

**AN EXPLORATIVE STUDY OF THE EXPERIENCES AND  
NEEDS OF FOSTER CARERS OF HIV POSITIVE CHILDREN  
IN THE WESTERN CAPE, SOUTH AFRICA**

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University of Cape Town

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**Jenni-Kate Warwick, University of Cape Town, 2013**

**ABSTRACT**

This explorative study of the experiences and needs of foster carers of HIV positive children in the Western Cape was carried out in order to gain an understanding about this particular group of foster carers and their subjective experiences and needs in relation to the care of their foster children. Foster care is currently the main form of care available to HIV positive children in South Africa, who are no longer in the care of their parents. For this reason, it is important to understand the challenges and needs of foster carers as they care for their foster children. It is hoped that some of the insights gained by this study may lead to further study in this field and could inform policy, planning and intervention. The study was conducted at two organisations that work with HIV positive children and their foster carers. 18 foster carers were interviewed over 17 qualitative, in-depth interviews. The results show that the challenges facing foster carers are multifaceted and include the initial adjustment period, interactions with biological parents, finances, dual diagnoses, stigma and fear, the foster carer's own mental and physical health, management of the child's medication and dealing with the child's emotional pain. The study found that support for foster carers comes predominantly from their families and organisations and desired support took the form of financial and emotional support and training. The foster carers perceived their role as being to provide love and a sense of belonging for their foster child, as well as discipline and boundaries, medical support and educating their foster child about the child's history and HIV. Health care services were

found to be easily accessible, but social services and educational support proved to be a challenge to foster carers. The recommendations of the study are that further research be conducted in this field; that social services make provision for easily accessible support groups for foster carers of HIV positive children; and that policy makers develop clearer policy around kinship care.

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And to Jesus, for Your abundant blessings and for giving me strength through the course of this research.

Jenni-Kate Warwick

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## **DEDICATION**

This research is dedicated to my parents, Ant and Sue Ryan, and my littlest sister, Lerato, who were the inspiration for this research study.

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## CHAPTER ONE: INTRODUCTION

In this chapter, the context of the problem will be explored, including a statement of the problem and the rationale behind the research study. The purpose of the study will be described, along with the research design and concepts relevant to the study will be explained.

### **Background and Context**

According to the 2011 progress report of the Global Human Immunodeficiency Virus (HIV)/Acquired Immuno-Deficiency Syndrome (AIDS) response (World Health Organisation (WHO), Joint United Nations Programme on HIV/AIDS (UNAIDS), & United Nations Children's Fund (UNICEF), 2011), it is estimated that at the end of 2010, there were 34 million people living with HIV around the world of which 3.4 million were children.

South Africa has the largest population of HIV positive people in the world (WHO, et al., 2011). It is estimated that 5.6 million HIV positive people live in South Africa (UNAIDS, 2010b). According to the 2010 National Antenatal Sentinel HIV and Syphilis Prevalence Survey in South Africa (Department of Health, 2011), this total can be broken down into an estimated 4,030,000 adults over the age of 15, 2 million females and 438,000 children below 15 years of age. It was estimated that 194,000 South Africans died of AIDS in 2010, of which 173,000 were adults, resulting in approximately 1,670,000 AIDS orphans (Department of Health, 2011). It is estimated that in 2010, there were 54,000 new infections among children under 14 years of age (Department of Health, 2011).

From these statistics, it is clear that South Africa is at the centre of the HIV/AIDS crisis. While progress is being made in the provision of anti-retrovirals to those that are infected, the stated facts highlight the discrepancy between the current roll out of such drugs,

compared to the need for the drugs. As long as that discrepancy exists, there will be a need for alternative care for children who are orphaned by HIV/AIDS.

At a global level, foster care has been implemented unofficially for many years, with formal laws to govern its practice only being drawn up in the last century (Rymph, 2012). The practice of foster care is viewed with a fair amount of diversity across the world. In America, foster care is seen as a short term intervention, lasting up to 22 months, during which time preparations must be made for the child to return to their home or to another form of long term care (Maluccio, 2003). In the Netherlands however, foster care is seen as both a short term and long term intervention, depending on the circumstances of the child and family (Strijker, Knorth & Knot-Dickscheit, 2008). As a short term intervention, it has the aim of treating a child or parent with the view of returning the child to their birth family (Strijker, et al., 2008). The second approach is to provide long term foster care until the child is 18, with the aim of providing continuity of care and respect for the child's right to a stable rearing situation. (Strijker, et al., 2008).

The South African model of foster care is comparable to the model used in the Netherlands, as it makes allowances for both short and long term forms of foster care. Foster care, on an informal basis has been a recognised form of alternative care for many years in South Africa, predominantly in the form of kinship care (Thomas & Mabusela, 1991). Since the move to deinstitutionalise the care of HIV positive children, foster care, on both a formal and informal basis has become one of the preferred methods of providing care for these children (Townsend & Dawes, 2004). While appearing to have good potential as an effective means of providing care for HIV positive children, foster care comes with many challenges. Murray, Tarren-Sweeney, and France (2010), suggest that the combination of a high burden of care and perceived disempowerment, together with dysfunctional relationships with social services contributes heavily to a lack of sustainability in foster placements. They also suggest

that some of the main challenges of foster care include unhelpful interaction with the children's agency social workers, difficulty in accessing specialist services, contact with the child's birth parents, lack of respite care, training and support (Murray, et al., 2010).

### **Rationale and Statement of the Problem**

Prior to the introduction of anti-retrovirals in South Africa, adults and children were becoming ill quickly and many HIV positive mothers could not manage or afford to look after their sick children. Grandparents were being overwhelmed by taking care of both their sick children and sick grandchildren (Kiggundu & Oldewage-Theron, 2009, Townsend & Dawes, 2004). This, along with the increasing death rate of adults with AIDS, led to the establishment of many residential facilities for such children, where appropriate care could be provided.

Since the introduction of anti-retrovirals, many children who had previously been very sick, now have the opportunity to live long, healthy lives. This change meant that the move to residential care needed to be re-evaluated as children were no longer in need of just day to day care, but more importantly, they needed to be raised with the future in mind. While in residential care, the children were guaranteed good nutrition and strict adherence to their drug regimes, but they were missing out on life in a family in a broader community. It is for this reason that the Department of Social Development shifted their position to increasingly advocate for care within homes in communities, rather than in institutions and it is for this reason that this study focused on foster care being provided in the context of a family home rather than an institution.

An example of this is Beautiful Gate, an organisation on the Cape Flats that set up a residential care facility in 1999 for children diagnosed with HIV/AIDS. As anti-retrovirals became available and children's health began to improve, Beautiful Gate realised the need for

the children to be raised in a family rather than in an institution. Their focus then shifted to providing an interim safe environment, rather than a permanent home for the children. By the end of 2012, 58 children had been successfully reunified with members of their extended family, or were placed in foster care. (Beautiful Gate annual reports, 2008, 2009, 2010, & 2012).

A fair amount of research on the challenges of providing foster care for AIDS orphans has been carried out in the rural areas of KwaZulu-Natal and in Gauteng (Jones, Sherman, & Varga, 2005; Kiggundu & Oldewage-Theron, 2009; Kuo & Operario, 2010; Ogunmefun, Gilbert, & Schatz, 2011; Rajcoomar, 2005), but to the best of the researchers knowledge, research in this field is lacking in an urban and peri-urban setting within South Africa, and in the Western Cape in particular. While much of the mentioned research has focussed specifically on grandmothers providing care, the reality in the peri-urban areas of the Western Cape is that many adults of working age have come to the areas to seek work, some bringing their children with them, away from their family support. In situations like this, where there might not be a familial safety net in which to catch the orphaned child, foster care with non-relatives might be necessary. There are also other circumstances which sometimes make it unrealistic to expect extended family members to take on the care of an HIV positive orphan. For this reason it was felt that it would be important to include in the study, both family members and non-family members that are providing foster care for HIV positive orphans.

There also appears to be a gap in research specific to the foster care of children who are HIV positive, as much of the research that has been carried out seems to group AIDS orphans together, regardless of whether they are infected or just affected. There also appears to be a lack of research related to the care of children who are infected but have been abandoned as opposed to orphaned, even though this is a common occurrence in South

Africa. It is for this reason that this study focused only on HIV positive children, in order to try to ascertain the experiences of care givers specific to their care.

### **The Purpose of the Study**

The purpose of the study was to investigate the experiences and needs of foster carers of HIV positive children. It is hoped that the information that was gathered through the study will be of use to government services, NGO's, current and future foster carers. While in theory, foster carers of HIV positive children are put through training on looking after an HIV positive child, in reality many have not completed this training, or started fostering before training became available and as a result, are not prepared for the reality of the emotional baggage that these children bring. The researcher hopes that by giving a voice to some of these experiences and needs, foster carers will be able to learn from one another. The researcher also hopes that those considering fostering HIV positive children will be able to enter the process with a clearer idea of what such care will look like. Ultimately, it is hoped that the results of the study will be of use to inform future policy making and service provision for HIV positive children and for the people that care for them.

### **Significance of the Study to Social Work Practice**

Foster carers of HIV positive children are required to have contact with social workers through social services, as part of the requirements of the foster care order which placed the child in their care. As this study will show, there are many challenges facing foster carers of HIV positive children and it is hoped that by shedding light on some of these challenges, social workers might be able to approach this group with more of an understanding of their needs.



## **Problem formulation**

### *Research objectives*

The specific objectives that the study sought to explore were:

1. To identify the challenges facing foster carers of HIV positive children.
2. To identify support mechanisms for foster carers of HIV positive children.
3. To examine the foster carers perception of their role in providing care for their HIV positive foster child.
4. To assess the foster carers experience of access and utilisation of the health, social and educational services available to them, specific to the care of their HIV positive foster child.

### *Research questions*

The research questions that the study attempts to answer include:

1. What are the challenges facing foster carers of HIV positive children?
2. What are the support mechanisms for foster carers of HIV positive children?
3. How do foster carers perceive their role in the care of their HIV positive foster child?
4. What is the carer's experience of access and utilisation of the health, social and educational services available to HIV positive children?

### *Main assumptions*

- That the foster carers experience numerous challenges in their efforts to provide care for their HIV positive foster children and as a result, have specific needs.

- That this research study might provide the first opportunity that many of the foster carers have to talk about their experience of providing care for their HIV positive foster children and the challenges that this entails.
- That not all of the foster carers will be providing care to their HIV positive foster children by choice, but some out of a sense of obligation, especially in the case of kinship placements.
- That the socio-economic standing of the foster carers could influence their ability to access the support that they might need in the care of their HIV positive foster children

### **Concept clarification**

#### *HIV*

HIV stands for 'Human Immunodeficiency Virus' and refers to the virus that attacks the immune system, negatively affecting its ability to fight infections. People can live with HIV for years without feeling sick. A person will be said to be HIV positive when HIV antibodies are found in their blood (Whiteside & Sunter, 2000).

#### *AIDS*

AIDS stands for 'Acquired Immuno-Deficiency Syndrome' and is caused by HIV. AIDS presents itself as a number of serious illnesses that the infected individual will eventually struggle with, as a result of HIV's destruction of their immune system (Van Dyk, 2008). The diagnosis of HIV changes to a diagnosis of AIDS when the individual's CD4 count drops below 200 (Whiteside & Sunter, 2000).

### *Foster care*

Foster care is when a child in need of care and protection is legally placed in the care and safety of an adult person other than the biological parents. This adult may be a family member or unrelated to the child. This placement is made by order of the Children's Court (Department of Social Development, 2007).

### *Foster carer*

A foster carer is an adult who has been appointed by the Children's Court to provide a home for a child whose parents are not able to look after them. Traditionally this is on a temporary basis, but legislation does also allow for permanent foster placements (Department of Social Development, 2007). A foster carer can be a member of the child's extended family or can be from outside the family. For the purposes of this study, the foster carer had to have been looking after the child for at least 2 years.

### *Kinship care*

The term kinship care is used to describe care provided by a family member who is not the biological parent of the child (Dubowitz, Feigelman, Harrington, & Starr, 1994).

### *Kinship foster care placement*

This term refers to the foster placement of a child with a family member who is not the biological parent of the child (Dubowitz, et al., 1994).

### *Non-kinship care*

This term refers to care provided to a child by an adult who is not related to the child.

### *Non-kinship foster care placement*

This refers to the foster placement of a child in the care of an adult who is not related to the child.

### *Children*

According to the Constitution of the Republic of South Africa (1996), the term 'children' refers to persons under the age of 18.

### *HIV positive children*

Any persons under the age of 18, infected with HIV.

### *HIV positive orphans*

UNAIDS and UNICEF (2004), define orphans as follows:

- *Single orphans (a child who has lost one parent)*
- *Double orphan (a child who has lost both parents)*
- *Maternal orphan (a child whose mother has died – includes double orphans)*
- *Paternal orphan (a child whose father has died – includes double orphans)*

In summary, "an orphan is a child under 18 years of age whose mother, father, or both parents have died from any cause" (UNICEF, UNAIDS & President's Emergency Plan for AIDS Relief (PEPFAR), 2006, p. 4).

For the purposes of this study, only the foster carers of HIV positive children or orphans under the age of 18 were considered.

## **CHAPTER TWO: LITERATURE REVIEW**

This literature review will seek to explore some of the literature relevant to the proposed study. It will begin by providing a brief historical background to HIV/AIDS in the world and South Africa specifically. It will then go on to look at issues that have been raised by the literature with regards to HIV and children in South Africa, foster care in South Africa, support mechanisms for foster carers of HIV positive children, the challenges facing foster carers of HIV positive children, and access to government services with regard to the care of HIV positive orphans.

### **HIV/AIDS in South Africa**

In 2010, it was estimated that 17% of the population of South Africa (aged between 15 and 49) were infected with HIV/AIDS (Department of Health, 2011). The incidence of HIV/AIDS in South Africa is compounded by issues of unemployment, poverty, lack of education and limited access to necessary medical treatment (UNAIDS, 2010a).

The antenatal incidence of HIV in South Africa seems to be stabilising between 29 and 31% and the prevalence thereof varies significantly from province to province, with KwaZulu-Natal having the highest incidence at 39.5% and the Western and Northern Cape having the lowest prevalence at 18.5% and 18.4% respectively (Department of Health, 2011). While this statistic might look good for the Western Cape in comparison to the rest of the country, it still represents a steady climb in the prevalence of HIV within the province, as the prevalence has increased by 3.2% since 2007 (Department of Health, 2011).

These statistics point to the fact that while much is being done in an attempt to curb the tide of HIV/AIDS in South Africa, there is still much to be done before this epidemic will be brought under control.

## **HIV/AIDS and Children in South Africa**

It is estimated that there were 3.4 million children living with HIV worldwide by the end of 2010, of which an estimated 438 000 were living in South Africa (WHO, et al., 2011, Department of Health, 2011). While not all of these children will be orphaned at once, the main means of infection of children is through mother-to-child transmission, making it likely that those children will be orphaned in the future, if they aren't already. It was estimated that 194 000 South Africans died of AIDS in 2010, of which 173 000 were adults, resulting in approximately 1 670 000 more AIDS orphans (UNAIDS, 2010a). The UNAIDS Global report (2010a) found many improvements in statistics relating to AIDS; however this did not pertain to the area of AIDS orphans. While they reported a modest decline in HIV prevalence worldwide, the number of children being orphaned by HIV/AIDS continued to increase, with 90% of those children living in sub-Saharan Africa (UNAIDS, 2010a)

Children that have been orphaned by HIV/AIDS have generally been affected in a number of ways before they reach foster care. The impact of HIV in their lives will most likely have included poverty to some extent, the emotional trauma of standing by and watching and often nursing parents as they died, stigma related to their diagnosis and the diagnosis of their parents, and they could possibly have spent time living on the street or in institutions (Townsend & Dawes, 2004). The effect of such experiences so early in a child's life creates stress, uncertainty and anxiety and can have a long term impact on their future development, including a higher risk of psychological distress and to some extent, behavioural problems (Townsend & Dawes, 2004; Mueller, Alie, Jonas, Brown & Sherr, 2011).

Thomas and Thomas (2005) paint a dismal picture of the cycle of HIV/AIDS in the absence of adult intervention for the orphans that are left behind. They predict that the cycle starts with parental HIV/AIDS infection, followed by death of the parents, leaving children as

orphans. These children are then forced to fend for themselves as a result of the poverty in which they live and many turn to prostitution and other risk taking activities. They are then infected with HIV and possibly become pregnant, producing a potential second generation of HIV orphans (Thomas & Thomas, 2005). While this does paint a 'worst case scenario' picture, it is unfortunately a picture that could very well become a reality if adults, be they family members or non-family members, don't step up to provide care for the children that are orphaned by HIV/AIDS.

### **Foster care in South Africa**

#### *History of foster care in South Africa*

Historically many African cultures have been characterised by strong extended family networks (Thomas & Mabusela, 1991; Kuo & Operario, 2010; Kiggundu & Oldewage-Theron, 2009). In South Africa, the Apartheid laws that limited the ability of black families to work and live in the same place meant that children were often left in the care of grandmothers in rural areas while their parents sought employment in the cities (Thomas & Mabusela, 1991; Madhaven, 2004). This informal fostering was wide spread and a generally accepted practice as the parents would send money back to cover the expenses for their children (Thomas & Mabusela, 1991).

#### *Change in fostering dynamics due to HIV/AIDS*

The dynamics of this form of care has changed significantly due to the impact of HIV/AIDS on these families. The middle generation of working parents are the ones that are becoming ill and passing away, leaving the older generation to care for the youngest generation with scant opportunity for income generation (Kuo & Operario, 2010).

Results of recent studies have suggested that extended family networks that have historically provided care for children have become stretched too thin by the volume of orphans that have resulted from the AIDS crisis (Kiggundu & Oldewage-Theron, 2009, Townsend & Dawes, 2004). Townsend and Dawes (2004) also make the astute observation that the next generation of grandparents will be much smaller than the current one due to the effects of HIV/AIDS on that generation. This will therefore mean that grandparents will often not be alive to provide care for their orphaned grandchildren (Townsend & Dawes, 2004). The options are therefore to find other families to care for the children or to institutionalise them. Townsend and Dawes (2004) cite research which found that institutional care can have a damaging effect on a child's physical, psychological and emotional well-being. They therefore make recommendations that foster care outside of the family network should be promoted as a form of care for these children, in order to reduce the burden on the grandmothers of South Africa and in order for these children to experience some form of family life (Kiggundu & Oldewage-Theron, 2009; Townsend & Dawes, 2004).

#### *Purpose of foster care*

According to the Children's Amendment Act (Department of Social Development, 2007) there are three main purposes to foster care. These purposes are to protect and nurture children by providing a safe, healthy environment with positive support; to promote the goals of permanency planning, first towards family reunification, or by connecting children to other safe and nurturing family relationships intended to last a lifetime; and respect of the individual and family by demonstrating a respect for cultural, ethnic and community diversity (Department of Social Development, 2007, p. 72).



### *Types of foster care*

Madhaven (2004) divides foster care into two categories, namely voluntary and crisis-led fostering. Voluntary fostering refers to arrangements made between biological and foster carers for the children to be placed in the care of the foster carers, who generally share the same cultural norms around child rearing as the biological parents do (Madhaven, 2004). Crisis-led fostering seems to be the type of foster care that is happening most often in the context of AIDS orphans and is generally in response to death or economic hardship (Madhaven, 2004). De Jager (2011) suggests that there are 4 categories of foster care, which include informal foster care, formal foster care, kinship care and non-relative foster care. Each of these types of care can be as a result of a voluntary or crisis-led placement and can vary from a short term placement to a permanent placement (De Jager, 2011).

### *Who provides foster care?*

Studies have found that much of the foster care that is currently being provided in South Africa is still through the extended family network (Madhaven, 2004). A study of registered foster carers and adoptive parents of a child welfare NGO in Cape Town and George was carried out in an attempt to ascertain whether those who had already committed to fostering or adopting children would be willing to do the same for children orphaned by AIDS (Townsend & Dawes, 2004). Their study found that 76, 25% of the interviewed potential foster carers and adoptive parents were willing to care for a HIV negative orphan and 62, 2% were willing to care for a HIV positive orphan (Townsend & Dawes, 2004). These statistics are promising as they show that there is hope for care for these children beyond the extended family.

### *Foster care legislation*

According to the Children's Amendment Act (Department of Social Development, 2007, p. 74), a foster carer should be a fit and proper person to be entrusted with the foster care of the child; they must be willing and able to undertake, exercise and maintain the responsibilities of such care; they must have the capacity to provide an environment that is conducive to the child's growth and development; and they must be properly assessed by a designated social worker for compliance with the afore mentioned criteria. The assessment by the social worker should also consider the cultural, religious and linguistic background of the child; and the availability of a suitable person with a similar background to that of the child, who is willing and able to provide foster care to the child (Department of Social Development, 2007). A child may only be placed in the foster care of a person from a different cultural, religious and linguistic background to that of the child if there is an existing bond between that person and the child, or a suitable and willing person with a similar background is not readily available to provide foster care for the child (Department of Social Development, 2007).

While foster care is often considered a temporary solution, the Children's Act does make provision for longer term care. According to the Act (no 41 of 2007), if a child has been in foster care with a person other than a family member for more than 2 years and considering the need for creating stability in the child's life, it can be decided that no further social worker supervision or reports are required for the placement and that the placement should continue until the child turns 18 years old, unless otherwise directed. In addition to this, the Act (no 41 of 2007) also states that an order of the Children's Court may grant parental rights and responsibilities to a foster carer in addition to those normally necessary, if the child has been abandoned, is an orphan or family reunification is not in the best interest of the child.

### **Support mechanisms for foster carers of HIV positive children**

According to Nixon (1997), the support elements needed by foster carers in general, are financial, practical, emotional, psychological, social, professional development, problem solving, respite and community support. When these needs are met, they are better equipped to meet the needs of the child in their care (Durand, 2007). Durand (2007) suggests that support for foster carers can come through the foster carer's own family, the foster child's biological family, professionals, other foster carers and foster carer associations. Of these support systems, it was found that family members were the most used form of support, followed by support from social workers (Durand, 2007; Brown, BeLue, & Airhihenbuwa, 2010). Durand (2007) found that there was a general lack of support from community and community resources and other foster carers, but that when there was community support, it generally came through the church, medical professionals and occasionally through the local schools.

Various studies documenting the challenges of caring for HIV positive orphans have also made mention of support mechanisms that are being used or that would be recommended for those providing care specifically to HIV positive orphans. For the most part however, these studies seem to show that current support structures are being overwhelmed by the circumstances facing foster carers (Kiggundu & Oldewage-Theron, 2009).

Simpson (2006) found that belonging to a church community was a significant form of support for caregivers (not specific to foster carers). Kiggundu and Oldewage-Theron (2009) however found that foster carers in their study felt that many at the church did not understand their circumstances. In this particular study, support groups provided by a local NGO for foster carers to discuss their concerns and challenges were reported to be the most effective form of support for the carers (Kiggundu & Oldewage-Theron, 2009).

Studies have shown that foster carers of HIV positive orphans would benefit from more support with regards to their emotional, financial and physical wellbeing (Rajcoomar, 2005; Kiggundu & Oldewage-Theron, 2009). The nature of this support should be in the form of support groups, income generation programmes, easier access to government resources, orphan education, parenting workshops, and an overview of the grant application process to make it more accessible (Kiggundu & Oldewage-Theron, 2009).

### **General challenges experienced by foster carers**

According to Thomas and Mabusela (1991) the challenges of foster care are numerous, including issues pertaining to loyalty and identity, problems with discrimination between foster children and biological children of foster carers, redefinition of the family, change of the family structure of the foster family and the resultant strain of the transition, feelings of loss on the part of the child and the biological family, and the need for the biological and foster families to work together.

According to the findings of research carried out by Kuo and Operario (2010) in KwaZulu-Natal, the challenges facing carers of AIDS orphans can be divided into three main groupings, namely, economic challenges, challenges related to children's needs, and physical and mental health challenges. The economic challenges included poverty, lack of food, accessing documents for social welfare grants, shelter, unemployment, clothing, transport, clean water, and school fees/uniforms (Kuo & Operario, 2010). These findings are corroborated by a study by Marais, Esser, Godwin, Rabie and Cotton (2008), whose findings suggest that the financial strain of looking after HIV positive children can place a heavy burden on caretakers. The need to take the children for regular medical appointments means that carers often have to spend significant amounts of money on transport (in proportion to their household income) and are often kept out of work, further jeopardising their financial position (Marais et al., 2008).

The challenges related to children's needs include sexual abuse of children, disciplining children, children's emotional needs, children's bereavement, and the children's physical health (Kuo & Operario, 2010). Lastly, the challenges related to physical and mental health included carer bereavement, disappointment with unmet expectations regarding life course, tiredness and stress due to caring for children, stigma, carer's sense of isolation, stress of combining families and the carer's physical health (Kuo & Operario, 2010). Findings from a study by Kiggundu and Oldewage-Theron (2009) corroborate these findings. Many of the guardians in their study struggled with high blood pressure, diabetes, arthritis and depression and some were also HIV positive (Kiggundu & Oldewage-Theron, 2009).

Stigma is one of the greatest challenges to all people affected by HIV/AIDS. Herek (1999, p. 1107) defined AIDS-related stigma as 'prejudice, discounting, discrediting, and discrimination directed at people perceived to have AIDS or HIV, and the individuals, groups, and communities with which they are associated.'

Ogunmefun, et al. (2011), conducted a study on secondary stigma with regards to older female care givers in the context of providing care for HIV positive family members. Stigma related directly to the infected person, whereas secondary stigma was stigma experienced by the care giver (Ogunmefun et al., 2011). Their study found that stigma and secondary stigma take similar forms, both often resulting in physical and social isolation and separation from family members, and being the target of gossip and finger-pointing (Ogunmefun et al., 2011). The study also found that the main protection from secondary stigma was the care givers own denial or non-disclosure of the HIV status of the family member in their care (Ogunmefun et al., 2011). The isolation that is a result of stigma and secondary stigma can often have a knock on effect to other areas of the care givers life, including gender roles and their ability to provide financially for themselves and those in their care, further impacting and entrenching the cycle of poverty that many families in this

situation find themselves in (Ogunmefun, et al., 2011). Studies have shown that the greatest motivation for stigma is a fear of infection (Ogunmefun et al., 2011, Brown, et al., 2010; Boyer & Poindexter, 2005).

### **Challenges specific to foster care provided by grandmothers**

Kiggundu and Oldewage-Theron (2009) found that extended family foster placements present additional challenges to those presented in non-kinship placements. In particular, grandmothers providing care for their grandchildren faced not only the loss of their children, but also the loss of the support that their children would have given them in their old age (Kiggundu & Oldewage-Theron, 2009). Old age and sickness were also challenges that, although not specific to family members, were often experienced by grandmothers providing foster care (Kiggundu & Oldewage-Theron, 2009).

Rajcoomar's (2005) study of the impact of HIV/AIDS on rural *gogos* (grandmothers) found that the main stressors of grandmothers providing care for their orphaned grandchildren were the financial costs of funerals and of raising the orphaned children, caring for sick children and adults, a lack of family support and grief counseling, and insufficient knowledge of HIV/AIDS and how to protect themselves from infection.

It has also been found that grandmothers providing care for their orphaned grandchildren have the additional stress of needing to plan for the real possibility that they too might pass away while their grandchildren are in their care (Kiggundu & Oldewage-Theron, 2009).

Boyer and Poindexter (2005) identified five barriers to permanency planning for older foster carers of HIV affected and infected children. These barriers include lack of knowledge about the legal process, lack of legal authority, emotional concerns, lack of informal social support and HIV-related stigma (Boyer & Poindexter, 2005).

### **Foster carers perceptions of their role**

A study conducted by Blythe, Halcomb, Wilkes and Jackson (2012) looked at foster mothers perceptions of their role in the care of their foster children and found that their perceptions differed, depending on whether the child in their care had been placed on a short or a long term basis. In the instance of short term placements, the foster mothers saw themselves strictly as foster mothers, whose role was to help in the facilitation of the child's transition back into their family or into another form of long term care (Blythe et al., 2012). They found that foster mothers providing care for foster children on a long term basis saw themselves as being the child's mom, not just their foster mother, which involved a wholehearted embracing of the child into their family (Blythe et al., 2012). The study found that while providing care for their foster children was often challenging, the foster carer's commitment to the children was unwavering and many described deliberate efforts that they had made to emotionally engage their foster children (Blythe et al., 2012).

In a study specific to the role perceptions of African American foster carers, the findings were that the foster carers placed a strong emphasis on tasks related to the direct care of their foster children (Warde, 2008). This study found that in particular, the African American foster carers saw themselves as having the highest level of role responsibility for tasks connected to their foster child's social and emotional development (Warde, 2008).

Kuo and Operario (2010) carried out research in the South African context where workers at local NGO's had experienced foster carers as being ambivalent about their ability to provide emotional support for the children in their care. They found that the carers were most concerned with meeting the child's basic needs, particularly food, clothing and shelter, but felt that they only had the capacity to provide love if there was time after everything else had been done (Kuo & Operario, 2010).

Respondents in the study carried out by Hearle and Ruwanpura (2009) reported often feeling overwhelmed in their role as caregivers, due to the challenging behaviour of the children in their care. They reported an increase in physical violence and lack of respect from the children towards their foster carers, which led to feelings of resentment over their role in the children's lives (Hearle & Ruwanpura, 2009).

### **Access to government services – grants, medical and educational support**

The Foster Care Grant was introduced as an intervention to address the needs of orphans and is accessible by children who are in the care of adults who are not their parents due to the fact that their parents have died of AIDS (Hearle & Ruwanpura, 2009). The aim of the grant is to enable foster carers to cover the basic needs of the orphan, including adequate housing, food, clothes, medical care and schooling, relieving the foster carer from the responsibility of providing to cover these needs (Hearle & Ruwanpura, 2009). The monthly grant amount for 2012 is R740 per month (Department of Social Development, 2010).

While the grant has been of great help to the many who access it, it has also presented a number of challenges to foster carers of the orphans entitled to this grant. The grant is administered based on the child's income, not the foster carers, and in order to apply for the grant, a copy of the child's birth certificate needs to be provided (Kiggundu & Oldewage-Theron, 2009). Guardians who were interviewed in Kiggundu and Oldewage-Theron's study (2009) verbalised the difficulty that they have with providing the documentation required by the state before the grants will be issued, in particular, the birth certificates of the children. Many had applied for grants but the process took such a long time that they felt that it was likely that the children in their care would turn 18 before the grants were processed (Kiggundu & Oldewage-Theron, 2009). In 2005 it was suggested that only 51% of eligible caregivers were receiving grants (Jones, et al., 2005).



Hearle and Ruwanpura (2009) found that the Foster Care Grant was becoming a contentious issue in families and following the death of a parent, there are often family fights over who will get the child's birth certificate, as that will influence who is able to claim the Foster Care Grant. They also reported that the orphaned children are realising that as long as they have the grant, they have the upper hand and as a result they use the grant to exert power over their foster carers (Hearle & Ruwanpura, 2009).

Yeap, Hamilton, Charalambous, Dwaadwa, Churchyard, Geissler and Grant (2010), found that long queues, overcrowding, negative staff attitudes, and fear of breaches in confidentiality were common obstacles facing both foster carers and parents of HIV positive children, as they attempted to access medical support for their children at local government clinics. They also found that employment or lack thereof was a significant barrier to accessing medical services (Yeap et al., 2010). Those that were employed found it difficult to take time off to make the hospital appointments as they knew they would generally have to take a whole day off, and those that were unemployed struggled to find the finances to cover the transport needed to get to the hospital (Yeap, et al., 2010).

Little research appears to be available on the topic of access to education and educational support for HIV positive foster children. It is however documented that foster children on the whole function at a lower academic level than their peers (Blome, 1997). A study cited by Blome (1997), found that as many as 59% of foster children were functioning below grade level. It can therefore be assumed that extra educational support would be important for these children.

It is clear that access to government support and services is full of barriers for foster carers of AIDS orphans.

## **Theoretical Framework: Family Stress Theory and Systems Theory**

The questions in this study attempted to explore foster carers perceptions of the stressors related to foster care, their resources and their resultant level of life satisfaction, in the hopes that a clearer understanding may be reached about the factors that help to facilitate positive levels of life satisfaction for foster carers and their HIV positive foster children.

This study utilized Family Stress Theory and Systems Theory as frameworks for understanding the experiences and needs of foster carers.

### *Family Stress Theory*

Family Stress Theory is a developmental theory that explores why some family systems adapt and even grow and thrive when faced with situational stressors or transitional events, while other family units deteriorate and disintegrate under similar circumstances (McCubbin, 1993). The stress linked to foster care is played out and experienced in the family in which the foster child is placed. It is therefore important to consider a theoretical framework that is concerned with family stress. Hill (1949 as cited in Hobfoll & Spielberger, 1992, p. 99) formulated the 'ABC-X' model of understanding family stress. In this model, 'A' refers to the stressor, 'B' refers to the resources of the family to deal with the stressor, 'C' refers to the family's definition/perception of the event, and 'X' refers to the outcome of the stressful event, and the utilization of resources, together with the perception of the event, which determines life satisfaction (Darling, Olmstead & Tiggleman, 2009; Hobfoll & Spielberger, 1992;). McCubbin and Patterson (1983) built on this theory to develop the double ABC-X model where the concept of pile up is introduced. Here the family face multiple stressors, the combination of which can stretch the family's capacity to cope. Buehler, Cox and Cuddeback (2003) found that this notion of pile up is one that is frequently

experienced by foster carers and is often associated with the breakdown of foster placements, making it an important theory to consider when looking at foster care.

### *Systems Theory*

Systems theory also plays a key role in understanding the impact of stress on the foster family, as it views the family as an interconnected system. Systems theory emphasises interdependence and interaction between the components of a system and has an interest in what makes social systems, in this instance, families, maladaptive or adaptive, making it useful for understanding family dynamics (Greene & Ephross, 1991). The basic assumption of this theory is that the whole is greater than the sum of its parts (Greene & Ephross, 1991). This theory suggests that in order to understand a family, each member should be viewed in terms of their relationships with other family members rather than in isolation, and each individual's behaviour is seen as a consequence of the total social situation, thereby providing a framework for thinking in an organised, integrated way about reciprocal interactions among family members (Greene & Ephross, 1991). Greene and Ephross (1991) state that in order to understand the family as a social system, one should see the family as a boundary-maintaining unit, which has varying degrees of rigidity and permeability when defining the family and nonfamily world. The family should also be seen as an adaptive and equilibrium-seeking unit where patterns of interactions repeat themselves over time (Greene & Ephross, 1991). According to Darling et al. (2009), the way in which families deal with stress is generally based on the way in which the parent's families of origin dealt with stress. This in turn will impact the way in which the foster child and any other children in the home learn to deal with stress which will in turn impact the community around them, showing the interplay of Family Stress Theory and Systems Theory and their importance in understanding the dynamics of a foster family.

In conclusion, this review of the literature on foster care reveals that there is extensive literature about the care of AIDS orphans specific to rural settings, which stands in contrast to the lack of research in urban and peri-urban settings in South Africa and serves to motivate the need for research in this area. The lack of empirical research specifically regarding foster care of HIV positive children in South Africa also stands as motivation for the specific nature of this study.

University of Cape Town

## CHAPTER THREE: METHODOLOGY

This chapter will discuss the methodology that was used in carrying out this research. It will explore the research design, the population and sampling, and data collection processes. It will then go on to discuss the data analysis, data verification, ethical considerations and limitations of this research.

### **Research design**

The study was carried out using a qualitative design. Fortune and Reid (1999, p. 94) describe the qualitative approach as a method in which “the researcher attempts to gain a first-hand, holistic understanding of phenomena of interest by means of a flexible strategy of problem formulation and data collection, shaped as the investigation proceeds.” This approach was selected as it allowed the researcher the opportunity to explore the respondents’ experiences in order to understand the meaning attached to their responses.

The research took the form of an exploratory study, as more information is needed in the area of foster care for HIV positive children, particularly in an urban and peri-urban setting in South Africa. A semi-structured interview schedule was used to guide in-depth, face-to-face interviews that were held with foster carers in order to elicit their perceptions of their experiences and needs in caring for their HIV positive foster child.

### **Population**

Foster carers of HIV positive children are the population that this study sought to investigate. In order to obtain a broad socio-demographic mix of respondents, two organisations were identified, from which the respondents were recruited. Due to the broad client base of one of the organisations from where respondents were recruited, a fairly diverse population was found in terms of geographical location, population group and socio-economic status. Of the 18 respondents that were interviewed, 16 were female, and two were

male. Four of the respondents were White, two were Indian, four were Coloured and eight were Black. Their socio economic standing varied significantly, from accountants to unemployed grandmothers, living off their state pensions and the foster care grant.

### **Sampling**

A purposive sampling technique was used to select foster carers to participate in the study. De Vos, Strydom, Fouche and Delport (2005), define purposive sampling as a form of sampling that is based entirely on the judgement of the researcher. The sample is composed of elements that contain the most characteristic, representative or typical attributes of the population (De Vos et al., 2005). This method was chosen due to the fact that the issues that were investigated are specific to foster carers of HIV positive children. The respondents were purposively sampled based on specific inclusion criteria. A total of 18 respondents were interviewed in 17 interviews.

### *Inclusion and exclusion criteria*

For the purposes of this study, the respondents needed to be foster carers of HIV positive children. They should have been providing care for the same child for a period of at least two years in order to attempt to differentiate between general 'teething' challenges and long term challenges that foster carers experience. It would for example, be difficult to differentiate between adolescent angst and rebellion and teething problems in a foster placement if both were occurring at the same time. According to Simms, Dubowitz, and Szilagyi (2000), there are a number of adjustment issues that arise when placing children in foster care. It often appears as if children entering foster care initially adapt well to their new homes, although this is most likely a time of intense internal emotional turmoil (Simms, et al., 2000). After about three months, foster children may begin to exhibit signs of acting out behaviour, limit testing, depression, aggression, or withdrawal, and those with attachment

disorders might show signs of sleep disturbance, hoarding food, excessive eating, self-stimulation, rocking or failure to thrive (Simms, et al., 2000). By focussing on longer term foster placements, the impact of such teething challenges were hopefully minimized.

## **Data collection**

### *Study sites*

There were two study sites where respondents were recruited and data was collected, namely Kidzpositive and Beautiful Gate.

The Kidzpositive Family Fund supports anti-retroviral therapy to more than 1400 children and 400 caregivers at five sites in the Cape Town metropolitan area (Kidzpositive Annual Report, 2012). By the end of October 2011, 1186 children were receiving care for HIV/AIDS from the Kidzpositive Groote Schuur treatment team, of which 423 were seen at Groote Schuur, 495 at Crossroads and 268 at Mitchell's Plain Day Hospital (Kidzpositive Annual Report, 2012). This organisation was chosen due to its large client base, in the hopes that they would be able to provide families that were diverse in terms of geography and socio economic standing, which they were able to do.

Beautiful Gate is an NGO operating in Crossroads. Once a long term residential care facility, it now focuses on family reunification and integration of children into foster families, while still providing short term residential care for children awaiting reunification or placement in foster families. Beautiful Gate reunified 13 children with their families in the 2011-2012 year (Beautiful Gate annual report, 2012). Beautiful Gate has a strong community presence and runs parenting courses and training programs in an effort to improve the lives of those in the community in which they are based (Beautiful Gate annual report, 2012). The families assisted by Beautiful Gate are predominantly from the Cape Flats.

### *Recruitment procedure*

This section will explain the different methods of recruitment employed at the two study sites.

#### *- Recruitment at Kidzpositive*

Once ethical clearance was obtained, the researcher met with relevant staff members at Kidzpositive to discuss potential respondents. A list of patients who are in foster care was drawn up and staff assisted the researcher to access the appointment schedule to find out when the relevant foster carers would be bringing their foster children for their appointments. Through this process, 16 potential respondents were identified and the researcher then made sure that she was at the clinic on their relevant appointment days. Staff members assisted the researcher by pointing out the foster carers when they brought their child in for their appointment and the researcher then approached the potential respondent to enquire about their willingness to be involved in the study. The researcher found that this to be a very effective recruitment strategy and 14 interviews were carried out through the clinic.

Respondents who took part in the interviews on their child's appointment day were reimbursed for their transport costs through the clinic, which is a standard practice for those who request it on appointment days. Those respondents that requested to come in at an alternate time were reimbursed by the researcher for their travel expenses. A trained field worker was ready to assist with interviews if necessary, but was only called on at one point when one of the respondents, who had chosen to conduct the interview in English, became emotional and chose to continue in Xhosa.

#### *- Recruitment at Beautiful Gate*

An initial discussion with staff members at Beautiful Gate was held to establish which of the children who had previously been in their care were now in foster care. Once a list of



these families had been drawn up, the researcher accompanied two staff members on home visits to meet the foster carers and to enquire about their willingness to participate in the study. This proved to be a time consuming and largely unsuccessful form of recruitment as many of the foster carers were not home when home visits were conducted. Three of the foster carers who were contacted via the home visits agreed to be part of the study. The goals and purpose of the study were explained during this initial contact. Once the respondents had agreed to participate, a separate arrangement was made for them to come to Beautiful Gate, where their interviews took place. All the respondents recruited through Beautiful Gate were reimbursed for their transport costs. The respondents that were recruited were fluent in English and a field worker was therefore not needed to accommodate other language preferences.

#### *Data collection method*

This study utilised in-depth interviews (IDI), which were conducted with foster carers of HIV positive children in the Western Cape, to obtain information about their experiences and needs. According to De Vos et al. (2005), interviews are the most commonly used method of data collection when undertaking a qualitative research study. The interviews were conducted in the preferred languages of the participants, making use of a trained field worker once, when it was necessary. The field worker was knowledgeable about the aims and objectives of the research, as well as about the ethical considerations that they needed to bear in mind while conducting the interview. The interviews, with the permission of the respondents, were recorded making use of an electronic recording device. Recording the interviews allowed for a much richer account of the interview than relying on field notes and it allowed the researcher to concentrate on the flow of the interview rather than on recording the content thereof (De Vos et al., 2005). In total, 17 interviews were conducted with 18 foster carers. Two of these interviews took place at Beautiful Gate, three of the interviews

took place in the respondent's homes (at their request) and 12 of the interviews were conducted at Kidzpositive at Groote Schuur. The interviews were carried out between September 2012 and March 2013.

### *Data Collection Tool*

These in-depth interviews were conducted using a semi-structured interview schedule as a tool to guide the conversation. A semi structured schedule provides guidance for the flow of the interview but is open ended, allowing the respondent the space to provide meaningful feedback (De Vos et al., 2005).

The interview schedule explored information about the challenges and rewards of providing foster care, the support that foster carers receive and the support that they wish they could receive, their perceptions of their role in their foster child's life and about their access to and utilization of medical, educational and social services pertaining to their child. (See Appendix 4 for a copy of the Interview Schedule).

The in-depth interview schedule was piloted with a population similar to that of the proposed study. The purpose of this pilot was to assess the schedule for consistency, regularity, timing and continuity. As a result of the pilot test, minor changes were made to the interview schedule that included the addition of demographic information, and the reordering of a number of the questions in the schedule in order to facilitate better flow in the interview.

### **Data analysis**

This study made use of an adaptation of Creswell's approach to data analysis (1998 in De Vos, Strydom, Fouche & Delpoort2004). He outlines a five stage cyclical process through which data is analysed. The first step involves collecting and recording data, the second step is managing the data, the third step is reading and memoing, the fourth step is describing,

classifying and interpreting and the fifth step is representing and visualising the findings (De Vos et al., 2004). Data was collected through in-depth interviews which were held with foster carers. These interviews were recorded using an electronic recording device and then transcribed.

During the second step of managing the data, the transcripts and recordings were organised, using colour coding to make them easily accessible and identifiable for analysis. The recordings were kept with the transcriptions, so that the researcher could listen to them to ascertain meaning, when necessary.

During the third step of reading and writing memos, the researcher read through the transcripts a number of times to get a sense of the interviews in their entirety before breaking them down into categories. At this time the researcher made notes in the margins of the transcripts about questions and themes that began to emerge.

This brings in the fourth stage of Cresswell's approach to data analysis, which is describing, classifying and interpreting. During this stage, the researcher looked for similarities, categories, themes and comparisons. The challenge at this stage was to holistically evaluate the transcripts, so as not to make hasty assumptions about the content that emerged. The researcher made every attempt to evaluate the transcripts holistically by reading through each transcript a number of times, over a number of weeks, in order to attempt to find the meaning in the responses, rather than making hasty assumptions.

The final stage of the analysis was to represent and visualise the data. This representation of the data provides the content of this research report. The bulk of the data is represented through the written word, making use of the themes and categories which emerged in stage four to order the information and using quotes from the interviews to substantiate the findings. These findings were then linked to relevant literature and the

researcher added her own critical commentary. Where applicable, tables were used to provide visual representation of the data.

### **Data Verification**

Lincoln and Guba (as cited in Babbie & Mouton, 2007), identify four criteria that can be used to assess the trustworthiness of qualitative research, namely, credibility, transferability, dependability and confirmability.

#### *Credibility*

According to Babbie and Mouton (2007), credibility refers to the compatibility between the constructed realities of the respondents and those that are attributed to them. In this study, the researcher ensured credibility by persistent observation, referential adequacy and peer debriefing. According to Babbie and Mouton (2007), these are important processes in the achievement of credibility. The researcher was intentional about looking at different ways of interpreting the data that was being presented and the influences behind it; each interview was recorded using a voice recorder to document the findings; and a colleague who was knowledgeable about the topic was consulted, in an effort to gain richer understanding and insight into the findings.

#### *Transferability*

Transferability refers to the 'extent to which the findings can be applied in other contexts or with other respondents' (Babbie & Mouton, 2007, p. 277). Guba and Lincoln (as cited in Babbie & Mouton, 2007) cite thick descriptions and purposive sampling as strategies for achieving transferability. In order to achieve thick descriptions, the researcher attempted to collect data that was rich in detail and meaning, so that the reader will be able to make judgements about transferability (Guba & Lincoln, as cited in Babbie & Mouton, 2007).

Purposive sampling was used in the selection of participants, where effort was made to interview a diverse range of respondents, across socio-economic standing, culture, and age.

### *Dependability*

According to Babbie and Mouton (2007), dependability refers to whether the findings of the research would remain the same, or at least similar, if it were to be repeated with the same or similar respondents. Guba and Lincoln (as cited in Babbie & Mouton, 2007) found that there can be no credibility without dependability and therefore, the presence of credibility is sufficient to establish the existence of dependability. The researcher therefore endeavoured to ensure dependability by taking the necessary steps to ensure credibility.

### *Confirmability*

Confirmability refers to the 'degree to which the findings are the product of the focus of the inquiry and not of the biases of the researcher' (Babbie & Mouton, 2007, p. 278). In order to ensure confirmability, the researcher has kept all the original data, including the interview schedule, field notes, recordings and transcriptions. This will ensure that the data and findings can be reviewed and confirmed by a third party, should the need arise.

## **Ethical considerations**

### *Risks and benefits of the study*

Due to the nature of the study, there was a risk that the respondents could struggle emotionally when answering the questions. The researcher is an experienced social worker and where necessary, stopped the interviews and provided counseling and containment for the respondent. The researcher erred on the side of caution and made sure that those respondents who became overwhelmed by their situations were completely ready before continuing with the interviews. It is hoped that a benefit of this study will be to provide this

population and other potential foster carers with much needed information about the challenges facing foster carers of HIV positive children.

#### *Human subjects' protection*

The University of Cape Town has a strict process whereby ethical approval must be obtained before a proposed study may be carried out. The research proposal for this study was reviewed by the supervisor and research co-ordinator of the Department of Social Development and ethical clearance was obtained. Additional applications and paper work were then submitted to the Health Sciences Ethics Council, and only after they had also given their approval did the research commence. Ethical approval was obtained from both of the study sites. (See Appendix 1, 2 and 3 for approval documentation).

Strydom (as cited in De Vos et al., 2005), suggests eight ethical considerations that should be addressed when undertaking a research study. These ethical considerations include avoidance of harm, informed consent, deception of subjects and/or respondents, violation of privacy/anonymity/confidentiality, actions and competence of researchers, co-operation with contributors, release or publication of the findings and debriefing of the respondents (Strydom, as cited in De Vos et al., 2005).

#### *Avoidance of harm*

For the purposes of the study, the researcher did all that she could to avoid harm to the respondents. Part of this avoidance of harm included asking all respondents to sign an informed consent form. As a qualified social worker, the researcher sought to conduct the interviews in a way that was respectful and did not ask unnecessarily intrusive questions, in an effort to protect the respondents from emotional harm.

### *Informed consent*

The rationale for the research, the process of the research, the issue of confidentiality and the way in which the findings will be published were verbally explained to the respondents before they agreed to take part in the study, so that they were able to consider all these factors before agreeing to participate. These details were outlined in a written informed consent form which each respondent was asked to sign and the respondents were given ample opportunity to ask questions about the research before being asked to give consent. (See Appendix 5 for a copy of the informed consent form).

### *Deception of respondents*

There was no intentional deception of the respondents in this research study and the researcher made every effort to avoid unintentional deception of subjects through the course of the study. The researcher is unaware of any such unintentional deception, but had any come to light she would have sought to rectify this immediately.

### *Privacy and voluntary participation*

The interviews were conducted in a private office in the preferred language of the respondent. The researcher obtained permission from the respondents (in writing) to use a digital voice recorder to record the interviews. Respondents were assured that the recordings would be used to help to ensure that the findings are as accurate as possible. The participants were reminded at the start of the interview that their participation in the study is voluntary and that they could withdraw from the study at any time and that their participation or non-participation would not jeopardise the relationship that they have with the study site or the services that they receive from these sites. Had the researcher's request for the respondent's involvement been met with refusal, this would have been accepted and respected.

### *Anonymity*

It was explained to the respondents that their names and identifying details would not be in anyway linked with their responses in the findings. Rather than using their names, it was explained to the respondents that they would each be assigned a letter of the alphabet that would be used to name each interview transcribed, thereby ensuring that their name and details are not associated with their responses. It was explained that where appropriate, alias's would be used in place of their foster children's names.

### *Confidentiality*

Respondents were assured that the recording device and all transcriptions will be kept in a locked cupboard that only the researcher and her supervisor has access to. They were also assured that the recordings would only be listened to by the researcher and her supervisor. The digital recordings were password protected and will be deleted once the study is complete. Transcriptions will be destroyed within 3-5 years of publishing the research findings.

### *Actions and competence of the researcher*

The researcher conducted the interviews in a way that was professional, respectful and free from judgement of the respondents and their often difficult situations. It was made clear to the respondents that they had the right to not answer any questions that they didn't feel comfortable responding to. The researcher is a registered social worker and submits to the ethical code of the South African Council of Social Service Professions.

### *Co-operation with contributors and release and/or publication of findings*

Any collaboration with colleagues or other professionals is noted in the research, in keeping with the ethical consideration of co-operation with contributors. The researcher has



aimed to compile this final research report in a way that is accurate, objective, clear, unambiguous, free from bias and containing all the relevant information (Strydom, as cited in De Vos et al., 2005).

### *Debriefing of respondents*

The respondents were debriefed directly after every interview. This involved discussing their feelings about the interview and provided an opportunity to ask any questions that the interview might have raised in their minds about the study. This also provided an opportunity to correct any misconceptions which may have arisen during the course of the interview.

### **Limitations of the study**

A number of limitations emerged in the course of the study.

The findings should be interpreted with caution due to the fact that the study was qualitative in nature and the findings can therefore not be generalised. This is compounded by the fact that recruitment was only from two sites, which could potentially have impacted the nature of the responses.

By conducting the interviews at institutions where the respondents receive services, the respondents could have felt the need to give what they deemed to be socially desirable answers, which could negatively impact the reliability of their responses.

The primary care giver was not always able to be present for the interview which meant that three of the interviews were conducted with an extended family member, which could have impacted the accuracy of the responses obtained.

One of the interviews was carried out with both foster carers present. In this instance, the foster carers were a gay couple. The fact that both of them were present may or may not have influenced the way in which they chose to respond to the questions that were asked.

The majority of the interviews were conducted through an organisation that provides medical services, which would impact the findings by virtue of the fact that the respondents' foster children were all therefore in receipt of at least some form of medical care.

The study does not take into account the perspectives of the foster children, and it can be assumed that they would have their own views of the issues discussed in the interviews.

### **Reflexivity**

The topic of foster care for HIV positive children is one that is very close to my heart, as I have an HIV positive foster sister. My family's experience of the challenges and rewards of fostering an HIV positive child provided the impetus for this research.

I am passionate about foster care and particularly in relation to the care of HIV positive orphans. I was aware that some of the people that I encountered in my study might not have felt the same way that I do about caring for these children and might have had the care of the child thrust upon them out of necessity rather than personal motivation. Being aware of my feelings about foster care, I made sure that I approached the interview subjects from an objective standpoint, regardless of their motivation for providing care, making every effort to keep my personal feelings to myself. I was aware of many of the challenges from my own experience and feel that this helped me to be empathetic in my interactions with the foster carers. My professional training as a social worker and my own experience with this form of care meant that I was tempted to intervene when I heard of some of the foster carer's experiences, but being aware of this, I attempted to adhere to the function of data collection,

without engaging in therapeutic intervention, while still providing containment and assistance where it was appropriate.

## CHAPTER FOUR: RESULTS

This chapter will present the findings of the research study. It will provide a written and tabular description of the study participants and will go on to discuss the findings under the main headings provided by the research objectives and then breaking these down further to discuss the findings under the headings of the categories and sub categories that emerged through the analysis of the data. Quotes from the interviews will be used to substantiate the findings.

### Description of study participants

There was great diversity in the demographics of the respondents who took part in the study. As shown in Table 1, the majority of the respondents (eight) were Black, four were Coloured, two were Indian and four were White. Of the 18 respondents, 16 were female, whereas only two were men, who happened to be married to each other and were both present for the interview about their child. The foster children ranged in age from seven to 16 and the respondents ranged in age from 21 to 68. The respondents came from across the greater Cape Town area, as outlined in Table 1.

Table 2 presents the placement characteristics and interview dynamics of the study. As shown in the table, there were 14 official placements and three unofficial placements. Official placements refer to placements that are as a result of a foster care order from the Department of Social Development, whereas an unofficial placement is often the result of an agreement between family members, in which social services has not been involved. Of the three unofficial placements included in this study, one was unofficial due to the child being international, one was unofficial due to the foster carers being international, and one as a result of an informal arrangement.

**Table 1: Socio-demographic Backgrounds of Respondents**

<b>Population Group of Respondents</b>	
	Number of respondents
Black	8
Coloured	4
Indian	2
White	4
<b>Place of Residence</b>	
Edgemean	1
Eerste Rivier	1
Hanover Park	1
Khayelitsha	3
Lentegeur	1
Mitchell's Plain	1
Nyanga	2
Phillipi	1
Pinelands	2
Plumstead	1
Sea Point	1
Strandfontein	1
Zeekoivlei	1
<b>Age range of respondents</b>	
21-30	2
31-40	2
41-50	4
51-60	9
61-70	1

As shown in Table 2, six of the placements were kinship placements, five were placements within the same population group but not family members, and six of the placements were across population groups. Two of the foster carers were fostering children who were not only HIV positive but also had special needs.

Of the interviews conducted, 14 were held with the primary caregiver of the foster child, with one of these interviews being attended by both foster carers, who were in this case, gay men. Three of the interviews were held with foster family members other than the

primary caregiver due to the primary caregiver being either too old, battling arthritis, or at work (Table 2).

**Table 2: Placement Characteristics and Interview Dynamics**

<b>Placement Characteristics</b>	
	Number of Respondents
Kinship care placement	6
Same population group, non-kinship placement	5
Cross population group placement	6
Official placement	14
Unofficial placement	3
<b>Interview Dynamics</b>	
Interviews with primary caregiver	14
Interviews with another family member	3
Interview where both foster carers were present	1

### **Challenges facing foster carers of HIV positive children**

From the interviews, it is apparent that the challenges facing foster carers of HIV positive children are extensive and can be overwhelming at times.

A range of challenges emerged with the main challenges including: the initial adjustment period, dealing with the child's HIV positive status, interactions with biological parents, finances, dual diagnoses, stigma and fear, the foster carers' own mental and physical health, managing the child's medication, and dealing with the child's emotional pain.

#### *The initial adjustment period*

The majority of the respondents reported really struggling to understand their foster child in the initial period of adjustment after the child moved in with their family. This was true for the children that came from residential facilities, and those who had just suffered the loss of their primary care giver.

This was evidenced in a number of the statements made by the foster carers.

Uh, there were things that we couldn't understand about her. Because sometimes she would become cross and we wouldn't know the reason. – *26 year old foster mother*

Another foster carer reported that:

Sometimes he would get so frustrated if he don't get what he wants...because there in the home... you play with everybody's toys, everybody's got one care giver you see, so um, I couldn't touch him or walk past him and touch him, then he will just hit you. But he's out of that now. That was one of the problems that I had. – *58 year old foster mother*

Most of the respondent's reported that while the adjustment period had been difficult, they felt that they had resolved their initial adjustment issues.

#### *Dealing with child's HIV positive status*

A number of the respondents alluded to their initial heart-ache, fear and uncertainty when learning about their foster child's status, particularly those in situations where the child was only diagnosed after already living in their care. For many this meant dealing with their own heart-ache, fears and concerns for the future, while remaining strong for their foster child.

A 32 year old unofficial foster mother spoke about her fear as follows:

I used to be scared! Because they say that if you touch the blood of someone who is positive, you will also be positive. So I tell myself, I must do this, because he must be well. Because he was really sick.

Another respondent shared about her emotional response to the news of her foster child's status:

I did cry for 2 days. For 2 days I couldn't eat, I couldn't drink. But I still say thank you Lord for helping me, and I'm still standing and I'm prepared to climb the mountain with my son, for better or for worse, I'll climb it, because he didn't ask for this. - *43 year old foster mother*

A 21 year old extended foster family member who lives in the same house as the foster child shared about the family's reaction to the news of their foster child's status:

So from then, we a bit freaky at home, we were scared, but as we learnt, we never criticised her, because we know it's a living thing. And my mother is also HIV positive, and her sister is also positive, and her older uncle is also positive, so we never have that criticism, because we know people in the same position...Now we have to focus on how she is living now.

Some of these foster carers also had the difficult task of explaining to their child that they have HIV. For example, a 43 year old foster mother shared the following:

Interviewer: And when you discovered that he was HIV positive, what was his reaction?

Respondent: Uuum. He was a little bit off. He didn't even question me. He didn't question my husband. He didn't question anyone... I say 'Andrew, um, I have to speak to you now. We are going to work with an illness, it can be deadly, but it can also help you. It's between me and you and Allah. We have to help each other now. I'm going to help you, you have to help me. We gonna talk openly. We don't hide things. If you need anything, come to me. Talk about sex, you come to me...Because I stand as a mother, as a father, as your counsellor. We talk openly with each other.

It seemed that despite the fear and uncertainty that many foster carers experienced as a result of their foster child's HIV status, the revelation of their child's status often resulted in a renewed sense of purpose in their care of their foster child.

### *Interactions with biological parents*

The foster carers who are not related to their foster children and who had interactions with the biological parents of their foster children reported those experiences to be fairly trying and often even traumatic.

In an interview where two foster fathers in a same sex marriage were interviewed, they reported on their experiences with their foster daughter's biological mother as follows:



Respondent 1: The woman in the ID book was a very beautiful black woman and the woman sitting in front of me was a woman that had had a very hard time...I cried, I held her and I cried.

Respondent 2: He cried for days. And then Thandi cries because then why is daddy crying. You know, it's addictive. And then I cry because they are both crying. It's still a very painful thought.

Another foster carer spoke about the drama that she had to endure as a result of interaction with the biological mother of her foster children:

... The mother knew where I stayed. When she brought Laura to me, I gave her my address and my telephone number so that she can't say I kidnapped her child. And then she just pitched up anytime she wanted and she never came by being sober, she always came here when she was drunk, so for me the most difficult part was the involvement of their mother. That was it. But now, I always say, I'm not glad that she's not there anymore, but it makes things much easier. - *58 year old foster mother*

Another foster carer spoke about her attempt to connect with her child's biological mother, but to no avail:

She was very rude and didn't want us to take her child... So I said to her, 'I don't want to take your child, but Sonja tells me that there are no other options. If you feel you want to keep him, it's not a problem, it's not that I have no children or something. We will bring him to see you, and you are more than welcome to come into my home to see him. So anyway, she ignored us, so she has always just been very rude. - *48 year old foster mother*

It is clear from the above quotes that establishing or maintaining contact with biological parents presents its own set of challenges, which can seem overwhelming for foster carers, in addition to the heavy load that they already carry.

### *Finances*

For the respondents who came from lower socio economic areas (11 out of the 18 respondents), the issue of finances emerged as the primary challenge. While most were in

receipt of the foster care grant, they did not feel that it was sufficient to cover all the expenses associated with raising an HIV positive child. A common complaint was the rising cost of healthy food and a genuine concern was shown by most of these foster carers that they struggle to provide their foster children with the healthy food that they know the children need, especially in light of their status.

This was evidenced through the following two quotes:

The most difficult part is when you don't have enough money. Because especially if you've got a sick child at home, you must make sure there's some veggies, there's food...you see, especially because I don't want her to be hurt. Because I'm always scared that if she can get hurt, she might be sick again...If I buy a pair of shoes, I have to buy another one. 'Mommy where is mine? Where is mine?' ... So if I'm going to buy something, I have to make the budget right so that, you see, they are the similar age and I buy one for the bigger girls, I must buy 2 pairs of them. If I buy for the little ones, I must make sure that I'm going to have something for the other one...When I'm looking I'm not only looking for today. I'm also looking for their future. Because I want my kids to be educated but I don't have the funds. - *39 year old foster mother*

I buy something nice for her because you know she must eat...she must eat to get healthy. So sometimes the money get finish. Sometimes there isn't enough to get something to eat. - *56 year old foster mother*

In many incidents, particularly with the older foster carers, they were often financially supporting not only their foster child, but also other members of the family who are unemployed. In 3 of the families, the foster child and the foster carer, who received a state pension or another grant, were seen as the bread winners in the family, due to the government grants that they receive and the widespread unemployment in their extended families.

This was evidenced through the following interaction with a 52 year old unofficial foster mother:

Interviewer: Does your mother receive a pension?

Respondent: Ja.

Interviewer: And that must feed everybody?

Respondent: Ja. It's the only grant money you see. You have to pay transport, pay the school fees, buy this, buy that.

Lack of finances can also make it difficult for the foster carers to get the children to the necessary medical appointments, as evidenced by the following quote:

Sometimes when I come here, when his date fall on the 22<sup>nd</sup> or 25 or so, up to 27 and 28, that time I haven't got money. There was two times I wasn't here but I phone in and I ask them can I come next week. Then it's the end of the month and I have money. - *52 year old foster mother*

The foster carers whose foster children receive their medical care through Grootte Schuur are able to claim transport money back from the Hospital Benevolent Fund, which many found to be of great assistance, provided they had enough money to make it to the appointment in the first place. It is clear that financial support is a big need for many foster carers of HIV positive children.

#### *Dual diagnoses*

Dual diagnoses refer to the presence of multiple diagnoses in the same child. Two of the foster carers interviewed had foster children for whom their HIV status was perceived by the foster carers to be secondary to other diagnoses, including Foetal Alcohol Syndrome (FAS), autism and cerebral palsy. For these foster carers, the other diagnoses were far more stressful and time consuming to manage than the HIV, as evidenced through the following quote:

HIV is the easiest thing to manage in my opinion. If you understand how to administer the dosages and you're strict about adhering to the regiments, its 2 minutes a day you know. - *51 year old foster mother*

However, both foster carers felt HIV was the diagnosis that hindered their ability to access the specialised services that their children require, as explained in this quote:

I think his status could at certain places also stand against him. They don't say it, but it is obvious. My L is in charge of the Edgemoor area and I have been trying him from the time Mark was 3 and Dr D sent his report through and I phoned him and asked him and he said 'oh I see the child has AIDS, I would suggest St Josephs home.' And we had one row, a big argument. - *48 year old foster mother*

These parents also reported feeling very isolated in their role of parenting their children as evidenced through the following quote:

And the parents, what I've noticed is, if their child is CP, they only want to deal with other parents with CP. If the child is Downs, then the facilities available are all specific to Down Syndrome. Deaf and dumb... blind school... each one has their clique. And then you get a child like Mark thrown in the mix. I mean I phoned the CP organisation. The lady is very nice but she told me I need to get hold of parents of HIV positive children, because he is not fully CP. And then he's not fully autistic. So that is the challenge. Where does he click? - *48 year old foster mother*

Social and emotional support seemed to be a prominent need for the foster parents dealing with dual diagnoses.

### *Stigma and fear*

Many of the respondents felt that stigma was not an issue when asked directly about it. However through further probing, it emerged that stigma was only a non-issue for them, due to the fact that most of them had not disclosed outside of their family circle. For those who have disclosed about their child's status, stigma and fear are very real challenges that they face on a regular basis.

One foster carer explained her decision to not disclose her child's status as follows:

... You start telling them that this child is HIV positive, they won't even want to sit next to her. You know that there are some people like that. They won't even want to drink from the same cup as her... so that is why I decided I can't tell my community, I can't tell the church people, it is going to be up to Nandi when she is big, who she wants to tell, or who she wants not to tell. - *39 year old foster mother*

Two men who are cross population group foster fathers explain their experiences:

Respondent 1: I'm still finding that even your upper class white community still don't understand. They still don't understand it.

Respondent 2: The ignorance is the biggest problem we've got. - *40 and 44 year old foster fathers*

Many of the foster carers described their disbelief that people who they believe should be educated about HIV, still appear to be so ignorant, as evidenced by the following quote:

... In my road, there is teachers staying, there is policemen staying, and I always, I don't know, but I always thought that they is the people that will actually know what it is and really accept... But then its the people that is not even educated that accept Tom. And they (the educated) are the people that should know better. - *58 year old foster mother*

This sentiment was echoed by another foster mother:

You know, we've lost a lot of friends that used to come here. I know one couple definitely because I asked outright... 'is it him? Because if it is, he's not going anywhere.' And the wife and the 2 little kids never even answered me, they just avoided me... it is more a case of fear than nasty people. - *48 year old foster mother*

Of the six cross population group foster placements, only one set of the respondents reported experiencing stigma based on their ethnicity being different to that of their child, as evidenced through the following interaction:

Respondent 1: Strangely enough the stigma we are getting is predominantly from the older Afrikaans women.

Interviewer: Oh really?

Respondent 2: And I have found it with African men. Twice I was in Pick n Pay and she was asking for stuff and I kept

saying no, no, no and eventually I stopped the trolley and said 'would you stop asking me for stuff because really, it's not going to happen. You've got all the stuff you're asking for at home.' And this black family stopped and the man said to me 'how dare you speak to her in that way, you don't deserve this child.' And I just turned to him and I said 'mind your own business' and he said 'she is my business, she's from my culture'. – *40 and 44 year old foster fathers*

As these quotes suggest, it became clear through the course of the interviews that stigma is wide spread and not limited to the uneducated.

### *Foster carers own mental and physical health*

A number of the foster carers reported struggles with their own health, which adds considerably to the load that they carry, as evidenced by the following two quotes:

I'm like a doctor in my own house. I have to sort out my husband, he has epilepsy, I have to take my medication for high blood, and I've got arthritis. I'm my husband's doctor, I'm my own doctor, I'm the kids' doctor. – *43 year old foster mother*

I got also diabetic...and I don't want to upset me or anything like that, otherwise I going to get a stroke and die. Where are they going then? I just take it cool. – *52 year old foster mother*

One foster carer chose to forgo her own medical treatment to take her foster child to appointments, as explained in this quote:

My grandmother used to, when it's Annie's appointment, maybe it's her (the grandmother's) appointment at the club for hypertension on the same day as Annie's appointment. Then she had to sacrifice for her treatment and come here for Annie. – *21 year old female extended family member*

A number of the older foster carers, particularly grandparents who are caring for their grandchildren, reported an added burden of dealing with their child's death and the reality that for many of them, at least one of their other children is also positive. This is evidenced through the following quote:

So there at home, I have nobody there, only my granddaughter...my daughter, my other daughter, she also got HIV. (breaks down and cries) – *56 year old grandmother*

It was clear that the older foster carers in particular found the stress of their own medical conditions and the emotional stress of looking after their foster child to be quite overwhelming at times.

#### *Managing child's medication*

The majority of the foster carers expressed a desire for their child to take responsibility for their own medication and many had made attempts to put systems in place to help their children to remember to take their tablets. One such attempt is described in the following quote:

My daughter, she did buy her a cell phone, but by the time the house burnt, then it burnt. But then she did have another one, lost. So now she don't have it. Because we did have it so that at 6 o'clock, the alarm can go and she must know to take her pills. – *52 year old foster aunt*

In most instances where foster carers had attempted to give their foster children responsibility for their medication (with age appropriate children), they had not been successful.

The majority of the foster carers reported that if they did not take charge of their child's medication, it would often be forgotten. This was evidenced through the following quote:

She is growing and getting a bit cheeky. Joh! She say 'ma, I'm going to eat the tablets, I'm going to eat the tablets', but she doesn't. And I say 'no, you mustn't do this, you saw your mother, she was so sick because she didn't drink the tablet, she did throw the tablet behind the bed. So you must drink your tablet.' Then she say 'ok ma, yes' and she drink the tablet. – *56 year old grandmother*

The sentiment was echoed by a 21 year old extended foster family member:

She was taking her medication but she didn't like it and we had to beg her, you know, you have to understand, this is the rest of your life, don't choose to dodge it. When time for treatment, she refuse it all. And we thought she had a psychological problem, because she got so cheeky when it came to treatment and we have to beg and shout 'take your tablets' and if she doesn't want, she doesn't want.

It seemed that for many of the foster carers the struggle lay with the fact that they understood the importance of their foster children receiving their medication on time, and felt a responsibility to ensure that the medication was taken, despite their desire for their foster children to take responsibility for it themselves.

### *Child's emotional pain*

In most of the circumstances it was clear that the child had been through significant emotional trauma. For many this involved the loss of a parent and many had been moved through children's homes or foster homes until eventually reaching the family where they are now.

Many of the foster carers felt a responsibility to help the children to deal with their pain, as evidenced in the quote below from a foster mother who took in three siblings, one of whom is HIV positive:

There was that time, especially for the bigger one, because she was the one who saw everything because the mother by that time was sick. She was the only one who was taking care of the mother and all that stuff. The only child that was not right is that big one. But because I talk, talk, talk with her, bit by bit, she became right, right, right. - *39 year old foster mother*

In one circumstance the teenage foster child had experienced the loss of her mother, and shortly after moving in with her grandmother, their house burnt down, killing her six year old brother. The foster carer was then dealing with her own grief about these circumstances and also trying to manage her granddaughter's grief. This was a huge burden for her, as expressed in the following quote:



We worry about her so much, she has gone through such a lot...and you know what, Nono doesn't talk. If I can tell you, she doesn't talk...so you know what, last time she got also shingles, so it shows that she is not coping. -52 year old foster aunt

Due to multiple failures on the part of social services, one of the respondents reported that she was told that she was not eligible to foster her child (due to the fact that she is foreign) after the child had already been living with the family for two years. The resultant uncertainty that this evoked in the foster child had a devastating effect on the child and the family, ultimately leading to the breakdown of the placement.

She freaked out one night and just tore apart her bedroom, throwing things and was sitting there with scissors in her hand looking at me...she was totally out of it, totally out of herself, and was just sitting there, with just like this look...She just sort of became angrier and angrier and just total lack of respect for us, not willing to engage... Kept herself isolated from the family and kind of would only join in when she felt like it and you know any kind of discipline or rewards or punishments didn't really have much of an effect. - 55 year old foster mother

One of the other respondents reported on the trauma that her foster child endured after being placed with the family. After having lost her own parents and then having lived in residential care for a number of years, the foster child was placed with this family and developed a very close bond with her foster mother. The foster mother then passed away too, in the presence of the child and the child had to move in with the foster mother's adult daughter.

And you know what was so bad about that, the worst thing. She died in front of Annie. That was so bad. We couldn't even talk to Annie for a week and we could see that there is a problem, that she is so scared. She hides every time behind the door. I took her here (Groote Schuur) so they counselled her but she didn't want to talk, she just cried...the first few months (after) she passed away, it was very difficult. We couldn't even know what to do. But she said you must not take Annie back to the organisation, she has to stay here. If she (grandmother) die, we must take Annie to my aunty in Mfuleni. We thought it

would be difficult, and it was difficult because we never know what to do, but then we decided as a family that really, she has to move to Mfuleni. Because there is no one here. My mum goes to work, my sisters go to school, I also go to school. – *21 year old female extended foster family member*

Five of the foster carers interviewed had taken on siblings and in each of these instances, only one of the siblings was positive. Each of them reported the strain that this had placed on the positive sibling at various times in their developing understanding of their HIV status, as evidenced in the following quote:

Interviewer: How does she cope with being the only positive one out of her siblings?

Respondent: It's like she is no different. It's not a big thing to us. It's like she's got um, flu, and stuff like that. We all involving her, go and have your tablets and all that stuff. The time is 7 o'clock now, go and have your tablets.

Interviewer: Ok, and she doesn't have a problem with taking her tablets?

Respondent: No. But there was a time when she did give me a hard time. 'No mom, I don't want to eat my tablets. It's like it's only me who is sick in this house and all that stuff. I'm sick and tired of the tablets.' - *39 year old foster mother*

It would seem that if too many family members are involved in the process of encouraging the HIV positive child to take their medication, it can serve to further highlight the difference between that child and the rest of the family, and thereby potentially serve as a hindrance, rather than an encouragement.

### **The support needs and mechanisms for foster carers of HIV positive children**

It was clear through the interviews that many of the foster carers do not feel well supported in their role in looking after their foster children. Family support, organisational support, and a belief in God all emerged as important support mechanisms for the foster carers involved in the study. It emerged that community support (support from neighbours and friends) and support from the foster carers' religious groups was lacking almost across

the board. Financial support, emotional support and training emerged as areas in which the foster carers felt the need for additional support.

### *Family*

It was very clear almost across the board that support outside of the immediate family is hard to come by for foster carers of HIV positive children. Some of the foster carers reported that their family members were initially hesitant when they took on their foster child, but all reported 100% support from their immediate family after the fostering had taken place. Levels of support from extended family networks varied across the families represented.

An interesting observation is that out of the 17 interviews that were conducted, 16 were with women, of whom 10 were single parents. Those who were married reported their spouse as being their biggest supporter, as evidenced through the following quote:

We do everything half half. We don't give half each, we give 100% each, which helps. – *44 year old foster father*

Those who were single parents reported needing to rely more on extended family networks:

Interviewer: And you say your family has been supportive?

Respondent: Very supportive...from the beginning, right from the beginning. For me, it's just me, my sisters and my brothers, that's all. So we is, we are a very close family. – *58 year old foster mother*

Support from older biological children was also key:

My kids are fully with him and they tell everyone that he's their little brother and my son will tell Lolo, his little daughter, that he is her uncle Mark...All the support is in this house. – *48 year old foster mother*

In many of the families, it seemed that family members would each take on different aspects of the child's care. One would be the primary care giver at home, one would see to it

that the child gets to their appointments, one will see to it that the child gets to school. This arrangement of mutual involvement seems to work well in these families.

So I'm the one now who took her for the medication, because if I leave the cards at the house, my sister sometimes don't want to accompany her. So then I took the cards to stay with me so I can always look the dates so I can bring her. – *52 year old foster aunt*

The role of extended family members in providing additional parental role models for the children was also important, as evidenced in the following quote:

We talk about him (the child's biological father) and he said 'he's not my daddy.' My one daughter's husband, she takes him as her daddy, because she was very small when she came to live with us. – *68 year old grandmother*

Family support was clearly the most readily available form of support available to the participants in the study.

#### *Community support*

The majority of the foster carers reported feeling quite isolated from the rest of their community and did not feel that the community was supportive, as evidenced through the following quote:

It's too hard. Because you know, the other Gogos, they don't know about this. Other Gogos don't know about this. Now that's why it is too hard for us to manage. – *56 year old grandmother*

In many instances, the family had not disclosed the child's status for fear of stigma or gossip from the community, as evidenced by the following quote:

If I've got a bad day, I'm staying with my bad day in my house...because you tell the neighbour that you've got a bad day, you thought maybe he can help you to sort your problem, but at the end of the day, you going to hear from the community gossiping about your things. – *39 year old foster mother*

A 52 year old foster mother felt that the community were unsupportive due to fear and ignorance:

I think they are afraid. They think it's a germ, like a thing like a magnet, it won't get off you. And they see it every day there by us. There's also classes (in the community)... you can come and learn about this and that, but they are not supportive.

In one instance where the foster carer did disclose to a neighbour, she ended up being very hurt:

... So I took one of my neighbours into my confidence about Tom's status and then she went and told everybody... At that time, Tom was around nine or 10. She told everybody. I said, I always thought that some of the people around here were very much educated, but they, it's almost like they didn't want to let Tom play with their children anymore. And they kept their children away from Tom and that made him like he just stayed inside, he didn't go out and play with the children. – 58 year old foster mother

The discussion around community support served to highlight the isolating effect that stigma and fear can, and often does, have on foster carers. While not explicitly stated, it seemed that many of the foster carers felt a strong need for community support but felt that desiring this kind of support was futile, due to the challenges that disclosure presented to them.

### *Organisations*

Of the 18 foster carers interviewed, ten had foster children who initially came from a children's home. The majority of these foster carers mentioned feeling that the organisation where their child had been prior to being placed in their care had been helpful and a good support to them, at least initially.

...that organisation is a very big support. They don't lose touch with us. Whereas it will take months for you to come again, but we feel that if we've got something that we're struggling with, we know where to come... – 26 year old extended family member

The majority of the foster carers mentioned that they would like additional organisational support, and many said that they know there are organisations out there that can help, but most hadn't taken the time to look into accessing the support that the relevant organisations might offer.

I think that I felt that I could cope on my own... I'm very much a loner and happy to be just on my own, um, I thought that I could cope without all of that. And yes, there is support out there, there are groups out there. There are support groups and offerings...but I thought that I could cope on my own, and it just showed that I couldn't. So that's why I ended up sick in hospital and that sort of thing. But yes, there is help out there if you need it. If you ask, there is. I just didn't ask. – *57 year old foster mother*

It would appear that many of the foster carers would benefit from a database of information about the support services available to them, as many were aware of resources available to them, but weren't sure how or where to access them.

#### *Religious groups*

Ten of the 18 respondents reported belonging to a religious group and the majority of them felt that they had been well supported by their religious leader or the staff, but not necessarily by the rest of their religious community.

The people, no. Because I don't think they feel the pain that we have to go through. All the things that we have to go through. – *43 year old foster mother*

#### *God/A higher power*

Many of the foster carers alluded to relying on God/a higher power to get them through the difficult days. Many reported a sense of calling to being a foster parent and spoke about drawing strength from God for the task at hand. One respondent became very

overwhelmed during the course of the interview and stopped to spend time in prayer, which seemed to strengthen her to continue with her story.

This reliance on God is explained in the following two quotes:

...because I know it is hard to look after our small babies, because we are grandmamma. It is hard because we don't know what...but we must get strong, we must get power from God in this time. This time is not nice, it is so bad. You must trust God also to help you. –*56 year old grandmother*

He gives me big, big strength, more than anybody who can talk to me. – *39 year old foster mother*

When asked what kept them going through the tough times, one of the respondents responded as follows:

Ja, just a conviction that you know, this was something that God wanted us to do and a commitment to um love her and do what was best for her. – *55 year old foster mother*

The belief in a greater power that would sustain them through their difficult times and the conviction that God had chosen them for the task at hand were clearly very important protective factors for many of the foster carers.

#### *Desired support*

When questioned about what kind of support they would like to receive, or receive more of, the responses mainly fell into 3 categories, namely, financial support, emotional support and training.

#### - *Financial support*

The majority of the respondents reported that while the grant is helpful, they feel that it should be more than it is, due to the many needs that they encounter in caring for their foster children.

Yes, it's not enough. Because I must buy something for school, and the winter things, and then the hospital also call me and tell me I must pay the money... – *56 year old grandmother*

They can give a little bit more than they giving now... If I buy everyday 3 breads and that money is gone! And where's the things you must put on the bread? Where is the plate of food? Where is the juices? - *52 year old foster mother*

One of the foster carers expressed disappointment that the foster care grant doesn't take into consideration those children that want to continue studying after school as it ends when the child turns 18.

The only thing that I was very disappointed... coz I got the foster care grants, and then when Laura went to college, I asked if there is no way that, because I'm alone, is there no way that they can maybe extend it. So they said no. They don't give the foster care grants to tertiary education. – *58 year old foster mother*

A number of the respondents also mentioned that they would like it if social services or the hospital were able to help them materially with clothes and food for the children.

I wish if you can, the social workers here, can give us some of the groceries you see. Because you see my mother is working there at home, and all the people there belong to her, she is the grandmother. You see, so I wish they can give her something to eat, you see. – *52 year old foster aunt*

So I can't buy everything – the clothes, the food, in order for them to be able to eat healthy, I wish it can help to have maybe sometimes when it's cold, some more clothes. Stuff like that, and with their education as well. – *39 year old foster mother*

- *Emotional support*

A number of the respondents reported a need for more emotional support than they currently have, with many suggesting that a support group that could offer on-going support would be a good vehicle for the emotional support that they desire, as evidenced in the three quotes below:



Um, if we can get a counsellor in our area, I won't mind... We have to stand together, we have to work together. If your child is sick, maybe I can help you. You don't know that work, maybe I do. Just to stand with each other. – *43 year old foster mother*

It's the on-going support, more than a course. Because once you've done a course, it's very seldom that what you've been taught is going to fit with that child. – *57 year old foster mother*

I can like to have a support group. As I said before, as the kids grow up, I don't know what things are coming for the future, so if everything comes, I must be stronger for them. - *39 year old foster mother*

Many of the respondents reported struggling to understand their foster child at one time or another and felt that they would benefit from being able to talk to someone who could possibly help them to understand and having someone that their child could talk to.

It's so difficult. My granddaughter will tell me 'oh mamy, you don't like me'. I think (I need) somebody to help me to know about her. – *56 year old grandmother*

Tanya had a very traumatic early childhood...they think she had been abused and neglected in her first 3 years of life. Besides then living in a group home for children for 9 years, um a lot of emotional needs, um counseling. But I think not the normal kind of sit and talk counseling, I think like the play therapy setting would have been better, but start that very early and just get them used to the idea of you know, what HIV is. – *55 year old foster mother*

Some of the respondents alluded to the fact that just being able to talk about their circumstances through the interview process had helped to lighten their load.

I feel so light after talking about it. It was nice to talk to you.  
– *43 year old foster carer*

#### - *Training*

All of the respondents reported that they would have felt better equipped to care for their foster children if there had been some sort of training course or material offered to them when they took on their children. Only the Xhosa speaking foster carers who had received

their children from one organisation reported having received any form of training and those interviewed felt that it was very helpful. The rest of the foster carers had not received any information on living with HIV or on the adjustment that they and the child would go through when the child joined the family, and as the following quotes show, many feel this needs addressing:

I think what would be helpful is if the government did have, um, someone to help people to deal with issues that are going to come up from the child's perspective... You know, what do you tell the child about fostering/adoption? When do you tell the child? – *40 year old foster father*

One foster mother sourced her own training when issues emerged with her foster child and felt that she would have been more prepared if she had received the information in advance:

After Tanya came to us I took a counseling course... you know, after pulling our hair out we talked to her (the counsellor) and she would give us some things to read. And I thought 'oh well, if I'd known this ahead of time it would have been easier.' You know, the honeymoon phase and then testing out lasts this long... –*55 year old foster mother*

While many felt that each child is different, so they would have never been completely prepared, they all felt that some kind of material to prepare them would have been helpful.

### **Foster carer's perceptions of their role in the care of their HIV positive child.**

Many of the foster carers seemed confused as to why this question was even being asked and all felt that there was absolutely no question that their foster child was 'their' child and that they were the parent. Many described their roles as being multidimensional and reported needing to be sensitive to their child before deciding which role to fulfil in the moment, as evidenced in the following two quotes:

My role is to be a mother, it's to be a father, it's to be a mentor...so I turn, you know? – *60 year old foster mother*

To be a mother. To love her, and just all that that entails. You know, making sure she has good health care, and eats well, and sleeps right and education, and um, and ja, just training, people skills, and just things I do with all my kids. – *55 year old foster mother*

A number of recurring themes emerged, namely the conviction that the child is 'their' child, to provide love and a sense of belonging, discipline and boundaries, medical support and education.

*A conviction that this child is 'their' child*

While this is not a role per se, many of the foster carers reported experiencing a moment where they just knew that this was their child, regardless of the fact that they had not given birth to the child. This seemed to undergird the way in which they saw their role in their foster child's life and for that reason is included in these findings. This sense of connection is evident through the following quote:

Respondent: He's not my relative, he's nothing but I don't know, I can't even explain how it is, but when he call me 'mummy, mummy' and I say to myself, 'you are mine, you are mine.' – *43 year old foster mother*

A 56 year old foster mother had a similar experience:

It is better with him in our family. It's my family. I feel like he is my child. I feel like he is MY child. I'm not feeling like he is not mine, no. Also my children, also my children. Even them. They touch him, they play with him, they love him.

A foster father's sense of connection to his foster daughter was explained as follows:

...because I mean we didn't, neither of us carried her, you know, so people also tend to, in fact yesterday, somebody asked us about 'do you think you love her as much as you would if you'd given birth to her' and I'm like 'I think I do.' Because at the end of the day she is very much a part of us. – *40 year old foster father*

This conviction that the child was ‘theirs’ is what seemed to help many of the foster carers to get through the difficult days that inevitably come up from time to time.

*To provide love and a sense of belonging*

All of the foster carers mentioned providing love as their first and foremost role in caring for their foster child. Across the board in the interviews it was clear that it was also very important to the foster carers that the child feel like they are part of the family, and not an outsider. Many of the foster carers reported going out of their way to make sure that their foster children are included and feel like one of the family.

A 55 year old foster mother described her role as follows:

I think um, consistent, loving care. I think the consistency of structure and a safe place for them, you know there is obviously the physical needs that they have, medical care and nutrition, all that but ja, the whole emotional thing and nurturing.

This desire to love the foster child and create a sense of belonging was an intentional decision for a 21 year old extended foster family member:

Now that she is HIV positive, and we’ve known now for 3 years, I told myself to love her as I loved her before. It had nothing to do with her status. My love for her never changed. Though I was scared what might happen, you know you hear rumours that if you sit next to someone like her, if you stayed next to someone who is positive, you can get the virus. But then I tell myself enough man, this is my sister. I’m going to love her the same way I did before I discovered that she was HIV positive...the same applies to the whole family.

Another foster carer described the shift in her role when her foster children’s biological mother passed away:

You know, um, I don’t know, maybe I’ve got two roles. Because in the past when his mother was still alive...I didn’t want to be called Mommy because I thought there was going to be friction...But now the role is different, you see. So now I

am more of a mother, because they call me mother, they take me as their mother, because I had to struggle, if I introduce them. My family know about Tom's status so when I introduce them to other people and I would say in the beginning, this is my foster child, I could see the looks on their faces, disappointment. So it's almost like they say 'why don't you take me for your child, my son or my daughter.' So I changed that also, so now I'm not saying this is my foster child, I'm saying this is my son, this is my daughter.' – *58 year old foster mother*

A 39 year old foster mother explains the importance of creating a sense of belonging for her foster children as follows:

I knew the way they grew up with their mommy, sometimes they sleep without food. So that's why I don't want, even my family, if they said, whose child is this? Uh ah (shakes head), I get upset about that because they can't ask my child whose child is this one. I'm telling them, these are my children...Because in everything that I do with them, I want them to feel at home. Even I don't want people to call me the foster mom. I don't like it. I am the mom.

The enthusiasm that the foster carers displayed as they spoke about their love and desire to protect their foster children almost spoke louder than the words expressed. Unfortunately it seemed that in some instances this meant that the foster carer was actively trying to shield their child from the realities of HIV.

#### *Discipline and boundaries*

Discipline and boundaries were seen to be important across the board in the interviews, but it seemed that for some foster carers this was a non-negotiable, while others seemed to really struggle to implement the appropriate boundaries for their children and teens.

What I've experienced out there is that the average person seems to think that they need to be their child's friend. And as nice as that sounds, you're not doing the child any favours. The child needs to know boundaries and the 2 things that we are very strict about is manners and boundaries. – *44 year old foster father*

And um, ja, but just um, trying to be consistent with setting boundaries. And what is not an acceptable way to act or talk to people and consequences. You know, if you get to be an adult, consequences get bigger and you can lose jobs and you can get arrested. – *55 year old foster mother*

#### *Medical support for their foster child*

Helping the child with their medication and keeping track of their general health was part of their role that the foster carers all found very important, as evidenced by the following quote:

They need your supervision all the time. Health wise, they need you to take good care of what they eat and each and every time make sure you see them taking their tablets. And you always have your own medication for them. Look, for instance, it was winter, you know, they keep you very scared, each and every time, you are always scared. When they cough, you always have that 'mmmm, she can't cough for the whole week!' You know? I've got to take her to the doctor, I've got to...The HIV children, you are always having fear. You need to take very good care (of them). – *60 year old foster mother*

For some, this was something that they just took in their stride, but for others, it proved to be quite stressful.

#### *Education*

The majority of the respondents saw the need to prioritise education as being an important part of their role, both the education of their child, and the education of others about HIV.

For many, this involved educating the child about their history and about living with HIV, as explained in the following two quotes:

To foster a child, it need a truth at certain stages. Sit down and tell the child where do you come from. Who I am. You know? That's not an easy one. I found that one very challenging. – *60 year old foster mother*

So the mother came...then we took a few pictures so now I've got her photo's here. So I always show him, since he came to me... So he said no, this is not my mommy, you my mommy. But then I told him...your mommy is in heaven but this is your mommy. And still today I've got an album, that I've got um, all his pictures of him, and all his um, photos... of both of them and the photo of their mother. – *58 year old foster mother*

One 56 year old foster mother explained her foster child's progression from feeling alone in the world to being part of the family in the following quote:

The other day I take Lutho, my daughter was saying, 'Lutho...you must draw your family. Lutho, he was only draw Lutho, only. So my daughter ask Lutho, 'why you draw one person? You got no family, why?' And he did say, 'why I draw that is because there is only me.' My daughter, she say 'no, today, you must know that you've got a family. Your mother, she was dying, because she didn't eat the tablets, the treatment, she didn't take the treatment, so that's why she was dying. And that's why you've got the HIV. And you mustn't be angry now. Now you've got a family, my mother, my brothers and me, it's your family. And my father, it is your father.' So the other day she say 'Lutho, you must take a paper and draw your family' and Lutho did draw all of the family.

For those foster carers who are open about their child's status, the focus was also on educating others and a number of the foster carers felt very strongly that they had a responsibility to educate those around them about HIV, in an effort to manage the stigma and fear that many of them encountered. Those who had not disclosed did not see education of others as part of their role.

I think we need to educate people around changes in HIV, we need to tell them that this has happened, that has happened. But I also think that, and this is something that I feel strongly about, that we must stop isolating HIV as a condition and treating it differently. We need to, at schools, have a sort of 'chronic conditions' policy, rather than an HIV policy. – *51 year old foster mother*

One of the respondents felt that a very important part of their role was to introduce the child to their extended family and their ancestors:

They call all the family to introduce her. So they slaughtered a sheep, introducing her to the ancestors, that this is our new child and that we got her like this, and this, and this. They explained everything. So that she can be welcomed by the family and not rejected. Like, we believe that if someone is not recognised by the family, bad luck will come and all that stuff. So she was introduced in that way. – *21 year old extended foster family member*

### **Experiences of access and utilization of health, social and educational services available to HIV positive children.**

The experiences of foster carers varied quite significantly in terms of their access to and utilization of health, social and educational services.

#### *Health*

A number of different aspects of the health services available to the foster children were discussed during the interviews. These included hospital visits and additional support from allied health professionals.

#### *- Hospital visits.*

Due to the fact that all of the foster children related to this study are on anti-retroviral treatment, very few of them have experienced extended hospital stays since being on the medication. The foster carers' experiences of the hospital services were therefore mainly limited to check-ups and referrals.

The respondents who go to the clinic at Groote Schuur all reported being very happy with the services that they receive there, as evidenced in the following quote:

You know, in my experience, the hospital has been amazing. Um, they really have been incredibly helpful. Their door is always open. – *44 year old foster father, IDI participant*



This was particularly true for those who had previously attended day clinics in their various areas of residence

The hospital, um, it's fine...coming here, it was more easier for me than going to the day hospital in the town centre because of the set up there. I don't know they say it's not like that anymore, but we used to sit under a tent outside and whether it was raining or what, now you've got this child who is healthy, you bring that child to hospital, now tonight you struggle with that child. So I said no. So when they asked me, when he turned 12, then they asked me if he wanted to come over here, I jumped at the opportunity, because the set up there was not so nice. But here, it's quite ok. – *58 year old foster mother*

One of the respondents who attended a day clinic reported on the challenge of attending appointments.

Sho. To wake up early in the morning, go to the day hospital in Crossroads, stay there the whole day. From the doctor, finish at the doctor, go to get medication. You can take a taxi and go to Claremont and come back again in the same amount of time I'm telling you. And you take a taxi again, go to Belville and come back again. – *60 year old foster mother*

Another respondent reported that while the hospital is very helpful, they are still not able to access the medical support that their foster child needs due to the fact that they cannot afford the operation that she requires.

So they say we must get those ear things, but we don't have the money because they say it costs R1000, more than R1000. – *52 year old aunt*

All except for one of the respondents who have teenage foster children reported that their teens attend the support groups offered by Kidzpositive when the teens come for their appointments and reported that they saw these groups as being an effective form of support for their teens.

- *Additional support from allied health professionals*

Those foster carers that had made use of allied health professionals through the hospital system reported that they were, for the most part, very helpful. A challenge is that it can take time to get appointments with psychiatrists and psychologists, and if the child is already in a tough space, having to wait to see the necessary professionals can add to the stress of the situation, as evidenced in the following quote:

It took like 6 months on a prioritised waiting list to see a psychiatrist and then that psychiatrist wasn't very helpful. He said 'no, I'm coming to the end of my rotation, she should see someone else who is starting their rotation.' So then there was a waiting period to see that person and he just said that you know, 'I've never seen an angrier child, you have your hands full.' - *55 year old foster mother*

Two of the respondents reported having received very good care from psychologists and psychiatrists that they had been referred to by their foster children's doctors, for their own emotional well-being and to process their concerns and experiences with their foster children. This is evidenced in the following quote:

Robbie's psychiatrist sent me to the clinic where I go and get my medication to see a counsellor and then a psychiatrist and then a psychologist because you know, I've been helping everybody and I wasn't getting any help. Ja, so now I'm in a bit of therapy and that has helped me and it came at a good time. - *57 year old foster mother*

*Social services*

Questions around the foster carers' experiences of social services generally evoked sighs and head shakes from the majority of the foster carers. A number of aspects of social services service provision emerged as issues through the interviews, namely, access to and visits from social workers, paperwork, the turnover of social services staff, the foster care order and the foster care grant

- *Access to and visits from social workers*

Only five of the 18 foster carers interviewed reported that they had been visited by social services. Of those that had been visited, three reported that they found the social workers helpful, as evidenced in the quotes below:

The social worker from that organisation was really good, very helpful, and you know, kept phoning, and came around... - 55 year old foster mother

You know, every time that I had trouble with them, I could phone them. Even if it was in the middle of the night. They were always there for me. – 58 year old foster mother

The majority of the respondents interviewed expressed grave concern at the lack of resources, interest and involvement demonstrated by social services.

The load is too much and the workers, they are few. So on that case, it gives me to be more responsible and not have higher expectation from them, just because they carry a huge load, you know? - 60 year old foster mother

A 51 year old foster mother explained her concern about the broader issues:

I've never seen a social worker which suits me down to the ground but it's also indicative of a much bigger problem. I've never ever, ever had a visit... I mean I could have sold these kids off in body parts and nobody would have known and they still wouldn't know...I find social development, and as I say, I will say it on record, very ineffectual. I'm not surprised that we have the kind of social problems that we have. I think social workers, particularly government ones, are clock watchers. And I'm not saying that's necessarily wrong, but you've got to show some level of commitment and sometimes you've got to put in a bit more.

This concern was echoed by a 44 year old foster father:

They don't have the transport to get to court, let alone house visits, and then the social worker we were dealing with...had stacks and I'm talking about a meter high pile of files that she was going through. That's why it takes them so long. And they can't find the files because they are so disorganised...How the hell are you going to do home visits? They are over worked, under paid and horribly understaffed.

A 57 year old foster mother expressed concern about the lack of availability of her social worker:

I think um, I just find it difficult getting stuff done with the social worker because they are so inundated with files...I think that there should be more access, there should be more support from the social workers, with their foster children...I think that because everything is going fine, then something goes wrong, then you try to get hold of them and it's not easy because they are very busy. So I basically think there should be more social workers. Because they just can't get to do everything that needs to be done. And sometimes it's an emergency, you know, and you just can't either get hold of them, or they're on calls, or they're out on visits... There should be less children per social worker, that's how it should be.

A common frustration amongst the majority of the respondents was that if anything needed to be done related to social services, they had to drive the process, mostly figuratively, but sometimes even literally.

So when it came to putting all the wheels in motion, we did all that. So that speeded up the process a lot. I mean I drove to bloody Mitchells Plain to go and drop papers off with the sheriff so he could take them to the mother and then I had to go and fetch them again...we drove the process...We drove the social worker. What was lucky about the government social worker was that it was her first experience. She hadn't done this before so we basically told her what to do and drove her. – *44 year old foster father*

I actually went to Elsie's River with them to go and do the paperwork and I went to fetch the paperwork. That is what actually had to happen. – *51 year old foster mother*

Another common frustration for those who had involvement with social services was the lack of respect for the foster carers time, especially when it came to court appearances.

They tell you they're going on Monday, and they actually go the following Monday...I mean, even the day she said she was going to court, we got to court at 9 o'clock in the morning and she arrived at 5 to 1. – *40 year old foster father*

A 48 year old foster mother was particularly upset about her experience with her social worker on their court date, as the following quote explains:

Then I got a call that I must come to the court the next day and I must be there at 7.45... I get there and at 8.05 my daughter phoned me to say that the social worker had phoned to see if I was there, or where I was. So I said but she told me to be at the children's court so I'm sitting here outside. I didn't feel safe, there were very unsavoury people sitting there. The court wasn't open yet. So I said to her, phone her back and find out what is going on. So when she phoned her back she said 'oh, ok, no I didn't know she was going, so I'll go now.' So then she was leaving Belville. So I phoned back to the office and they said she had left so I said 'you know what? What's wrong with you people? You tell me to be here at 7.45 and where is she?' Anyway, she rocked up at about 9. No apology. She walked past me... I was the first person there and the last person seen. She went in and sat down and there was no place for me to sit...She's having a long conversation on her phone and smsing and I hear the clerk saying to her 'do you have a parent to see the judge today?' she said yes. 'Then you must wake up and sort out your file otherwise how does the judge know that you're waiting to see her?'

It was clear that this apparent disrespect was an issue that many of the foster carers felt very strongly about.

- *Paper work*

The majority of the foster carers reported having problems with finding the correct paperwork that they needed for accessing the grants and those affected put this down to social services inefficient and ineffective system of keeping and transferring paperwork, as evidenced by the following quotes:

Christy's social worker was at Mitchell's Plain and then they change him to Elsies and then from Elsies he go to Goodwood but I don't know why he's travelling with all the information. I thought he's supposed to leave everything. – *60 year old foster mother*

...So when I started phoning them from September, I left message after message after message and one day she phoned me and apologised and said that she can't locate his file. And this carried on. Then we got to the beginning of November and I asked to speak to someone in charge who told me that they don't have his file, those cases had all gone to another organisation. So I said 'ok, that's wonderful, when were you going to tell us that?' ...If I wasn't phoning, I wouldn't know

that this child had moved from one organisation to another and they haven't phoned me and his paperwork ends at the beginning of December. – *48 year old foster mother*

Two of the respondents made suggestions about how they felt the paperwork situation could be improved:

I think what they must do, as soon as the social worker transfers a child to the foster parent, as soon, must go to social services, the social worker and go straight to social services and put everything in the computer there and then. – *60 year old foster mother*

I do think that maybe there needs to be a computerised system where the child's history is put in and it says what has happened, the mother is known to be abc, etc. – *51 year old foster mother*

Many of the foster carers seemed to think that a central system would be the best way to streamline the services and reduce the amount of paperwork confusion that seems to exist within social services.

- *Turnover of social services staff*

The majority of the respondents who reported having had interactions with social workers reported that they rarely spoke to the same person twice. They perceived this as adding stress to their load as it often means retelling their story and having to build a relationship with the social worker from scratch every time you need to access their services.

Now every time you speak to a new social worker, you have to tell the whole story from the word go and that I find is a big frustration because they don't understand, and they shouldn't have to understand. – *51 year old foster mother*

One foster mother explained the social worker turnover she has experienced as follows:

Since the beginning of last year I've had one social worker, but when I say one social worker, I mean one office. We've had three social workers in that time, and last year for 8 months there was no social worker. So we're in Elsie's River,

with the office there, but we just got a new social worker finally a few months ago at the beginning of the year and hopefully she won't move soon. Because when they move then you have to start all over again. - *57 year old foster mother*

- *Foster care order*

The majority of the respondents reported that their foster children are still on 2 year foster care orders, despite many of them having lived with their foster family for most of their life. It was clear that the process of moving over to a permanent foster care order is not an easy one, and the respondents feel that this is mainly due to social services inefficiency.

I think my problem with foster care at the moment is a number of things. One, your foster care order is only valid for 2 years. ... It's due for renewal at the end of this year and I actually have to phone them to remind them that I have a foster care order. I need it for medical aid purposes, I need it for school purposes, I need it for legal purposes. We only discovered in 2012 which office I am a foster carer with. The children were with me from 2008. - *51 year old foster mother*

- *Foster care grant*

When it came to receiving the foster care grant it was clear across the board that the process of applying for the grant was burdensome and challenging. Of the three foster carers who aren't receiving the grant, two have applied but have not yet received the grant and have not been told why. They don't know whether they are missing paperwork or if their application is just stuck in the system. Through the course of applying many who now receive the grant and those that don't yet receive it, have repeatedly gone back and stood in queues only to be told that their application is in the pile and they just have to wait.

My grandmother, she had to wait in the line, and you know my grandmother, she is not well. She has got the arthritis problem. But she has given up. Because they don't update her, they don't tell her. They don't tell her you're not going to get it because of one, two, three...She did hand in everything! She did hand in everything. She will go and do it a dozen times. She did everything. But she didn't get it. - *26 year old extended family member*

Many reported struggling financially and feeling very alone in the waiting period between applying and receiving the grant. Two of the carers reported waiting three years to receive the grant, as one explains here:

I live with Christy three years and social services do nothing. The home they were from do nothing...so here I am, I am standing in the middle with these sick children, alone. – 60 year old foster mother

Those who have made it through the application process successfully, all reported being very happy with how the system works and none had experienced any problems with receiving the grant. The respondents all received their grants into their bank accounts or via the South African Social Security Agency (SASSA) card.

A 40 year old foster father explained his experience as follows:

Applying for the grant was hideous but once that was done, it was in my bank account every month on the same day and it was cool.

This was similar to the experience of a 57 year old foster mother:

Well, to get registered is a nightmare because you sit there sometimes for 3 days but once it's done, it's done and then this new transformation, which we went to on 15 January, I had to take all 4 foster kids there and we sat from 6 in the morning until 5.30 in the evening but we got our card and its working. It's the second month now that it's been paid on the right day. So yes, it's a long wait, but its working now.

In summary, it appears that the main need of foster carers related to their experience of social services is for more effective, efficient, respectful interactions with social services professionals.



### *Educational*

When discussing educational needs of their foster children, it became clear that schooling and additional educational support were two separate areas of concern for the foster carers.

#### *- Schooling*

The majority of the respondents had disclosed to at least one person at the school about their child's status. This was done predominantly after the child had already been accepted into the school. While acknowledging the shortage of special needs schools, the two respondents with special needs children felt that they had a much harder time getting their child into school as a result of their child's HIV status, which they both disclosed upfront, rather than as a result of their special needs.

I can't get him into a school...there is such a shortage of special needs schools that can cater for him...and its stressing me that I'm holding him back...I have everything at my fingertips and I can't find a facility. How must they (others who aren't as well off) access it? For many of the places there is a 2 year waiting list! – *48 year old foster mother*

About half of the children related to the study were not in age appropriate grades at school. The foster carers responses to this varied from family to family, with most not showing too much concern about the fact that the child was a few years older than his/her classmates. For some foster carers, this was however a grave concern, as highlighted by the following quotes:

She is in standard 3. Coz her mama, the time she was staying with me, she was just, 'I'm taking my kids and going out.' So she didn't go to school, that's why she is now in standard 3. Supposed to be in grade 6 I think. It's not good. - *56 year old grandmother*

He was only in grade 1 and he struggled a lot so I requested that he just be kept back because I didn't want him to struggle with reading. He was good in maths but his reading, he

struggled a bit with the reading. But then he was kept behind and after that, when he was in the middle of grade 1 for the second year and I saw him watching 7de Laan and he was reading that words, and I thought to myself 'no, you are ready now.' – *58 year old foster mother*

A 56 year old foster mother described her experience of trying to find appropriate schooling for her foster son:

Lutho, he must go to school, because the school was there in Mitchell's Plain, but he was not working nice there, and I was looking for a special school. I tell the school that they must find a school for Lutho because he is in grade 7, he is only staying there, he doesn't know anything. Every December he is coming with the report and the report is 1's and 2's. Yesterday I was happy, the school was calling me, they said, they have found a school for Lutho. Then tomorrow, he is going to start at another school, a special school in Khayelitsha.

- *Additional educational support*

The majority of the foster carers from the lower socio economic areas didn't seem to have much of an expectation that the school would provide any more support than classroom teaching. Those that felt that it was required felt quite passionate about it, as the following quote highlights:

I think they need an extra educational support just because what I experience, they don't, they are not the same. I want to make an example. I've got Siphos and Christy. Christy is ok...but Siphos is lower functioning. He is more in demand you know? And then at school the teacher is 1 with 50 something children, he doesn't have time for lower function children so it's painful to me. Just because he like to go to school, he is trying hard to learn, you know? But he can't help it, he can't cope. He can't cope. – *60 year old foster mother*

It is clear that for those who are concerned about their foster child's academic performance, the lack of additional educational support that they perceive to be available, especially in light of limited finances, presents a real struggle for them.

## CHAPTER FIVE: DISCUSSION AND CONCLUSION

The findings of this study show that foster carers face tremendous challenges and as a result, have significant needs, as they go about trying to care for their HIV positive foster children.

Some of these challenges include the initial adjustment period, dealing with the child's HIV positive status, interactions with biological parents, finances, dual diagnoses, stigma and fear, their own mental and physical health, managing their foster child's medication and dealing with their foster child's emotional pain.

The finding that the initial adjustment to a foster care placement presents challenge to foster carers is in agreement with the study by Simms, et al. (2000), who found that a myriad of adjustment issues should be expected from children entering foster care. In the researchers personal experience this was certainly the case, and it can take anywhere from months to years for these adjustment issues to be resolved.

The strain of finances, dual diagnoses, stigma and fear, their own mental and physical health, managing their foster child's medication and dealing with the foster child's emotional pain are consistent with findings from the research conducted by Thomas and Mabusela (1991), Kiggundu and Oldewage-Theron (2009), and Kuo and Operario (2010) who found similar challenges to those identified in this study, and who arranged these challenges into the categories of economic challenges, challenges related to children's needs and physical and mental health challenges.

In this study, many of the foster carers reported not having experienced stigma. This may be due to the fact that they are too afraid to disclose their foster child's status. This finding is consistent with a study conducted by Ogunmefun, et al. (2011), where foster carers were found to protect themselves and their foster child from stigma by choosing not to

disclose. Unfortunately, by choosing to not disclose, they are potentially protecting themselves from stigma, but also potentially jeopardising their ability to access support that might be available to them if their foster child's HIV positive status was known (particularly at an organisational and schooling level).

In terms of support for foster carers, the finding that family is the most accessible and utilised form of support available to foster carers is consistent with the studies conducted by Nixon (1997), Durand (2007) and Brown, et al. (2010), who also found that family support was the most frequently used form of support by foster carers.

The study found that support from the community was hard to come by linked to the research conducted by Durand (2007). The finding that religious communities were not seen to be supportive links to the study by Kiggundu and Oldewage-Theron (2009) but stands in contrast to studies by Simpson (2006) and Durand (2007) who found that churches in particular are often a significant form of support to foster carers and caregivers in general. It is possible that the foster carers' definitions of support, as well as their particular religious affiliations could have influenced the way in which they perceive the support, or lack thereof, that they receive from these communities.

The finding that organisational support was helpful to foster carers' links to findings by Durand (2007) who found that support for foster carers is more likely to come through organisations rather than on an informal basis.

The areas of greatest need identified by foster carers were financial support, emotional support and training. This is consistent with prior literature by Durand (2007) who found that when these needs are met, foster carers are better equipped to provide care for their foster children. The finding that the foster carers have a desire for a support group in which to discuss their concerns and challenges links to the study by Kiggundu and Oldewage-

Theron (2009) who found that such groups are the most effective form of support for foster carers.

This study found that the foster carers perceive their role as that of providing love and a sense of belonging, discipline and boundaries, providing medical support, educating the child about their history and about HIV and the education of others about HIV. The finding that providing love and a sense of belonging was key for foster carers links to findings of studies by Blythe et al. (2012), and Warde (2008) who also found that foster carers saw emotional engagement as being a very important part of their role. These findings differ however to other research that has been carried out in the rural context of South Africa (Kuo & Operario, 2010 and Hearle & Ruwanpura, 2009) where it was found that the day to day financial and material challenges as well as the challenging behaviour of foster children made it difficult for foster carers to prioritise or feel passionate about providing love for these children in their care. The study by Hearle and Ruwanpura (2009) found that foster carers found that it was virtually impossible to enforce any form of discipline or boundaries with their foster children and as a result, many had given up. This is in contrast to the findings of this study, where the foster carers were realistic about the challenges of enforcing discipline and boundaries, but most still seemed to prioritise it as an important part of their role. It seemed that this aspect of discipline was most difficult for grandmothers, who struggled with their own feelings about their grandchild's loss and status and as a result saw discipline as adding to the child's difficulties. Due to the small scope of literature specific to foster carers of HIV positive children, there did not appear to be any previous findings relating to the experience of providing medical support for their foster children or the role of educating others about HIV. The findings of this study will therefore add to the body of knowledge on the topic.

The finding that those who access government clinics face struggles of long queues and poor environmental conditions when trying to access medical services for their HIV positive children ties in with the findings of Yeap et al. (2010). However the finding that those who attend Groote Schuur are very happy with the care that they receive stands in contrast to those of Yeap et al. (2010). This discrepancy could be due to the fact that Groote Schuur is a tertiary hospital and is therefore better equipped than the government clinics.

This study found that the cost of medical care for their HIV positive foster children is too high for some of the foster carers, and that just the transport to the hospital hinders many from making their appointments. This finding links to the findings of the study by Yeap et al. (2010) and highlights the often expressed need for additional financial support in addition to that which is currently available to foster carers.

In terms of access to social services, this study found that for the most part, with only small exceptions, foster carers experienced social services as being ineffectual, understaffed and ill equipped to deal with their needs. They expressed a desire for more efficient and respectful interactions with social services professionals. There is a gap in the literature around foster carers' experiences of social services in the South African context, which highlights the importance of the findings of this study, as they will add to the body of knowledge about this topic.

With regards to the foster care grant, this study found that many foster carers initially struggled, or are still struggling with securing their foster care grant. This is consistent with the research by Hearle and Ruwanpura (2009) and Kiggundu and Oldewage-Theron (2009) who found that the paperwork required in order to apply for the grant, as well as the long waiting period after application is often a big challenge for foster carers.

The findings about foster carers' experiences of accessing education and educational support for their children showed that many of the foster children are functioning at an academic level that is lower than their peers, which links to the research of Blome (1997). Extra educational support was hard to come by for these children and there were mixed reactions from the foster carers as to whether the state of their foster child's education was cause for concern or not.

## **Conclusion**

It is clear that the experiences of foster carers of HIV positive children are dominated by challenges that are both extensive and multifaceted in nature. The needs of these foster carers, while also significant, are more specific and mainly focussed around additional financial and emotional support and training. One of the main things that stood out for the researcher as she conducted this research was the passion with which the foster carers approached the care of their foster children. Many of them were from extremely difficult backgrounds, facing multiple stressors, and yet despite their hardships, their eyes lit up when they spoke about their foster children. By providing the opportunity for the foster carers to talk about their experiences, it was clear that many felt better about their circumstances just because someone had taken the time to listen to what they were going through. This highlights the need for additional emotional support for foster carers and the importance of creating forums in which they can be given the opportunity to talk through their struggles and concerns and when appropriate, receive training. The old adage that a problem shared is a problem halved seemed to ring true for the foster carers. While it would be simplistic to believe that creating a space in which foster carers could talk would provide the answer for all the challenges that they face, the researcher feels that it would go a long way to equipping them to deal with the inevitable challenges that will and do arise. It is hoped that the Department of Social Development could gain insight from the findings of this study with

regards to foster carers' experiences of social services service delivery, as well as their need for further financial assistance as they care for their foster children.

In conclusion, this research study has sought to add to the literature on the needs and experiences of foster carers, specifically in the field of providing care for HIV positive children. Further research, in both rural and urban areas in South Africa and further afield is needed to develop a more comprehensive body of knowledge related to this topic, in order to appropriately inform service provision to, and understanding of this particular subgroup of foster carers. The researcher would suggest that further research with HIV positive foster children might help to create a broader picture of the experiences and needs of all the role players in these foster care relationships. Further research could also be carried out to investigate Social Services Practitioner's perspectives of foster care of HIV positive children. Research with organisations involved in service delivery to HIV positive children and their foster carers would also add to this body of knowledge. It would appear that policy isn't always consistent with regards to the role out of the Foster Care Grant and another interesting angle for further research to explore would be the differences between foster carer and kinship carer access to resources. It is recommended that policy makers in South Africa develop clearer policy around the issue of kinship care.



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University of Cape Town

## Appendix 1: Ethical approval letter from the Department of Health Sciences



UNIVERSITY OF CAPE TOWN

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Faculty of Health Sciences  
Faculty of Health Sciences Human Research Ethics Committee  
Room E52-24 Groote Schuur Hospital Old Main Building  
Observatory 7925  
Telephone [021] 406 6338 • Facsimile [021] 406 6411  
e-mail: [sumayah.ariiefdien@uct.ac.za](mailto:sumayah.ariiefdien@uct.ac.za)

26 November 2012

HREC REF: 622/2012

Mrs J Warwick  
c/o Dr J John-Langba  
Department of Social Development  
Leslie Social Science  
Level 4  
Upper Campus  
UCT

Dear Mrs Warwick

**PROJECT TITLE: AN EXPLORATIVE STUDY OF THE EXPERIENCES AND NEEDS OF FOSTER CARERS OF HIV POSITIVE CHILDREN IN THE WESTERN CAPE**

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee for review.

It is a pleasure to inform you that the Ethics Committee has formally approved the above mentioned study.

Approval is granted for one year till the 28 November 2013.

Please submit a progress form, using the standardised Annual Report Form, if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period:

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the HREC. REF in all your correspondence.

Yours sincerely

Signature removed

**PROFESSOR M BLOCKMAN**  
**CHAIRPERSON, HSF HUMAN ETHICS**

Federal Wide Assurance Number: FWA00001637.

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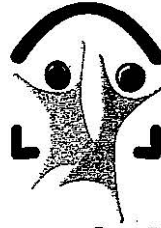


Institutional Review Board (IRB) number: IRB00001938

This serves to confirm that the University of Cape Town Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP) and Declaration of Helsinki guidelines.

The Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

**Appendix 2: Letter of approval to conduct research at Beautiful Gate**



**beautifulgate**

Together Bringing Hope to Children & Families

1 August 2012

Dear Mrs Jenni-Kate Warwick

**Re: proposed research study on the experiences and needs of foster carers of HIV positive children in the Western Cape.**

Thank you for your interest in our Child and Youth Care Centre/Children's Hospice. This letter serves as confirmation of our acceptance of your request to conduct your proposed research study at Beautiful Gate.

Your contact person will be Ms Karien Beukes. Please liaise with her to take the process forward.

Kind regards

Signature removed  
~~Vaughan Stannard~~  
Executive Director

Beautiful Gate South Africa | PO Box 144, Mitchells Plain, 7789, Cape Town, South Africa | 73 Stock Rd, Lower Crossroads, Philippi-East, 7785  
Charity Reg. No. 005-086NPO, VAT No. 4730166404, Public Benefits Organization No. 130002944

Tel. +21 (0)21 370 2500 | Fax. +27 (0)21 374 8237 | E-mail. support@beautifulgate.org | www.beautifulgate.org

Beautiful Gate SA seeks to care for & protect children, empower & preserve families & mobilize our community

**Appendix 3: Letter of approval to conduct research at Kidzpositive**

Jenni-Kate Warwick  
2 Tecoma Way  
Pinelands  
7405

jakes@pbc.org.za

12 November 2012

Dear Jenni-Kate

This letter serves as written consent for you to carry out your explorative study on the experiences and needs of foster carers of HIV positive children at the Kidzpositive units in the Western Cape.

Kind regards

Signature removed

Dr. Paul Roux

## Appendix 4: Interview Schedule

Age of respondent:

Sex of respondent:

Population group of respondent:

Age of foster child/ren:

Sex of foster child:

Population group of foster child:

Is the foster child a relative:                    YES                    NO

Length of placement:

Family composition:

Geographic area of residence:

**Introduction** (*please go through this introduction even if you are repeating what was said during recruitment*).

a) *Thank you for agreeing to do this interview.*

b) *I am ..... from the University of Cape Town. We are conducting research to explore the experiences and needs of foster carers of HIV positive children in the Western Cape.*

c) *Please feel free to talk openly. If you feel uncomfortable talking about something, or would rather not answer a question, please tell me. You do not have to answer questions if you do not want to.*

d) **Time:** *The interview will last up to an hour. If you are tired or need to stop and do something else, please tell me and we can take a break.*

e) **Confidentiality:** *Everything said in this interview will be treated as confidential by the researchers. When we report the findings, we will make sure that everyone remains anonymous.*

f) **Recording:** *Do you mind if I record this interview? It's only for research purposes. That way I don't have to write down lots of notes while we talk. Nobody except the researchers will listen to the recording. (Wait for the participant's response). Please speak clearly so that we can hear what was said on the tape.*

g) **Test recording:** *Before we start, I would like to make sure that the tape recorder is working properly. (Interviewer: start recording, say your name and the date, and say something light hearted – like an observation about the weather today. Ask the respondent an innocuous question to hear their voice – or ask about their age and occupation, sitting in their natural position where they will sit for the interview. Stop the recording and play it back to make sure it is working and that both voices can be heard).*

**Start recording:** Remember to press record again before you start the interview. Once again, state the date and place, your name and the respondent's occupation.

*Make sure that you position the tape recorder so that your voices are still audible, even if you are looking down at the paper. Write down as many of the answers as possible in the spaces provided.*

1. Please tell me about how your foster child came to be placed in your family. (probe: what is your experience of the foster care system in South Africa?)

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2. From your experience, what are the special needs of HIV positive foster children?

(Do you think the foster care system is responding adequately to the needs of foster children and their families?)

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3. How do you perceive your role in the care of your HIV positive foster child/ren?

(probes: How do you see your role in caring for your foster child?, How do you think your family members see your role?, Do you feel equipped to care effectively for your foster child? Explain. If not, what do you think would help you to be better equipped?)

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4. What are the challenges facing foster carers of HIV positive children?

(probes: What is the most difficult part about being a foster parent?, What is the most rewarding part?, How do you deal with the challenges of fostering an HIV positive child? What do you think could/should be done to overcome these challenges?)

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5. What are the support mechanisms for foster carers of HIV positive children?

(probes: What would make your role as a foster carer easier for you and/or your family?, Do you feel like you are supported in your role as a foster carer of an HIV positive child?, Who has been the main provider of this support?, Is the support adequate? Who do you feel should be providing this support?, Should it be family and friends or institutional? What kind of support do you feel that you should be receiving?)

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6. What is your experience with access to and utilisation of the health, social and educational services available to HIV positive children?

(probes: What has your experience been of taking your foster child to get his/her medication?, Do you receive a foster care grant?, If yes, what has been your experience of receiving the grant. If no, why not and would you like to receive one? What are the challenges/barriers to receiving the foster care

grant?, Do you feel that you have enough access to support services?, Describe your experience of working with your child's social workers., What has been helpful and not helpful?, What would be helpful?

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7. Are there any additional services that you feel would help you with caring for your foster child?

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Conclusion:

We have come to the end of the particular things I wanted to ask you about. Before we close: are there any other issues or challenges that you would like to mention?

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Thank you for your input and for making the time to take part in this interview. It is much appreciated.

Name of interviewer: \_\_\_\_\_ Signature: \_\_\_\_\_

Date: \_\_\_\_\_

## Appendix 5: Informed Consent Form

Principal investigator:

Jenni-Kate Warwick

Tel: 074 104 2522

Email: [jakeswarwick@gmail.com](mailto:jakeswarwick@gmail.com)

Description:

I am interested in the experiences of foster carers of HIV positive children. You, as the foster carer of an HIV positive child, are the best person to describe these thoughts and feelings. This research study will involve one interview with you which will last approximately 1 hour. The interview will be recorded using a digital recorder. The recordings will be typed out as word-for-word transcripts of the interviews. The recordings will then be erased.

Anonymity and confidentiality:

Your name will not be attached to your interview responses. Your name and any other identifiers will be kept in a locked file that is only accessible to me or my research associates. Any information from this study that is published will not identify you by name.

Privacy:

The interview will take place in a private room where you will be able to speak freely without being overheard. The researcher will be the only other person present during the interview.

Benefits:

The results of this study may benefit potential foster carers of HIV positive children by providing information that could better inform their decision to foster. The information from this study could also be used by service providers to tailor their interactions with foster carers. There will be no direct benefit to you from participating in this study.

Voluntary nature of participation:

Your participation in this study is voluntary. If you don't wish to participate, or would like to end your participation in this study, there will be no penalty or loss of benefits to you to which you are otherwise entitled. In other words, you are free to make your own choice about being in this study or not, and may withdraw at any time without penalty.

If you have any queries or concerns, please contact:

The Human Ethics Committee

Associate Professor Marc Blockman

Tel: 021 406 6492



Signature:

Date:

Thumb print:

Your signature on this form indicates that you fully understand the above study, what is being asked of you in this study, and that you are signing this voluntarily. If you have any questions about this study, please feel free to ask them now or at any time throughout the study.