It was God’s plan.”

Though participants admitted that there were some challenges in caring for a disabled child, their comments suggested that having a child with a disability was not a punishment but a blessing.

Participant III: “God gave me the child with a disability so that I can exercise the command of love. This is a blessing and not a punishment at all.”

Participant VII: “This is not a punishment. Some people are not blessed with kids. I am blessed with T. So how can he be a punishment?”

Church Support

In dealing with challenges associated with child disability, participants’ comments suggested that the church played an important function. .

Participant V: “...and these Catholic Church members make me understand what it means to have child with a disability... how to care for and love a child with a disability.”

Participant II: “It is from my Catholic Church that I learnt that I have to love my child the way he is. I now understand the meaning of disability much better than before.”

Apart from the spiritual and church support, participants acknowledged the material support that they received from their churches as integral.

Participant V: “The Roman Catholic Church priest in Gugulethu paid the fees for my child. I am very happy to be part of that congregation.”

Participant I: “I am a member of the Muslim congregation in Athlone. They paid for my child’s fees and gave us clothes and blankets every winter.”

Not only did the participants acknowledge the support received from churches, comments from one key informant living with a disabled child even suggested that churches played an important role in supporting her and the child:

Participant XI (K.I): “I also thank the church that I go to because they sometimes pay my child’s school fees. Some of the church members understand my situation. Some assist me with food parcels and clothes for my child.”

Parent Support Groups

Apart from the above-mentioned forms of support, comments by some participants suggested that support from disability support groups was necessary in caring for a disabled child.

Participant I: “I rely on this disability support group for information on how to care for my child.”

Participant V: “This disability support group is part of my family. Everybody is open to share challenges with one another. It is a family.”

Though some participants acknowledged support groups as being central to their caring for their disabled children, some comments from other participants suggested they were not happy with their exclusion from the disability support groups.

Participant III: “I know that it is important to be part of a disability support group. However; they do not like foreigners to be part of that group. It’s sad. They told me I cannot be a part of them, even though I am like them.”

4.11.2 Formal Support

Health Professionals

The phrase, “I am impressed with the doctor for my child”, as reported by some participants, indicates how many of them were impressed by the assistance they received from health professionals, in particular doctors’ informative and emotional support.

Participant X: “I am impressed with the doctor for my child. He goes the extra mile in providing all the information we need about my child.”

Participant VII: “At times he gives me money for transport or drops me at the taxi rank. This doctor was sent by God for the disabled. He must be blessed.

Teachers/Schools

In seeking information that would assist them in dealing with the identification of disability, participants were grateful with regard to the informative support they received from schools, especially in the years of early childhood development. Assistance given by teachers on the subject of early childhood development was seen as vital in preventing the worsening of the child.

Participant III: “The teachers just gave all the information to me so that I get in contact with specialists for my child.”

Participant IV: “The school detected my child’s learning problem. This was wonderful. I am very grateful and more details on where to find other assistance were given to me.”

4.12 Signs of Resilience

This study defines resilience as the ability, by Zimbabwean asylum-seeking parents living with disabled children in Cape Town, to endure the adversity and recover from harsh conditions, thereby becoming stronger and more resourceful. These families started to (1) make meaning of their hardships in caring for a disabled child, and (2) started to turn every situation into positive one.

Love the Child

The phrase “My child is all I live for”, a sentiment widely repeated by participants, indicated a loving attitude toward their children. Participants preferred to isolate themselves from the community gatherings and be with their children, rather than being in the presence of those reject their children. They appear to be strong advocates of their children. Their children came first before anything.

Participant IV: “They feel I must not be part of their gatherings. One community member told me people are afraid of my child’s disability. So, I just lock myself in my shack and play with my child. I will rather be with my child. My child is all I live for.”

Participant III: “They don’t even inform me if there are any gatherings of importance in the community. I know it’s because of my child. I don’t care. I stay away from them too. I came from Zimbabwe because of a hostile community that was worse than this. I don’t care. My child comes first.”

Positive Outlook

Many participants felt that the only way of coping with the challenges that come with caring for a disabled child was to maintain a positive outlook on their disabled children. Families’ comments suggest that they put their disabled children above their “normal” children.

Participant I: “M weighs 16 kg now. At her age, she is one of my healthiest children.”

Participant IV: “I wish all my children could be respectful like him. He is really a good example.”

No-Pity Attitude

For many disabled families, pitying a child with a disability was regarded as disabling in itself. Thus, the “no-pity” attitude was felt by participants as an appropriate way of coping with the challenges of caring for a disabled child.

Participant IX: “I just treat him like his younger sister and they sweep the house together.”

Participant VII: “She learnt to go up the stairs and there is no problem with that.”

Acceptance

Comments by participants suggested that accepting a child with a disability is a good thing for parents to do. However, participants revealed that accepting that one’s child is disabled is not an easy task.

Participant III: “I used to deny that my child is disabled but now I have learnt how to accept my child’s condition and, thank God, I am living a stress-free life.”

Participant IV: “I only accepted the disability of my child 3 years ago. I used to deny his disability. Now I have accepted that that he is disabled and nothing will change. He is my child and I love him.”

Perseverance

Comments by participants suggested that perseverance was perceived as a good way of managing child disability challenges. Many felt that it is only through perseverance that they will find ways of doing things right, of discovering new strategies after many failures.

Participant V: “I kept going to the clinic, even though they were not happy with my child’s disability. Now they like him because I can speak their language.”

Participant IV: “I realised that the only way was to slowly learn isiXhosa for the sake of my child’s treatment at clinics. It was not easy but now I can speak it fluently.”

Normalcy: Normal vs. Special

Some comments made by the majority of participants indicated that they were caught between normalcy and the disability of a child, and as a result, grappled to see their children as simultaneously disabled and as normal.

Participant I: “He is a normal child like any other children who are not disabled, and the teacher must assist him, taking into consideration that he takes time to understand concepts in class, when compared to other kids.

Participant IV: “It’s only that there are times when I must not go to work because of her condition, but otherwise she is a normal child like any other child in the community.

Participant XII (K.I): “Many of these families don’t want to accept the disability of their children. Disability is a reality and they must accept it.”

However, this wavering back and forth exhibited by other disabled families suggests the need by disabled families to make integrate their disabled children into the society and prevent them from experiencing discrimination and harassment.

Participant V: “You can only notice my child’s disability when you talk to her. That’s why I told the principal of the school that my child was very normal when I was enrolling him. If he could have asked one question to my child, [the child] might not have been enrolled.”

Participant VII: “I ticked NO on the box where the school was asking for the disability of my child. They enrolled him. They only discovered [the disability] after she was already in class. They would not have enrolled her. Now they can’t deregister her because it’s unlawful.”

Stories of Hope

The majority of participants felt that reading material especially that written by parents with disabled children about their own experiences, gave them strength and hope to conquer some of the challenges caring for a child with a disability.

Participant IV: “I was happy when I read in one pamphlet that their disabled child was given a bursary at a school in town. I felt that my child could also be lucky one day.”

Participant VI: “I was touched by that story, in the Vukani paper, that the parent of a disabled child was earning a living through selling sweets and airtime at the taxi rank. I was inspired. I can also do the same and earn extra money during weekends.”

4.13 Chapter Summary

From the above findings, it is clear that Zimbabwean asylum families living with disabled children in Cape Town were forced to migrate to South Africa, having experienced different challenges that range from the economic to the intolerant views on disabled children. Comments by many participants indicated that the challenges they faced in Zimbabwe left them with no other options but to migrate to South Africa. Having gone through these challenges in Zimbabwe, and also having learnt from other family members and friends in Zimbabwe and in South Africa about the economic situation and accepting attitudes, South Africa became the only answer for them to improve their lives and that of their disabled children. Families of disabled children reported that the situation in South Africa was much better

since the majority of them were employed and as a result were able to pay specialists and buy food for their children.

Though South Africa was much better for these families compared Zimbabwe, these families reported that they also encountered certain challenges in accessing some services in South Africa. Because of these challenges, the study's findings indicate social support as key for these disabled families living in the Cape Town province. As acknowledged by participants, the informal and formal networks were crucial in dealing with the challenges encountered by these families in their day-to-day living. These challenges include, among others, discrimination, discriminatory laws and policies, xenophobia and language issues. The combined available social support structures were seen as helpful in dealing with these challenges.

On the question of informal support, many families acknowledged the support they received from their families and friends as being of paramount importance. This can best be described as a kind of emotional support: in other words, the loving, caring and sharing of problems with family members and friends. Families highlighted that friends and families were there for them to share in the challenges they faced in caring for a disabled child. Instrumental and informational support structures were also mentioned by participants as part of the support they received from their families and friends.

Apart from the support received from family and friends, findings indicated that religion played an important role in providing social support for these families.

Many parents indicated that a disabled child was a gift of love from God. As a result they saw the child not as a punishment, but rather as a blessing.

The support provided by health practitioners (formal) was rated on a spectrum that ranged from those who were happy with the services provided, to those who were not impressed. In situations where the nurses were very negative about attending to disabled asylum-seeking children, one could argue that xenophobia is embedded within professional practice, because incidents of discrimination are so recurring. Many themes emerged regarding the perceptions of a child with a disability. Parents' responses pointed to the fact that they used different frameworks to

understand and explain the conditions of their children. These aid them in dealing with the challenges they face in caring for their disabled children.

The next chapter presents the link between the literature and the study's findings. In this following chapter, all the themes that surfaced from the preceding chapter will be analysed by interweaving them with the reviewed literature. Importantly, the results deal directly with the question of the family support of Zimbabwean asylum seekers living with disabled children in Cape Town. Apart from dealing with these disabled families, the results are reflective of the current literature available on the family-support structures of asylum-seeking families living with disabled children.

5. CHAPTER FIVE: DISCUSSION

5.1 Introduction

The family support of asylum-seeking families living with disabled children is fairly new in the disability discourse, and accordingly there is a dearth of knowledge on the growth of family support, not only in the developed countries but also in Africa—and especially in South Africa, where the majority of asylum seekers are reported to reside. There is still some vagueness surrounding what family support is, who provides it, and how it is provided. Given this vagueness, and my interest in and commitment to the family support of asylum-seeking families living with children with disabilities, the overarching aim of this research thesis is precisely to explore the family support of asylum-seeking families living with children with disabilities.

This chapter discusses the study's findings, based on the results in the previous chapter. The parents' responses are synthesised and discussed in relation to the three main objectives of the study:

- (1) To explore the perspectives of disabled Zimbabwean families living in South Africa's Cape Town Metro Region.
- (2) To identify the barriers that prevent these families from getting the support they need.
- (3) To investigate the resilience strategies employed by Zimbabwean asylum-seeking families living with children with disabilities in Cape Town.

All the themes that surfaced in the preceding chapter will be analysed through the lens of the reviewed literature. Importantly, the results deal directly with the family support of Zimbabwean asylum seekers living with children with disabilities in Cape Town. The results are also cognisant of the current literature on the family support of a family living with a child with a disability. Some of the themes that emerged in the study are distinctive in the sense that they are less detailed in the literature particularly on support to the families living with a child with a disability, though not

spoken by families that participated in the study, a number of them were deduced only by listening to the narratives of families.

5.2 The Study Theory: Ecological Systems Theory

In order to understand the impact of child disability for asylum-seeking Zimbabweans living in Cape with their disabled children, it is essential to take into account the ecological theory that was developed by Urie Bronfenbrenner. Bronfenbrenner's ecological systems theory will assist in explaining how an asylum-seeking Zimbabwean family with a child with a disability functions, and how the surrounding environment affects how the child in question grows and develops. The theory is comprised of five levels, which include the microsystem, the mesosystem, the exosystem, the macrosystem and the chronosystem.

Of the five levels, this study will only make use of the microsystem, exosystem, and the macrosystem. These levels clearly show the experiences of Zimbabwean asylum-seeking families living with a child with a disability in Cape Town, because their way of living is affected by each level. In other words, their way of life cuts across these three levels. The levels will be discussed below in brief. It is vital to note that discussing the life experiences of asylum-seeking Zimbabweans living with their disabled children in Cape Town level by level is not feasible, since their life experiences cut across *all* levels. Their life experiences cannot be discussed in relation to one level in isolation, because activities in one level affect those in the other levels.

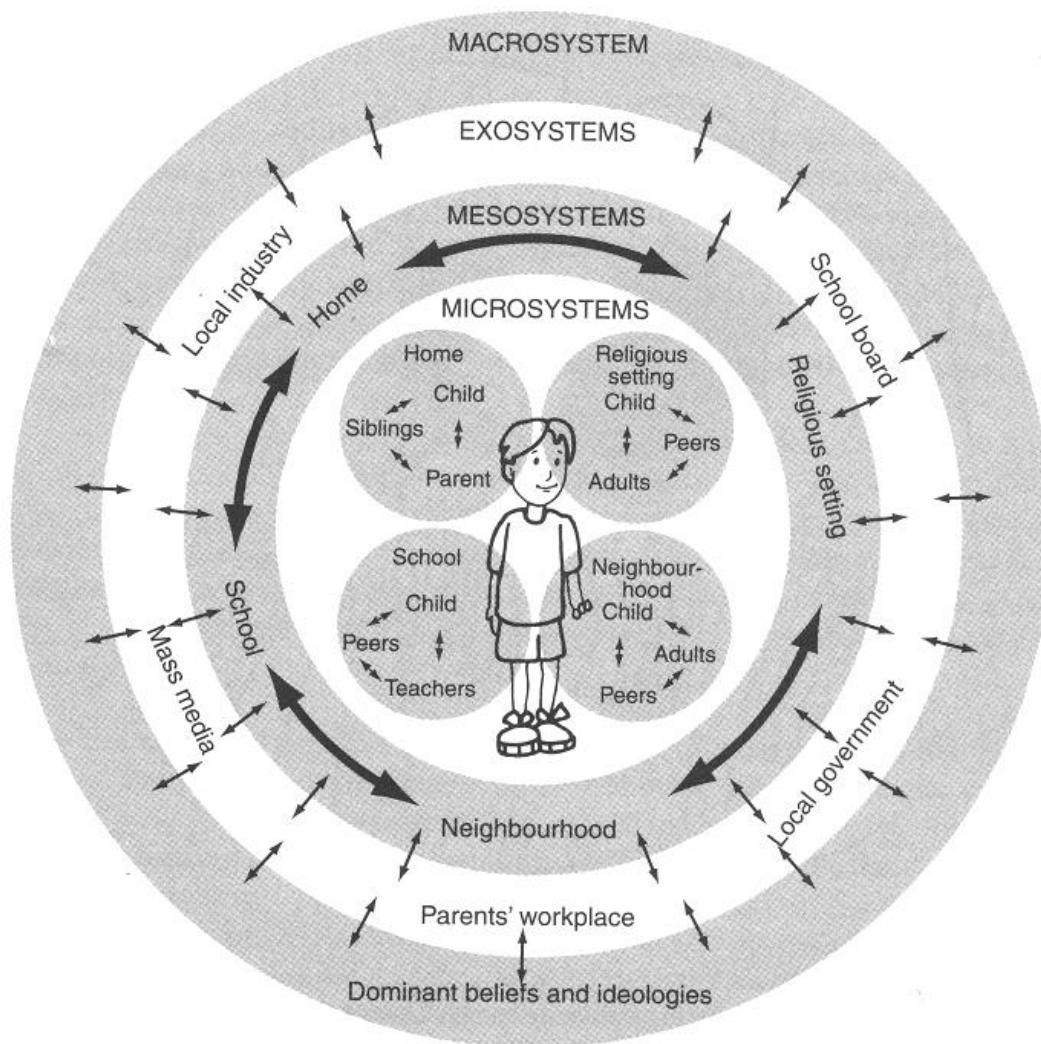


Figure 1: The ecological diagram: The ecological approach, which hypothesizes the layers of influence on a Zimbabwean asylum seeking families living with a disabled child in Cape –South Africa. (Picture adapted from Penn, H. 2005. Understanding early childhood education, Issues and controversies).

The microsystem, exosystem, and the macrosystem levels as highlighted and shown in the diagram above will be discussed below.

5.2.1 The Microsystem Level

This level refers to the institutions and groups that most immediately and directly impact the child's development, including family, school, religious institutions, neighbourhood, and peers (Bronfenbrenner, 1979). The association between the child and family, church and teachers may have implications for the growth of the child.

5.2.2 The Exosystem Level

The exosystem level is the link between the social setting, in which the individual does not have an active role, and the individual's immediate context (Bronfenbrenner, 1979). For example, a parent's or child's experience at home may be influenced by the other parent's experiences at work. The parent might receive a promotion that requires more travel, which might increase conflict with the other parent and change patterns of interaction with the child. What happens in the exosystem is mainly influenced by what happens in the macrosystem. Immigration laws can have an impact on how such families are treated in clinics. Once the families living with children with disabilities are affected by the macrosystem and the exosystem, the microsystem level also suffers, as this is the level directly connected to the child.

5.2.3 The Macrosystem Level

The macrosystem is analogous to the global world, and comprises the political situation, the economic situation and the nationality of these families (Bronfenbrenner, 1979). When families move to South Africa due to the political and economic situation in their country, they are faced with immigration challenges from the South African government.

5.3 The Relevance of Ecological-Systems Theory for Zimbabwean Asylum Seekers

Bronfenbrenner's model outlines the interaction of systems and the significance of biological, psychological, social, cultural and economic conditions that impact on the Zimbabwean asylum-seeking families living in Cape Town with disabled children.

His theory emphasises that a family—in this case, a Zimbabwean asylum-seeking family with a disabled child (microsystem)—can simply be understood through the relationship of the family to school, the church, the neighbourhood, the parents' work setting(exosystem) and society at large (macrosystem) (Bronfenbrenner,1979). As Stevenson (1998) has noted of the theory, “though it is theoretical, it is very practical, it provides a kind of map that guides us through very confusing terrain” (p.19).

All the three levels described above are equally important for the survival of a Zimbabwean asylum-seeking family and their disabled child. Having one form of support would not be enough for the family of a child living with a disability. Once the circle of care or support system is destabilised, the possible solutions to the predicament of care that such a family faces are reduced. In this study, Bronfenbrenner's theory proves useful in exploring the relational difficulties within a Zimbabwean asylum-seeking family living with a disabled child in a migrant community in Cape Town. His theory helps explain how a Zimbabwean asylum-seeking family can be fitted into or included in the larger global community, as a way to improve their access to the support structures they may require for their survival and that of the child.

5.4 The Perspectives of Disabled Zimbabwean Families Living in Cape Town

In order to understand the significance of this study, it is necessary to examine the technical and legal definition of asylum seekers and refugees. These definitions impact upon the kinds of services to which these Zimbabwean asylum seekers are entitled and the particular challenges they might face.

As stated in previous chapters, literature on Zimbabwean asylum-seeking families living with disabled children in South Africa is scarce. This scarcity makes it difficult to deduce why these families decide to migrate to South Africa. More can be deduced from the literature available on disability in Zimbabwe, which portrays the disabled community of Zimbabwe as living under harsh and poor conditions.

As indicated in the literature review, numerous reasons exist for disabled Zimbabwean families leaving their country to live abroad. One significant reason—not often explicitly cited, but embedded in the basic human-rights framework—is the impact of the disability of a child on a family (Williams, 2013). A closer look seems to suggest that Zimbabwean families living with disabled children are confronted with other enormous challenges, such as the strict societal and cultural beliefs about disability (especially regarding a child), poverty, drought, famine, a lack of housing and other basic resources. It may be the consequence of living with the totality of this deprivation that drives immigration (Tilden & Weinert, 1987). Certainly, these factors help explain why some disabled families end up in South Africa. The strict cultural beliefs on child disability in Zimbabwean culture point to the social model of disability, where a disability—in this case, the disability of a child—is caused by the way society is organised, rather than by an individual's impairment (Oliver, 2004).

Research that investigates people's decision to immigrate and explores their experiences during and post-migration is necessary for understanding the current health status of Zimbabwean asylum-seeking families living with children with disabilities, as well as the global health needs of similar immigrant families at all stages of the immigration process.

How does one explain the dangers for a family migrating to a foreign country with a child with a disability? Are these families not heading towards an unknown future? How will these families learn the norms of a new country with its own culture, meet new people, learn new languages and access different services? In terms of whether going to South Africa would exacerbate or ease the challenges these families face in their own country, one is left with more questions than answers—especially given reports that families living with children with disability are better off with supportive people around them who genuinely care for them.

Leaving the country that offers support structures may be a wrong move for these families. One such support structure is the extended family: according to Nyamukapa and Gregson (2005), the extended family system is usually the first point of reference when a problem arises. Though the consolidated extended family

was affected during colonial and apartheid Africa (African Rehabilitation Institute, 1991), African cultures, unlike European cultures, still put emphasis on extended families as pivotal points of assistance in times of need (Peters & Chimedza, 2000). Uncles, aunts and nephews are seen as part of the family. For families with disabled children, migrating to South means leaving behind extended-family members, friends and a community that understands their plight well. The circle of care for a disabled child is therefore disturbed. Once the circle of care is disturbed, the challenges of caring for a child with a disability (as revealed by the findings) may increase. For example, when a disabled family that was used to the (emotional) support of a grandmother has moved away from that source of support, there may be serious consequences for the family. In South Africa and Zimbabwe, as in many other African countries, children—in this case, children with disabilities—are members of a broad extended family, and arrangements for their care and upbringing are the concern of not only their biological parents but also an extensive network of relatives (Nyambedha, Wandibba & Aagaard-Hanse, 2003).

Though the role of the extended family in taking care of children with disabilities cannot be ignored, my practical experience suggests that the meltdown of the Zimbabwean economy and persistent droughts have contributed to an impoverished relationship between families living with children with disabilities and their extended families. Families living with disabled children are pointed to as the reason the community is experiencing these economic challenges and droughts, because they have been punished by the ancestors. However, blaming a family with a disabled child for droughts and misfortune can be viewed as a symptom of the economic situation in Zimbabwean communities, where extended families simply have limited or no means to support a family with a disabled child. Though there are many other reasons that families can cite for isolating and stopping their support of families in need, blaming the family of a child with a disability is one that is caused by extended families to create a bad family relationship, in a bid to withdraw support for this family. In short, although moving away from such a large family-community support network to South Africa may correlate with an increase in stress levels for a disabled family, because part of the support is lost, it should be

noted that the extended family might be one of the factors that lead these families to migrate to South Africa in the first place.

In a sense, the migration of disabled Zimbabweans to South Africa affirms Peters and Chimedza's (2000) position that the concept of the family as a social unit that takes responsibility for its disabled members is changing in Africa. This concept is being eroded by the pressures exerted by urbanisation and by changing patterns of production and employment, all of which substantially weaken the institution of the family and replace it with the nuclear-family system, which has a very loose extended-family base (African Rehabilitation Institute, 1991). This loose support is a possible explanation for the widespread sense of rejection and isolation we see in families living with children with disabilities in Zimbabwe, and hence for their migration to South Africa.

Having said all this, though, what is the situation of Zimbabwean families living with their disabled children in Cape Town? What forms of support are available to them? Are those forms of support easily accessible to them? If there are challenges in this respect, how do these families manage and address these challenges, in the foreign country in which they find themselves?

5.5 The Nature and Meaning of Social Support for Disabled Families

The findings of this study reveal that families living with children with disabilities in Cape Town made use of two inseparable forms of support. Both formal and informal sources of support were tapped into by these families, in a bid to deal with the challenges associated with caring for a child with a disability. These two forms of support were acknowledged as tools that empower these families to live in a foreign migrant town in South Africa. In an attempt to flesh out what social support means, Findler (2010) proposed a two-tier, dimensional perspective of social support: the formal vs. informal. This formulation of social support as a complex phenomenon with varying definitions was in part driven by the need to understand social support in families with children with disabilities (McCubbin & Patterson, 1983).

What separates these two forms of social support is primarily the composition of the individuals involved in each system and the family's relationship with those individuals. In this study, both forms of support were found to be indispensable when caring for a child with a disability, especially while living in a foreign country. This indispensability confirms what has already been discussed in relation to ecological theory. Ecological systems theory put emphasis on the connectedness of all ecosystem levels, when trying to achieve positive results for the child (Bronfenbrenner, 1979). The family living with a disabled child (the microsystem level) connects with the environment outside the family, which can in turn influence the wellbeing of the child with a disability (the exosystem level). The microsystem and the exosystem levels also depend on the macrosystem level (that is, the global level) for the survival of the family and the child with a disability.

5.5.1 Informal Social Support

Support from Family Members and Friends

The use of informal support was acknowledged by participants as being critical in dissipating some of the stressful challenges associated with caring for a child with a disability. The informal circle of care was depicted by participants as crucial. This circle consists of individuals, such as family members and friends, and social groups, such as church affiliations and social organisations, and it was always accessible. The importance of the support of family and friends comes across strongly in the findings of this study, especially when participants reported that, when they have a problem at any time of day, social-networking supports were considered the first point of call. It is no wonder that Findler (2000) states that social networks assist in offering social support for daily-life routines. Commenting on the importance of informal supports is Baker (2011), who showed that support from the family provided much-needed assistance in managing and caring for a family living with a child with a developmental disability. From the results of the study, it seems that emotional support—which includes, among other things, the sharing of problems related to the care of a disabled child—was provided by the friends and family members of the disabled family. Apart from the emotional support provided by friends and family members, the results indicated that valued information was also

retrieved from the Internet. Hence, the results show that informational support was of paramount importance for these families. Instrumental support—where money is provided for transport to the doctor and for purchasing other things that a family may need—was also mentioned by a number of participants in this study. These findings are in line with those of Agosta (1998), who maintained that the provision of cash services (instrumental support) empowers families to select and purchase supports and services tailored to their own unique needs.

The above findings are consistent with the scientific literature on the importance of financial support as a vital resource for individuals who are dealing and coping with a stressful situation, such as parents raising a child with a disability. Freederman et al. (2000) state that families living with a disabled child are more likely to require extra financial support to pay for therapies, medication and adaptive equipment. This becomes a challenge for Zimbabwean asylum seekers with disabled children, due to the burden of care involved in caring for the child. They are forced by their circumstances to work fewer days, because of the extra care needed by the child. However, with the church, family and friends (informal support) sharing the burdens of care, the families are comforted and better care is provided for the child.

Previous research on the topic, such as that of Freederman et al. (2000), who defined social support within a framework of a family system, is affirmed by the captioned results of this study, which showed that a family network (family, friends and church) is critical in ensuring that the necessary support is provided for a child living with a disability. Though Freederman's definition of social support is limited, in that it does not include other forms of support like the instrumental or the informational, his definition of social support is in this case accurate, since it covers the emotional resources that are desperately needed by a family living with a disabled child. Comments by participants suggested that emotional support was very important to these families.

Though the majority of participants revealed how crucial their friends, relatives and families were, not all participants shared this view. Certain participants expressed their displeasure in the way some of their family members and friends perceive

them and their disabled children. These participants reported that this perception is rooted in traditional Zimbabwean beliefs about disability, where a mother is blamed for the disability of her child. The traditional beliefs that were directed at the disabled families can be linked to economic status, since the researcher discovered that the majority of these disabled families are from poor socioeconomic communities, where the majority of people live in the informal settlements and work as domestic workers and gardeners. Socioeconomic circumstances notwithstanding, the displeasure that emanates from traditional beliefs impacts negatively on the informal support from family members and friends. Family members and friends who believe in the traditional concept of child disability will isolate a family living with a disabled child, providing no informal support.

Support from Spouses

Some participants revealed how their spouses support them in caring for a disabled child. These participants stated that the burden of care was lessened by the involvement of their spouses. This finding of spouse involvement in the care of a disabled child is consistent with Kersh et al. (2006), who reported that spouses are key in caring for a child with a disability, since duties can be shared between the parents. Those who spoke of the support they received from their spouses, from the diagnosis to the treatment of their child, presented it as vital. This finding is further summed up by Kersh et al. (2006), who state that some fathers are aware of the needs of their children. Understanding the needs of the child will help parents work together to overcome the challenges involved in caring for a child with a disability. Understanding the needs of a child with a disability is therefore useful in and of itself, as it facilitates accepting the child into the family, regardless of his or her condition.

Lack of Support from Spouses

Though the support of spouses was acknowledged by some participants, the majority of participants reported that their spouses were not interested in caring for their disabled child. Some highlighted how burdensome it was having a child with a disability in a Zimbabwean marriage, while others reported that their marriages came to an end as a result of their disabled child. This finding is

consistent with Sobsey (2004), who showed that, for the parents of children with developmental disabilities, marriages are often difficult, dysfunctional and more likely to end in divorce, due to unresolved grief and the extreme demands associated with raising a child, which result in extremely high levels of stress and produce, in turn, dysfunctional marriages and high rates of divorce.

Contributing to the finding of child disability as a strain and a cause of divorce in marriages, a study by Charowa (2005) in Zimbabwe indicated that some husbands separated with their wives because they could not come to terms with the disability of their children, and because they were under pressure from their relatives.

Families living with children with disabilities in this study reported that Zimbabwean cultural beliefs about disability, as well as family members' and friends' educational levels, contributed to their state of divorce and caused some of their family members, friends and spouses to be unsupportive and uncaring towards them.

Family Isolation from the Community

Relatedly, African family dynamics can work to exclude members with a disability, causing stress to all family members (Booyens, Van Pletzen, & Lorenzo, (2015).The community may choose to segregate a family with a disabled member and may even force a husband to neglect a child with a disability and divorce the mother of the child. However, the exclusion of a family with a disabled member or a disabled person in the community is not unique to African cultures alone. South Asian cultures like Pakistan, for example, hold the same belief that a girl is expected to be like her mother, and a boy like his father (Baker et al., 2010). When this resemblance does not occur, it is seen as a disturbance in the natural order. In traditional communities, a family may wonder whether their disabled child has been taken over by djinn (spirit), or else they see him as a "changeling". Parents may even feel isolated from the rest of their community because of the perceived stigma of having a child with developmental disabilities.

Religious Support

None of the participants mentioned African traditional healers as a source of support, and it is worth pointing out that the role of traditional healers in solving challenges is highly contested in modern Zimbabwe. Zimbabwean traditional

religion (ZTR) sees traditional healers as vital sources of support in times of social and economic turmoil. However, some Christian Zimbabweans believe that traditional healers are no longer worth consulting when a family is faced with challenges. Participants in this study viewed traditional healers as part of the “evil” affecting their communities, including the disability of their children. They suspected that traditional healers had used herbs to disable their children during their pregnancy. This may be why all the participants in the study rejected the idea of consulting traditional healers: they believed that their having a child with a disability was partly caused by these healers.

The findings of this study reveal that participants used the Christian religion as one of their means of support in caring for their disabled child. They experienced their religious lives from the distinctive viewpoint of being parents to a disabled child in a foreign land, and thus also experienced disability through a Christian lens. In its more personalised form, as faith or spirituality, religion may give individuals strength, patience and a sense of God as a supportive partner in daily life and stressful times (Fewell, 1986; Pargament et al., 1990).

The above finding is in line with previous research suggesting that families living with disabled children lean on their religious beliefs when dealing with the challenges associated with caring for a disabled child. Denby (1996) reported that religious belief can manifest in a belief structure of perpetual optimism and the ability to recover from adversity. Other studies have found that religion can play a supportive role for families with disabled children, providing both practical and spiritual aid, as well as religious education and rituals that are meaningful and comforting to the family (Fewell, 1986; Rogers-Dulan, 1998; Rutledge et al., 1995; Tarakeshwar & Pargament, 2001).

Many participants believed that religion was the only solution to their care-based challenges and the only means of positive interpretation for their disabled child. While their surrounding culture was oppressive, and viewed their disabled child as a punishment, these families believed that their child was a gift from God. Even when the parents of disabled children narrated their challenges and difficulties, they still

viewed their children as blessings from God, believing that there was a reason for them having such a child.

This positive view of participants is consistent with Elliott's et al.'s (2002) findings that parents with disabled children believed they had been chosen by God to do something (i.e. care for a child with a disability) that others could not or would not do. From my personal experience, in the Shona tradition, the belief that a disabled child is God-given is only held by those parents whose children are disabled. For these parents, the disability of a child is the result of nature, and nature is controlled by God. This is why parents with disabled children refuse to seek ancestral interventions for their children. The belief in God as the provider of life is translated to mean that God is also the provider of a child with a disability, and there is nothing that the ancestors could do to correct what God has decided.

Parent Support Groups

Participants regarded support groups as one of the main sources of support in caring for a child with a disability. Interaction with other parents of disabled children was acknowledged as pivotal. However, some participants were not so lucky: they were refused entry into these social-support groups because of their nationality. This phenomenon is not new to South African communities, and it is not unique to Zimbabwean immigrants. Recently, immigrants of all nationalities were forcibly removed and attacked by local people from their communities (SAMP 2011). Such xenophobic violence can affect the well-being of a child with a disability. For example, transport can be disrupted and appointments with doctors can be missed.

In conclusion, it is evident from the results of this study that parents benefited immensely from informal support networks consisting of family, friends and the church. The analysed data indicate that the availability of informal forms of social support for these Zimbabwean asylum-seeking families positively reduces parents' stress and enhances parents' capacity to provide quality care for their disabled children. A sense of camaraderie and respite and the ability to get advice about child care and its attendant challenges were some of the major benefits reported by these families. This kind of kinship network has been described by Boyd-Franklin

(2003) as a “process of helping each other and exchanging and sharing support as well as goods and services”, which is a key process in many African cultures.

The literature available, specifically on the stress placed on families living with children with disabilities, strongly endorsed the importance of informal social support. Ekas, Lickenbrock and Whitman (2010) amplify this importance by illustrating that having a steady foundation of informal social support is associated with a reduction in negative outcomes like depression and caregiver-burden, while also increasing positive outcomes like a sense of confidence and accomplishment.

Though the results and findings, together with the literature review, highlight the importance of informal support (family and friends) for a family living with a disabled child, the use of formal support structures was seen to complement this use of informal support.

5.5.2 Formal Support

Formal support is defined by Tilden and Weinert (1987) as those services provided by professional, trained employees, typically paid for their work, such as the personal care assistant who helps with child-bathing, or by professional facilities, such as a nursing home. In this study, professionals such as education workers and health workers were mentioned by participants as important forms of social support. The acknowledgement of health professionals as vital for a family caring for a disabled child is consistent with Homby (1994), who stated that healthcare and educational professionals are helpful in promoting the healthy functioning of families living with children with disabilities. In this study, it was mainly the direction and guidance that these families received after meeting such a professional or after diagnosis that was important. Participants reported that they face regular challenges, like the illness of a child, and that these challenges require specialists. It is mainly during such times of illness that they find themselves at clinics and hospitals, seeking guidance on how to deal with the child’s condition. The question of seeking guidance from experts is also reported by Shisheva (2010), who found that, when families are faced with health issues pertaining to their children, they find themselves a professional guide or expert in the disability area

most relevant to their child—someone who can assist them in becoming a happy, healthy and fully functional family again.

Conversely, some participants seemed indifferent to this view of professionals as supportive. They expressed their displeasure about the manner in which professionals offered their services. The issue of displeasure during the diagnosis process is not a new phenomenon within the research on families living with disabled children. Many studies before have flagged the diagnostic process as stressful for these families (Braiden, Bothwell & Duffy, 2010; Moh & Magiati, 2012; Siklos & Kerns, 2007). Cultural insensitivity and the preponderance of assumptions about the needs and wants of these disabled families were other issues raised by the participants. The fact that Zimbabwean culture respects the traditional approach to disability does not mean that all Zimbabweans renounce the medical approach. Though some may strictly adhere to their traditional beliefs, others may decide to combine the two approaches, or to follow the medical approach that is dominant in South Africa. Lumping all Zimbabweans into one category and assuming that they all believe in the traditional approach to health, as many professionals do, is one of the generalisation fallacies that scholars like Baker, Miller, Dang, et al. (2010) warn health care professionals to avoid. These scholars urge health care professionals to never make assumptions about the needs or wants of a newcomer-family based on their ethnic background or cultural practices, since there are always differences among and within cultural groups (Baker et al, 2010).

Indeed, disabled Zimbabwean families' perceptions of the support provided by their formal network system varied both within and across participants. Some participants acknowledged the formal healthcare system as a double-edge sword: both supportive and unsupportive. While some parents praised the professionals for supplying them with relevant information and advice that would assist them in coping with the numerous challenges associated with child care, others expressed their displeasure about certain specialists. The constraining language and behaviour of some specialists was one of the reasons certain participants were not happy with their specialists. Participants complained that their specialists used local languages

(IsiXhosa and Afrikaans) to communicate with them, even though they cannot speak or and understand these language. These findings on language barriers are consistent with other studies, like the SAMP (2011), which found that health officials in the Western Cape often use their local languages with foreign nationals and refuse to use English, despite English being the accepted international language of communication.

Adding to participants' woes were the unexplained medical terms employed by some health officials. Participants reported that, many times, they did not understand the terminology used by the doctors, which left them completely ignorant about what was happening with the progress of their children. However, previous studies have found that parents living with disabled children sometimes do not ask for clarity when a specialist says something they do not understand. McGill-Smith (2003), for example, warned against this tendency and advised parents to stop the conversation whenever they are lost and ask the person speaking for an explanation of the confusing term.

In conclusion, formal and informal support networks can be viewed as complementary to each other. A family living with a child with a disability should have access to both these forms of support: family, clinics and friends are all vital in assisting them with their challenges. Formal support can assist parents with personal health care duties, while informal support can assist with duties like bathing the child and cleaning the house. When formal and informal support structures complement each other, the child with a disability is likely to get good quality of care. The combination of formal and informal structures enables the development of a comprehensive plan for meeting the needs of the child and the family. This complete circle of care is well-suited to the ecological system of care. Be that as it may, it must be noted that accessing the relevant support—both formal and informal—was not easy for these disabled Zimbabwean families. The findings highlighted in the previous chapter revealed barriers that participants encountered in accessing the support they needed to cope with the challenge of caring for a disabled child.

5.6 Barriers to Support

This study's findings indicate that the support of health professionals and schools is pivotal in assisting the families of children living with disabilities. However, some variation in the socioeconomic and educational level of these families was noted, particularly in the way they commented on the services provided by service-providers. Families with lower levels of education were negative in their view of the health services that specialists provided. Mainly, it was the technical jargon used by these specialists that disabled families found difficult and complicated. Linked to language barriers was the medium of communication used in the delivery of health information. An effective and efficient health service is based on strong communication between the health official and the patient. Poor communication between the two parties poses a danger, especially to the patient, who may be given inadequate attention or prescribed the wrong treatment. For many Zimbabweans migrating to South Africa, communication with health officials is a real challenge, since the majority of Zimbabwean migrants struggle to speak and understand the South African languages spoken at health care centres (SAMP, 2011). There are also no translators at clinics and hospitals. Health officials' refusal to use English as a common language only exacerbates the problem. Most health officials prefer to speak in their local language, which most families they come into contact with are familiar with. The families of children living with disabilities saw the end result of this entire language saga at health centres as harmful to the child, since the child is often not given the necessary attention or the proper medication.

It is interesting to note that, given all the challenges discussed above, and despite the cultural stigma surrounding disability, participants saw their disabled child as a blessing. And yet the findings of the study certainly reveal the traditional Zimbabwean view of disability. The mother who bears a disabled child is believed to have been involved with other men during her pregnancy, and so the "solution" to the child's disability is a cultural one. The mother is required to brew beer for the ancestors to restore the health and well-being of her child. (Incidentally, the same ancestral beliefs are reflected in traditional Chinese Confucianism, which sees the

birth of a child with a developmental disability as a punishment for parental violations of traditional teachings [Martin-Herz et al., 2012].)

For Zimbabwean families living with disabled children in Cape Town, however, the situation is very different. These families accept that some of their family members and friends advocate a cultural approach to disability and advise them to go back to Zimbabwe to appease the ancestors, but, surprisingly, no single participant reported having actually tried this cultural “solution” to their child’s disability.

The issue of culture, as it is practised by the main Zimbabwean ethnic groups (the Shona and Ndebele tribes), was a barrier for families living with a disabled child in their search for support. During the discussions, “culture “had very different connotations and meanings for different participants. What this suggests is that, since these disabled families were not living in isolation from other family members, it was shameful for them to be seen going to clinics with a child with a disability.

Living with a child with a disability remains a tremendous challenge for many families, and devastation, heartbrokenness and confusion are the order of the day. Caring for a disabled child brings with it serious depression, a fact supported by a number of studies in the literature. Several studies have revealed a disproportionately heavy amount of stress and burden experienced by family members with developmentally disabled children (Blacher & Baker, 2002; Hassall, Rose & McDonald, 2005). All these emotional and physical challenges force parents living with children with disabilities to redefine their personal understanding of disability in relation to their spiritual beliefs. The cultural misperceptions surrounding disability lead to the community and services providers demonising and rejecting the child with a disability and its family.

Some participants reported feeling rejection, isolation and alienation from medical personnel on the basis of their disabilities and their status as foreign nationals. Others were also discriminated by the church and the community. Participating families reported that the stigmatisation of their children was common, and they wondered why people with disabilities, and especially young children, are still stigmatised. On the stigma of people living with disabilities in Africa, UNESCO (2001) reported that the enabling view of disability in many African contexts is that

disabled children are a curse and should be hidden away. There a host of different stigmas attached to different disabilities across African cultures; the phenomenon is widespread.

Regarding education for their children, participants reported that, at some schools, their children were not given places to study because of their disabilities. The reported academic exclusion of disabled children is congruent with the views of Charlotte Chipangura (2013) of the Zimbabwe Independent Newspaper, who maintained that many children with learning disabilities are rejected by mainstream education and, in some cases, by special schools themselves, which purport to cater to only certain kinds of disabilities. This particular challenge was reported by many participants, who said their difficulty was doubled because of them being foreign nationals. Participants reported that the condition of disability is one of the first factors that certain schools consider before they enrol a child. The more severe the disability, the slimmer the child's chance of getting a place at the school. Interestingly, in a study by Landsman (2005), mothers' perceptions of child disability is shaped or influenced by factors such as discrimination, stigma and oppression.

Inability to participate in school programmes that they felt would be good for their children, because of exclusion and stigma, was as a major barrier that parents in this study cited. For participants, their inclusion in the programmes was seen as an important toolkit that would allow continuity from school to their home environments. They felt that their exclusion prevented them from advancing their skills in taking care of their children. These families felt that taking part in some of the programmes at schools was important, since their children would be more interested in the programmes if they saw their parents as examples, which could help promote an optimistic attitude in a disabled child towards learning and the value of education. Attending school programmes was seen as a means to assist parents in planning for the future of their disabled children, with the assistance of professionals running these programmes at schools. Planning the future of a child who is not disabled is different from planning the future of a child with a disability. Hence, parents felt that the only way they could properly plan for their children's

future was through these school programmes, from which they were unfortunately excluded.

Turnbull Summers and Brotherson (1986) offered insight into this question. They argue that parents do not know how to make future plans for their disabled child, and feel more comfortable making future plans for their child without disabilities. That parents should be empowered in this regard was put forward by Templeman and Brostrom (1987), who stated that schools need to implement transition-programming early in the child's educational experience, and must include the parents of these children in this process, to help the parents develop insight into planning for their child's future. The cause of the exclusion of the participants in this study from such processes and programmes is not immediately clear, but many parents assumed that it was linked to them being foreign nationals.

Many parents reported that the most common barriers to support were the attitudes they encountered in their day-to-day living. They reported that the negative attitude of ordinary locals, professionals and the church was something they endured in their search for support for their children. Problematic attitudes towards people living with disabilities were also noted in the Human Rights Commission report. In its report, the Human Rights Commission (1999) revealed discrimination against people with disabilities and their families to be the most reported kind of complaint.

Having considered the overwhelming barriers that prevent these families from receiving the levels of family support they require for their children, how do they nonetheless manage to care for a disabled child in a foreign country? How do they show resilience when faced with challenges of care?

5.7 Family Resilience

Though the challenges of families living with children with disabilities are manifold, as highlighted in the literature review, many families living with disabled children were found to be resilient: they find ways of addressing their challenges positively, for the wellbeing of their children. Family resilience has not been directly studied in the disability field, but there is increasing evidence to suggest that the families of

children with disabilities demonstrate a great degree of strength, articulating the positive contributions of disability to their family's life and well-being (Skinner et al. 1999; Scorgie & Sobsey 2000; Taunt & Hastings 2002; Hastings et al. 2005).

Resilience is a person's ability to withstand stress and be positive, optimistic and stronger as a result of life experiences, whether positive or negative (Rutter, 1985). Resilience refers to a dynamic process of positive adaptation within the context of significant adversity (Lutharet et al., 2000). Resilience has been described as the ability to withstand hardship and rebound from adversity, becoming more strengthened and resourceful (Walsh 1998). While there are a number of definitions of resilience, Masten's (2001) assertion that resilience represents "good outcomes in spite of serious threats to adaptation or development" (p.228) is one that resonates across a broad audience—from policymakers to practitioners to academics. It also has relevance for family support.

There are several key factors that are believed to contribute to a family's becoming resilient. They are: (1) making meaning of adversity; (2) affirming strength and keeping a positive outlook; and (3) having spirituality and belief system (Walsh, 1998). Broadly, being resilient can be defined as the ability to rise above difficult situations and maintain relative stability and healthy levels of psychological functioning (Criss, Pettit, Bates, Dodge & Lapp 2002:1220; Garmezy in Olsson, 2003:3), or as positive adaptation in spite of significant adversity or risk (Masten & Reid, 2005:74; Luthar, Cicchetti & Becker, 2000a:543; Masten in Lewis, 2000:2). Bonanno (2004:21) observes that resilient individuals experience transient disruption to normal functioning after significant negative life experiences and then "bounce back". This scenario of bouncing back is precisely what the findings of this study revealed, in relation to families living with disabilities. Confronted with numerous challenges, these families become more supportive, and their love for their children grows.

The results of this study clearly affirm what other research on families living with children with disabilities have suggested. Green et al. (2005) and McDermott and Varenne (1997) have revealed that societal and medical ideas, such as biomedical models of disability, religion, normalcy, labelling, and stigma and discrimination,

influence how families view and respond to their disabled child. Diagnosis, treatment and prognosis are contingent on these various factors.

The resilience of disabled Zimbabwean families in the face of the challenges associated with raising a child with a disability in South Africa also came across strongly in this study. Here, family resilience refers to disabled Zimbabwean families' ability to overcome challenges using both formal and informal family supports. Their resilience is evidenced by the fact that these families grow stronger rather than weaker through the process of raising a disabled child.

Given the enormous challenges that are associated with caring for a child with a disability, strategies for addressing these challenges were reported to be vital. This study found that disabled Zimbabwean families are influenced by numerous factors in their day-to-day living with a child with a disability and use a number of methods to try address their challenges. Some of the coping methods that these disabled families reported using were not reported in the previous literature—possibly because this is a group of people that faces the double impact of being a foreigner *and* raising a child with a disability.

In this study, participants reported that seeking information and guidance from a specialist was one way they could cope with the disabilities of their children. They completely renounced the notion that their children were disabled because they had been involved with another man during pregnancy. For them, the disability was not a result of their own actions. Instead, for participants, the disability was best explained from a medical point of view. This is in line with a dated but still relevant paper by Parson (1951), where it was found that the parents of disabled children who believed in medical interventions always employed the assistance of health professionals when making decisions about their children's conditions. In this regard, health professionals are perceived as pivotal both in diagnosis and in the provision of informational support for affected families. Positive medical intervention assists families in their perception of their child's disability.

In addition to information from medical professionals, information from other parents in a similar situation—via support groups—was very important and valuable for participants. The Shona phrase "*Mazano marairanwa*", translated to mean "*You*

have to share ideas in order to know that which is hidden”, was used by a number of participants when acknowledging the support they had received from other parents. The importance of assistance from other parents has been documented and affirmed by many authors, notably McGill-Smith (2003), who advised that parents living with children with a disability must seek out the assistance of other parents whenever they are in need.

Religion emerged as an interpretive and explanatory framework through which families could view the disability of their children. The findings of the study reported that participants used religion as one of their means of support when caring for their disabled child. Their religious beliefs were acknowledged by many as a source of hope when dealing with the question of why they have a disabled child. Previous research supports this finding of families leaning on their religious beliefs in response to the challenges associated with caring for a child with a disability. Religious belief has also reported been as a major support structure in other cultures, beyond Zimbabwean families living with children with disabilities in Cape Town. Griffin-Fennell & Williams (2006), for example, reported that African-American women have much higher levels of religious affiliation and church attendance, and are more likely to believe that the church can improve their lives.

The issue of parents trying to mould their children into the category of “normal” is rooted in their attempt to avoid societal discrimination, labelling and stigmatisation. This normalisation-effort became clear in this study, especially when parents reported, “My child is normal like other kids but only that he is a slow learner at school”. These parents’ fear of discrimination replicates Landsman’s (2005) research, where mothers worked to make their children appear as normal as possible so they would not experience discrimination or stigmatisation. On the other hand, seeing the child as disabled (rather than “normal”) may help parents to keep on trying to improve the condition of the child. It is vital that healthcare specialists, teachers and social workers acknowledge that, in order for disabled families to deal with the challenges of child disability, they may at times view their children as normal; professionals should allow for and work with these perceptions when delivering the appropriate treatments and services.

Closely related to the issue of normalcy is the issue of accepting a child with a disability into the family. Among disabled families, acceptance was reported as one of the best tools for confronting the challenges of care that they faced. Many participants pointed out that there is no way one can deny creation, since it is something that is natural. They believed that their children's disability was a natural phenomenon that they could only accept. These families viewed this acceptance as a strong coping strategy. This finding replicates Carver et al. (1998), who describe acceptance as a positive strategy when enduring difficult circumstances, for it allows individuals to be engaged in coping.

Having a positive outlook and believing in the child with a disability was also revealed by participants to be important when caring the child. Similar findings have been reported in a number of studies. For instance, Hastings, Kovshoff, Ward, degli Espinosa, Brown and Remington (2005) found that parents of children with autism "identified positive perceptions about their child as a way to deal with issues associated with condition of their children". In addition, Risdal (2004), Ylven, Bjorck, and Granlund (2006) and Beresford, (1996) all show the impact that positive conceptions of children with disabilities have on parents, the children in question and other family members.

The support of family and friends was identified by participants as a major crutch in challenging times. Participants reported that caring for a disabled child was a task that required friends and family members to team up with them to overcome the attendant challenges. Findings from other research affirm the importance of family and friends when dealing with the burden of care. The National Information Centre for Children and Youth with Disabilities (2003) reported that, for families living with disabled children, having family and friends around can be extremely beneficial, if the family and friends are reliable and can help carry the emotional burden. In his thesis, Rhett Maurice Billen (2012) reported that parents of young children with developmental disabilities receive additional support from informal sources such as family members, neighbours, church members, and online communities. This was seen as a way of coping with and lessening the burden of care, a proposal supported by Armstrong et al. (2005), who indicated that it is vital for disabled

families to have support from people who genuinely care for them, like close family members.

Belonging to a support group was another method that families with disabled children employed to cope with the challenges of care. For these families, it was not only the information about caring that was important but also the feeling of belonging to a community of people in the same situation. In line with this concept of support groups as useful for families living with children with disabilities, Kerr and McIntosh (2000) found out that parent-to-parent support provided a sense of normality, and the knowledge that there were other families out there experiencing similar things lessened feelings of isolation and gave these families a more positive vision of what their child's future could be.

Non-governmental organisations were another support structure that participants acknowledged as being useful for dealing with the challenges they face. Some participants reported that non-governmental organisations were their only source of support and that they relied on them for urgent issues. Such organisations, like People Against Suffering Oppression and Poverty (PASSOP), have often played an important role in providing practical and emotional support for newly arrived asylum seekers, and have increasingly found themselves in the position of providing basic services. They offer free paralegal advice on documentation, labour and other issues, as well as assistance in finding employment (PASSOP, 2014).

Participants reported that NGOs helped them with fees, food stuffs and clothes, and most importantly with getting documented at the Department of Home Affairs. PASSOP was highly praised by participants as a saviour in times of crisis. Researchers have found that the information provided by NGOs can be a guiding light for families living with disabilities. They have urged such families to find suitable programmes for their children and themselves within nongovernmental organisations.

5.8 Chapter Summary

The aim of this study was to examine the formal and informal support systems employed by families living with children with disabilities. The main analytical

finding is that these families employ neither form of support exclusively but instead journey *between* formal and informal support systems. There is no single best form of support for them: used in combination, the two modes of support can offer essential social and economic assistance, in an environment far from home.

Interestingly, this study found that families living with children with disabilities have very different perspectives on their situation. Participants reported both negative and positive perceptions of the family environment. While all families reported challenges in caring for the child, some families reported receiving support from professional services, or from spouses/partners and family members. However, some of these families were concerned that the level of support they receive from family and friends is inadequate, since it is not commensurate to their economic situations. This inadequacy may in turn have an effect on how these families care for the disabled child. This study also found that, although participants were not fully happy with the support they receive from professionals, the only way to move forward was to develop coping mechanisms for dealing with the challenges of care. As discussed above, these coping methods seem to be working for these families.

In spite of all the barriers they face, disabled families exhibited resilience in caring for their children with disabilities. They acknowledged that, though they are significant challenges associated with living with a disabled child in South Africa, their current situation is much better than the situation they were in while still in Zimbabwe.

The next chapter will present the study's conclusions and limitations, including the researcher's recommendations and suggestions for further research on the topic.

6. CHAPTER SIX: CONCLUSIONS AND RECOMMENDATIONS

6.1 Introduction

This study analysed interview data that reflects the family-support needs, perspectives and experiences of Zimbabwean asylum-seeking families with disabled children in Cape Town, South Africa. It is the socioeconomic and cultural diversity of these disabled families that increased the rigour of this study.

6.2 The Perspectives of Disabled Zimbabwean Families Living in Cape Town

The rationale in carrying out this study was to examine different aspects of families' perceptions of living with their disabled children in Cape Town, and the social support available to them. The findings of the study revealed that formal and informal support networks are complementary networks that, when combined, can provide adequate support for disabled families. This study has identified a number of important findings about the perceptions, experiences and support strategies of disabled families in the Metro Region of Cape Town.

One important finding is that parents living with a disabled child who receive adequate support (from both informal and formal support systems) will have positive perceptions of their family environment and of the way they are coping with and managing the challenges of disability. Though the support they receive from family and friends in Cape Town is not as much as they received while in Zimbabwe, the study showed that disabled families who received support from family, friends and relatives showed fewer signs of stress compared to those who relied only on formal support systems. In general, this study of Zimbabwean disabled families in Cape Town has established that the use of both the formal and informal systems by disabled families helps these families to function efficiently and deal with the challenges associated with the care of a disabled child.

Participants' comments suggest some satisfaction with the support they receive from professional services, and from family and friends. It is critical for a family

living with a child with a disability to have both of these forms of supports available to them, and to not rely entirely on informal (familial and communal) assistance. Formal support can assist with personal health-care duties, while informal support can assist with home-based child care and domestic chores. When formal and informal support complement each other, the child with a disability is likely to receive a high quality of care.

However, participants reported various obstacles that made it difficult to access the necessary support for their disabled children.

6.3 Barriers to Required Support

Disabled families, according to the findings of this study, seem to be confronted with a variety of barriers when seeking support for their children with disabilities. These barriers may in turn shape the way a family manages the challenges associated with caring for a child with a disability.

The use of local languages by service providers was one factor that participants pointed to as a barrier that prohibited them from using health services, since it affected communication between them and their service providers. Participants saw local language use as a form of discrimination, since they could not express themselves or communicate in a language that is not theirs. This caused participants additional emotional stress and discomfort, over and above the routine stress that accompanies medical consultations.

Participants reported that the discrimination they experienced from the community, health centres, schools and other institutions on the basis of their status as foreign nationals was a daily reality. Disabled families reported that they visit health centres more often than other migrants and that discrimination against them is a setback for their children's health.

Their lower educational, social and economic status and their limited income and financial means were other barriers that prevented them from getting proper care for their disabled child. Medical costs, for example, were reported by these families as high, since they are not entitled to the social disability grant for their children.

Because of these barriers in accessing adequate assistance for their disabled children, managing the challenges associated with their children's care was reported to be a burden for them. Hence, these disabled families utilised a number of coping strategies that include, among others, accessing reading materials for parents with disabled children, seeking help from support groups, the church, religion, and non-governmental organisations, and seeking information from teachers, doctors, family and friends.

6.4 Resilience of Zimbabwean Disabled Families

Resilience involves bouncing back from adversity and facing stressful situations. While an ordinary family living with a disabled child requires initiative in dealing with the challenges of care, this study revealed that, for asylum-seeking families, the initiative required to cope with the situation supersedes that of ordinary families. Disabled Zimbabwean asylum-seeking families living in Cape Town reported that the use of the aforementioned strategies were highly effective in dealing with their doubly taxing situation of being foreigners and at the same time living with a disabled child.

6.5 Limitations of the Study

There are two main limitations of the current study. First, the sample consisted of only 11 Zimbabwean asylum-seeking families with children with various disabilities. Moreover, one of the key informants was a Congolese national who was interviewed due to his expertise in issues related to asylum seekers. The composition of disability in the small group may also have been a contributor to the outcome of the study. A larger sample size would have included a more diverse range of disabled families and presented a wider range of scores, as well as more insights into the findings. Because of the small sample size, the results should be interpreted with caution. Future research must only include disabled families with children with the same kind of disability—for example, children with autism—in order to gain a homogenous sample by disability.

The geographic area of the participants also constitutes one of the limitations of this study. The Zimbabwean asylum-seeking families were recruited through a local

non-governmental organisation, PASSOP, in Wynberg, and the majority of the families live within a short distance from the Wynberg area and also not very far away from one another's locations. Thus, the families have access to similar family-support services, and consequently these families are likely to experience similar attitudes from their community, from the schools attended by their child and from the clinics and hospitals, all of which may affect how the family perceives their family environment and the support they are receiving. Thus, these findings on the support strategies and perceptions of disabled families may not be generalizable to all asylum-seeking disabled families living in Cape Town.

6.6 Recommendations

Drawing collectively on all the knowledge amassed in this study, a number of recommendations for the future of family support for asylum-seeking families living with disabled children will now be presented.

My research has various implications, particularly for those who provide formal support to disabled families and their children: namely, health care and educational professionals.

1. The study has found out that asylum-seeking Zimbabwean families living with disabled children live in highly difficult situations and do not receive enough support from both the informal and formal systems around them.
2. Health service providers may need to provide more workshops or other forms of assistance for these Zimbabwean asylum-seeking families, in order to increase the amount of information these families receive about their children with disabilities.
3. The finding that parents lack adequate support from the informal support system (family and friends) may also be seen as any opportunity for practitioners to step in and attempt to resolve this discrepancy by organising programmes for extended family and friends, providing them with specific information about the child's disability and giving them an understanding of how disability can affect the immediate family, along with practical

suggestions of how to provide support (for example, offering to care for the child while the parents take a break).

4. Interventions based on a family-systems approach were validated by this study's finding that the support of family, relatives and friends (informal support network) for disabled families was significant in helping these families cope with their child's disability.
5. Healthcare professionals, teachers and social workers (formal support network) need to work with these families to find out what would best support them. Understanding the cultural beliefs and background of these asylum-seeking families regarding child disability is essential, as it could help professionals grasp these families' perceptions of disability.
6. The study also encourages teachers and health professionals to consider conducting training and counselling, especially for male Zimbabwean asylum-seeking parents, in order to make these males more active in taking care of their disabled child and so to facilitate a more friendly, peaceful and positive home environment away from Zimbabwe.
7. The study also recommends that health professionals encourage families living with children with disabilities to form support groups that can assist them in dealing with the challenges of care.
8. Finally, this study about families living with their disabled children hopes to expand on the very limited literature on asylum-seeking families by focusing on how these constructs differ by ethnicity and economic levels.

The findings discussed above highlight the fact that Zimbabwean families with disabled children are often trapped in helpless positions. This helplessness is due to a number of factors, all related to the multi-layered marginalisation that immigrants face within South Africa on a daily basis.

1. Asylum-seeking disabled families are excluded in their communities and in public because they find it difficult to cope with the double stigma of being foreign in a xenophobic environment and having a disabled child in a society that lacks understanding and tolerance. To counter this, much more needs

to be done in terms of creating public awareness and anti-xenophobia initiatives and setting up effective support networks, both among affected immigrant families and among civil-society organisations. This will go a long way towards addressing the information gaps that currently seem to be so prevalent and that are holding vulnerable families back from accessing greater opportunities.

2. Families are also excluded from accessing service providers, such as schools and health-care facilities, because of the limited supply thereof, because they are unable to afford them in the absence of grants and financial assistance, and because, although access to these is a right stipulated in the Constitution, this right is often not delivered in practice for asylum-seeking families. While the recent policy change to allow refugees to apply for the care dependency grant was a step in the right direction, the fact that only a minority of immigrants can obtain refugee status means that the bulk of the problem is not being addressed. As such, an argument can be made that the care dependency grant should be made available to immigrants with asylum-seeker documents too. Moreover, service providers, including administrators at hospitals and schools, should be made aware that everyone, including undocumented immigrants, has the right to primary education and health care.
3. Immigrants with disabled children are excluded by South Africa's restrictive immigration policy that in most cases prohibits parents from being legally employed or from obtaining refugee status. Similar to South Africa's current policy, the refugee-admissions policy in the United States historically also hinged on the notion of "political persecution", which did not leave room for humanitarian migrants (Mirza, 2010). However, in 1996, this bias was addressed by revising the priorities for refugee resettlement to "vulnerable" groups, and including women at risk, persons in urgent need of medical treatment and people with disabilities in the top priority group (Mirza, 2010). Moreover, the UNHCR's resettlement guidelines have also evolved to better account for the vulnerabilities of people with disabilities. These

reforms need to take place in South Africa, and thus far, not enough is being done to address the problem. Migrant parents with disabled children, it can be argued, fall into this category of humanitarian migrants for whom there are no options in South Africa's immigration policy. In most cases, they have no other option but to apply for asylum and, in the vast majority of instances, are rejected.

It is up to the South African government to create an enabling environment that empowers families living with disabled children to be able to take care of themselves and their children. At present, it is falling short of that responsibility. In fact, it is the government's restrictive immigration policies that have created a large share of the vulnerability and dependence in the first place. Hence, if the government of South Africa is worried about not being able to fund the education, health care and other social services required by the disabled children of immigrant parents, then clearly it should give these parents the opportunity to provide for their disabled children, rather than put them in a situation where they have little choice but to beg for handouts.

To this end, while the government's Zimbabwean Special Permit (ZSP) programme, which allows many Zimbabweans to move beyond the category of asylum seeker, has some flaws in its implementation, it is a commendable effort. It should now be extended to immigrants from other countries with the same internal challenges that Zimbabwean people face. Moreover, immigration policy should progress and prioritise vulnerable groups such as disabled children. At the very least, it should provide an avenue for disabled humanitarian migrants to document themselves and gain the right to work.

6.7 Chapter Summary

This chapter reminded the reader of the background to the study and its objectives. It highlighted the key findings arising from the research, and made a number of recommendations about the family-support needs of asylum seekers with disabled children. This study sought to investigate the perspectives, experiences and support-needs of disabled Zimbabwean asylum-seeking families in the Western

Cape Province in South Africa. The study gained clarity about the family-support needs of families living with disabled children, the individuals involved in delivering the necessary support, and the delivery of this support to families coping with disability.

It is the hope of the researcher that the knowledge gained through this study will help advance family support as a practice (involving health workers, teachers and social workers) and ultimately contribute towards an improved experience for all those asylum-seeking families and their children who are in need of and receiving assistance. Asylum-seeking families and their disabled children must be supported and protected, and this research provides insights into what family support—especially formal support systems like health and education—can do to contribute further in this regard.

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8. APPENDICES

Appendix A: Semi-structured Interview Guide

Copies of the informed consent forms were provided to each participant and explained where necessary. Participants were given an opportunity to ask questions.

The ground rules were explained as follows:

Before we started I reminded participants that there is no right or wrong answer in the discussion. I also told participants that I was interested in knowing what they think, so they were to feel free to share their point of view.

(This guide may be modified following initial interviews. Probing was used to get a deeper understanding of the answers presented.)

1. When did you arrive in South Africa?
2. In what ways did having a disabled child influence your decision to come to South Africa?
3. What are the challenges you encountered on your way to Cape Town because of your disabled child?

(Probe: How did you address these challenges?)

4. Can you tell me in your own words about your experience living with a disabled child in a foreign country?

(Probes: How is this experience different for you and your child?)

5. What support is there, if any, for you or your disabled child?

(Probes: Did you find this support useful/effective?)

6. What type of challenges have you experienced when attempting to access support for your disabled child?

(Probes: Are these kinds of challenges common?)

7. What kind of support needs do you expect for your disabled child?

(Probes: Do you think these needs would be effective?)

8. What challenges do you think inhibit you from receiving family needs for your disabled child?

(Probes: In your opinion, can they be overcome?)

9. What support have you found helpful in dealing with these challenges?

10. Do you have any questions?

Thank you for taking your time to talk to me.

Appendix B: Letter of Invitation

Dear sir/madam,

My name is Willson Tarusarira and I am currently undertaking a research study as part of my Master's degree in Disability Studies at the University Of Cape Town.

This study aims to answer the following question: What are the perceptions and experiences of Zimbabwean asylum seekers living with disabled children in Cape Town, in terms of their family-support need? I hope to identify, highlight and improve any areas of support that may be in need of improvement or complete redevelopment. This will not only benefit asylum-seeking families living with disabled children but also aim to improve policies that govern asylum seekers in general.

I would like to invite you to assist in this research as a Zimbabwean citizen living with a disabled child in Cape Town. Anyone who chooses to take part will be requested to sign a form consenting to partake in one short audio-taped interview, with an estimated duration of 40 to 45 minutes. Any information gathered during this study that is identifiable to you will remain fully confidential, and anonymity will be maintained throughout the study. Your personal details will only be known to the researcher and his supervisor. All participants have the right not to take part or to withdraw from the study at any stage without penalty.

Thank you for taking the time to read this letter. Should you wish to take part in the study or have any further questions you would like to ask before making a decision, please feel free to contact me at the above address or alternatively you can ring me on 0743149085 or email me at wtarusarira15@gmail.com.

If you do decide that you would like to participate in this research study, please sign the consent form attached. Should I not hear from you, I will assume that you do not want to take part and I will not contact you again.

Yours sincerely,

Willson Tarusarira

Signed: _____

Appendix C: Invitation to Participate in a Research Project

Information sheet for the study: The family-support needs of Zimbabwean asylum-seeking families living with their disabled children in the Western Cape Province of South Africa.

My name is Willson Tarusarira. I am a student undertaking a Master's degree in Disability Studies through the University of Cape Town in South Africa. As a requirement for my studies, I am conducting a research project to understand the family-support needs of Zimbabwean asylum-seeking families living with their disabled children in the Western Cape Province of South Africa. This information is provided so that you can make a decision about whether or not you want to participate in this study.

I am collecting information about the family-support needs of Zimbabwean asylum-seeking families living with disabled children in the Western Cape Province of South Africa by interviewing these families directly. The names of the participants will not be mentioned in the reports, unless they have given me clear permission to do so. I will make all efforts to accommodate your schedules when planning for the interviews. Please read the information sheet below.

What will happen in this study and what will you be asked to do?

If you agree to participate, you will be asked a series of questions about your life and your experiences in living with a disabled child in Cape Town. If you give me permission to do so, I will take notes and also tape or digitally record the interview so that we can be sure to capture all of the information you provide accurately.

After the interview, the recordings will be handed to Dr Judith Mackenzie who is my supervisor in this study and a lecturer in Disability Studies Department at the University of Cape Town. My supervisor will be responsible for the recordings' safety by locking them up.

Permission to ask questions?

You are free to ask questions at any time during the research procedures. You are free to withdraw from the study without prejudice at any time.

Are there negative consequences that will happen if you take part in this interview?

No bad or negative things will happen to you by participating in this interview. You are free to take a break during the interview.

Can you decide if you want to or do not want to participate in the study?

Your participation is completely voluntary. You are free to participate or not to participate in the study and you may choose to stop participating at any time.

Your participation is kept confidential

The information you provide will be kept confidential within the limits of the law. Unless you provide your consent, your name will not appear in any report or publication of the research.

If you have questions about the study

For more information contact:

Supervisor	Researcher
Dr Judith McKenzie E-mail: Judith.mckenzie@uct.ac.za Tel: 0214066318.	Willson Tarusarira. Cell: 0743149085 E-mail: wtarusarira15@gmail.com

If you have any questions or concerns about the way the research is done and how it affects you then you can contact Associate Professor Marc Blockman at the Human Research Ethics Committee c/o Ms Lamees Emjedi.

Room: E52.23

Old Main Building, GSH

Tel: 021 406 6338

Fax: 021 406 6411

Lamees.emjedi@uct.ac.za

Appendix D: Consent Form

Iconfirm that the research procedures of the study have been explained to me through a written letter. I understand that I may ask questions at any time during the research procedures. I realise that I am free to withdraw from the study without prejudice at any time, should I choose to do so. I have been informed that the personal information required by the researchers will be held in strict confidentiality. I hereby agree to participate in this research project by participating in a maximum of 45 minutes long interview session.

I have carefully read this form. I understand the nature, purpose and procedure of this study. I agree to participate in this research project.

Participants Signature: _____

Date: _____

Researchers Signature: _____

Date: _____