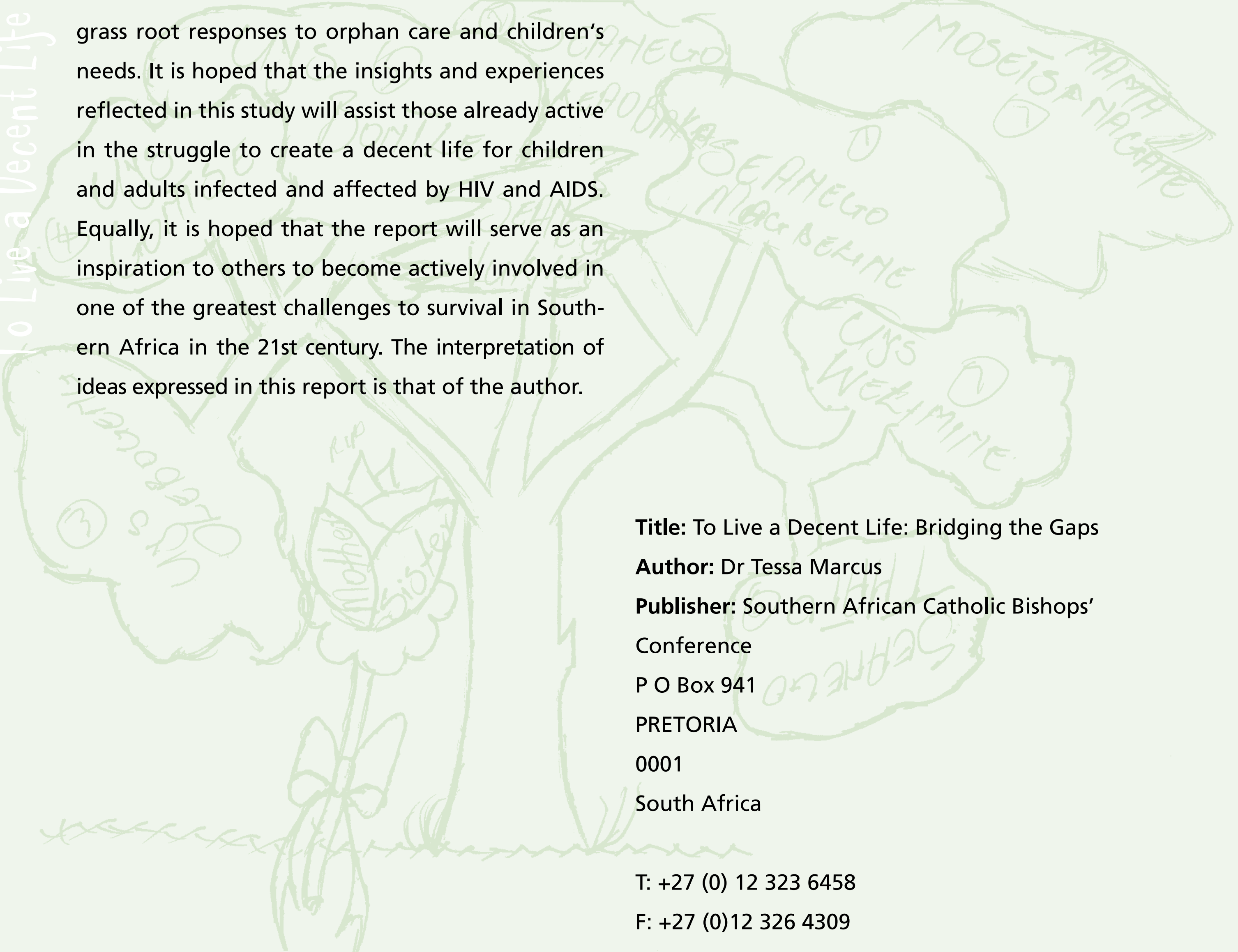
To Live a Decent Life: Bridging the Gaps

A study of SACBC programmes in support of Orphans and Vulnerable Children in South Africa and Swaziland

By Tessa Marcus
for the Southern African Catholic Bishops'Conference
September 2004

Acknowledgements

This research was made possible thanks to CAFOD and the Southern African Catholic Bishops' Conference, Sr Alison Munro and her team in the SACBC AIDS Office. It is also the product of all the people working in and with the various organisations who responded so generously with their time and ideas to this initative to better understand church driven grass root responses to orphan care and children's needs. It is hoped that the insights and experiences reflected in this study will assist those already active in the struggle to create a decent life for children and adults infected and affected by HIV and AIDS. Equally, it is hoped that the report will serve as an inspiration to others to become actively involved in one of the greatest challenges to survival in Southern Africa in the 21st century. The interpretation of ideas expressed in this report is that of the author.



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ISBN 0-620-33315-4

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Sibela Qhasha at Naledi Créche – Bethulie, Free State

Opening Words

The Southern African Catholic Bishops' Conference through its AIDS Office helps to support a number of initiatives in South Africa, Swaziland and Botswana addressing the needs of children infected and affected by AIDS. This book tells some of the heart-warming and heart-wrenching stories of what is happening in different places across the region. These are the stories of people driven to respond to what happens when their neighbours in need, particularly children, are orphaned and made vulnerable by AIDS.

What is striking is to see again and again how people see a need in their community and rise to meet the challenges it poses, often against unbelievable odds. They gather others to assist them and incredible, but yet so ordinary, things happen. Children are fed and clothed. They go to school, in uniforms. They are helped to mourn and grieve the loss of their parents and siblings in programmes offering psychosocial support. They are socialised, and given a chance to take their own place in the wider community. Some of them even receive anti-retroviral treatment, an unheard of possibility not so long ago.

Many children face adult responsibilities far too early in life, and the Church is saddened that there are even such places as child-headed households. The courage and resilience of children caring for siblings and for sick parents is a challenge to everyone, and to the Church itself.

The Church as the people of God is facing AIDS head on across a region so devastatingly affected at the household level. People inspired by their belief in a God who cares about everyone become the hands and feet of that God, working little miracles, making scarce resources go a long way, finding innovative ways of addressing daily problems, giving children a chance to grow up.

You who read this book can draw courage from others who have made a difference in their own communities to so many lives. Resources are needed, yes, but more important even than resources are the commitment and dedication of so many people across our region determined to make a difference, determined that HIV/AIDS and its effects can be turned around. Underlying structural issues won't go away overnight, but small steps to help children live a decent life are indeed possible.

Bishop Frank Nubuasah, SVD
Bishop, Francistown, Botswana
Chairman, SACBC AIDS Office Management Committee

October 2004

Love, Enterprise and Hope – Vukile's Story in 2004

My name is Vukile. I am 15 years old.

Every day I wake up, brush my teeth and wash my face. I then fetch water from the well. I wash dishes. I go to the shops at 3pm to buy bread. Usually, I play with my friends, but I only play for three hours. Then I come back home and help granny light the fire and cook. We sleep at 10pm.

The project first came in 1999-2000 when they heard about my mother's death. They came to comfort us and my granny. They brought food with them. Things changed when when my mother died ....(he stops talking).

The hardest thing now is that there is no money at home. (Is there anything you can do about it?) *Yes, my drawing and painting – I sell them. Also my gum boot dance group brings money. When I started the gum boot dance group I asked granny for boots and she helped me with that. My grandmother is the first person I go to (for help), but also Mrs Willeminah, our neighbour. She is granny's friend. I just feel alright, because my granny is around for us. I am doing well, especially with my dance group. Although, I (was worried) when you came. I thought you were the police, because my group is accused of stealing.*

(If you had three wishes?) *I want to get my grandmother her pension here in Taung. I want to be a lawyer if only I am successful. And I want to get my granny better help so that she can take care of us.*

Julia and her grandson Simothedo – Good Shepherd, Middelburg

Introduction

This is a study of Southern African Catholic Bishops' Conference supported AIDS initiatives in South Africa and Swaziland. It was commissioned by the SACBC in order to understand its programmatic responses to and impact on children, and the context in which they are occurring.

When you sit at the bottom of the pile and seek to attend to the needs of the millions of children, women and men who, through life's circumstances, find themselves in a wretched place, you can't help but ask yourself what it is that can, must and should be done to make a difference? Of course, posing such a question at the personal level will yield a multitude of responses that follow familiar patterns of reasoning and explanation. Yet, each of us knows – or needs to know – that taking responsibility for the world that we live in is the precondition of securing our humanity. This is a lesson of history and experience that is particularly relevant in Africa in the 21st century where the HIV/AIDS pandemic threatens the physical and social existence of millions of people – as individuals and in their various collectivities as families, communities and societies. This study provides a small insight into the ravages of the pandemic and the conscious responses that people are making, through the SACBC, to weather the tide of AIDS destruction and destitution.

Methodology

In directing this initiative the study framing document[1] set out a list of prescribed sources – namely, written records, staff and volunteers, adults and children, other key players working in the field, and SACBC staff. However, it explicitly did not prescribe any one methodological approach, suggesting that any number of approaches could be used as appropriate to particular contexts and respondents. The document also provided reflection points and questions as a guide to the enquiry, although emphasising, once again, that these were pointers to key areas of concern that could be considered in various levels of detail.

This study was carried out by a team comprising SACBC personnel[2] working at the SACBC head office led by a sociologist[3] with a track record of field work and research in HIV and AIDS. At the initial planning meeting it was agreed that the information generated through this exercise would only have value if it added new information and understanding to an already extensive literature on the challenges of meeting the needs of children and caregivers as well as people living with HIV and AIDS in resource poor settings typically served by the SACBC programme.

A study workshop[4] mapped the content of the framework reflection points, identified areas of focus, methodology and a timeframe for field work implementation. Pilot testing of the reflection points delivered in an unstructured way proved to be less than productive. Three field workers found it repetitive and frustrating for themselves and respondents and not suitable for engaging children. As a consequence, the team agreed that such an approach would not generate new knowledge and understanding and that more structured and refined instruments needed to be developed. These would attend to the sentiments of the original, be targeted appropriately for each respondent group, be made relevant and appropriate and thereby allow for the situation of answers in context. As such they could be used across a variety of localities. Four instruments were developed by the principal investigator. Time did not permit them to be piloted but they were critically considered with the team in a subsequent training workshop, before being administered.

In the field, the team agreed to capture responses to their questions or processes and take notes. These data were subsequently captured and analysed by the team leader who then circulated a draft report for team and SACBC comment. Field worker notes, together with post-field in depth interviews, were not analysed for this report as they are to be used by a field team member as data for analysing the role of field workers as mediators and interpreters of knowledge. These findings will be written up separately for master's degree purposes. The thesis will be made available to the SACBC and the entire initiative. While in the field, with people's permission, field workers took photographs of things and people of interest and relevance to the study.

Given time constraints it was not possible to carry out independent testing of local network activities and relationships. The data therefore reflects project representative reports on the existence of these, without any assessment of their strength and durability.

The field work for this study was carried out in the period June–July 2004. A total of 29 projects and programmes located in seven South African and one Swaziland province were visited. Each visit yielded interviews with between two and three respondents – ideally a project representative, a care giver and a child or group of children. Face to face interviews were conducted with 41 project representatives, 24 care givers and 38 children. The responses of these 93 study participants provide the basis for the findings presented here.

Since the pilot field work used the original reflection points as a guide in an unstructured manner, many questions were not answered and some were not asked. Time did not permit the team to revisit these project sites, mainly in Swaziland and northern KwaZulu-Natal. Under these circumstances, it was decided to include relevant information that could be retrieved from the pilot. This accounts for much of the variability in the numbers of responses reported in the description of the data, and the overall number of people interviewed, especially in respect of the project representative component.

None of the findings are representative of the class of people or the projects concerned as this would have required systematic sampling and more extensive interviewing. However, collectively the data provides the SACBC and other partners with an insight into the larger undertaking that they have embarked upon. Their work is clearly filled with both promise and challenge and it is hoped that this study will provide some insights into the work that they are involved with as well as ideas for programme focus and refinement.

In presenting the findings, respondents are quoted directly without making reference to their names or the projects they are working on. They are distinguished rather by their role in the initiative and, where appropriate, by their age.

The Findings

1. The context

The study framing document defines context in terms of the national, regional and local setting in which the SACBC interventions are operating. There is a vast literature on this subject which – nationally, regionally and at times locally – elaborates variously on

- i) the extent of HIV infection, AIDS illness and AIDS related deaths;
- ii) the age dimensions of the epidemic especially in respect of the children and the aged;
- iii) the gender dimensions of HIV and AIDS impacts;
- iv) the extent and nature of poverty and inequality and its interface with HIV and AIDS;
- v) the medium and long term economic and social impacts of HIV and AIDS;
- vi) the political and social responses from key institutions and organisations of society – be they governance, business, service, faith and civic society structures that claim to represent, act for and protect individual and collective interests;

Some key notions and facts include the following:

- i) South Africa and Swaziland are in the eye of generalised HIV and AIDS epidemics that are amongst the worst in the world. At the end of 2003 South Africa and Swaziland had HIV prevalence rates of 21.5% and 38.8% respectively, which translated in numbers

Orphan at Naledi Créche – Good Samaritan Hospice, Bethulie terms into 5,3 million and 220,000 HIV positive adults and children (2004 Update South Africa; 2004 Update Swaziland UNAIDS/UNICEF/WHO). These epidemics are creating chronic illness and untimely death for successive generations of young and middle aged adults that can be expected to persist for much of the rest of this decade, if not beyond. The AIDS epidemic was already visible by the year 2000 and continues to mount as the natural history of the disease sees people progress to full blown AIDS and death in ever increasing numbers. In 2003 alone AIDS deaths reached some 17,000 AIDS in Swaziland and 370,000 in South African (ibid.) with an estimated half a million people who are AIDS sick.

ii) The HIV and AIDS epidemics render up an unprecedented number of children without adult protection and care. In 2003 there were an estimated 1,1 million AIDS orphans in South Africa and 65,000 in Swaziland (2004 Update South Africa; 2004 Update Swaziland UNAIDS/UNICEF/WHO). It is presently estimated that approximately 23% of Swazi and 16% of South African children will be orphaned by 2010 (Africa's Orphan Generations 2004 UNICEF). Within the decade as many as 30% of 15-17 year olds will be orphaned.

iii) The epidemic is shifting the burden of child and family care upwards to the aged, outwards to relatives, friends, neighbours or even strangers and downwards, to children themselves. In the process, the family, the traditional institution of care and support for children, is being incapacitated as it strains to attend to even a modicum of the reproductive and productive needs that are demanded of it.

iv) Women bear the biggest brunt of the disease. They are disproportionately infected at an earlier age than men. In South Africa in the age group 15-24, prevalence rates among men were just under 5% compared to over 15% for women in 2003 (UNAIDS 2004). Women also carry the lion's share of coping with epidemics' consequences. 71% of households with orphans in South Africa and 50% of those in Swaziland are female headed (Africa's Orphan Generation UNICEF 2004). They carry this burden on fewer resources because women are economically disadvantaged in both societies.

v) The social and economic effects of HIV and AIDS are long term and myriad – impacting negatively on nearly every aspect of local and national life. HIV and AIDS is not a disease of poverty, but it creates poverty and aggravates inequality. At the household level the economic impacts of HIV and AIDS on families are felt up to eighteen months prior to adult death and for years thereafter. It is estimated that Gross Domestic Product declines by 1% per annum where 15% of the adult population is HIV positive (UNFPA State of World Population 2004 Report). Cumulatively the worst case scenario prepared for the World Bank predicts that in three generations there could be complete economic collapse (SA Reserve Bank October 2003 "Labour Markets and Social Frontiers"). Generally, it can be expected that poverty and inequality will grow in both absolute and relative terms, and the core institutions of society will become increasingly dysfunctional.

vi) The economic, social, political and psychological consequences of large scale young adult HIV infection, chronic illness and early death as well as widespread orphanhood will resonate through both societies for decades to come. Their desire to create democratic, knowledge based, socially stable environments that can compete in the contemporary global order will be difficult to achieve. Certainly, they already find it difficult to provide conditions that allow the majority of their citizens to meet their basic needs.

vii) There is a need for multiple and various interventions at all levels of society to help South Africa and Swaziland see their way through these epidemics. There has been an unprecedented response from millions of ordinary people, in particular, those who have been directly touched by the disease syndrome and the epidemic. This response has been matched (although not always equally or adequately) by non-governmental and faith based organisations. Both governments have created national oversight and technical bodies to coordinate and manage the national response. And both have set aside resources – the South African government set aside R1,3 billion for the 2003/4 financial year while the Swazi government has secured US$2,2million. While South Africa has yet to actually cost the real financial needs, the estimated resources needed to tackle the epidemic in Swaziland is put at US62 million over five years – 30 times the present funding (UNAIDS National Response Brief South Africa; Swaziland 2004). Presently, everyone's best efforts reflect a struggle for survival and they are critical. However, they are unlikely to make significant inroads into the disease and its consequences without a clear and unequivocal commitment from the respective governments that is purposively translated into practical and meaningful interventions on a significantly different scale.

These and other ideas provide the wealth of knowledge and understanding about the epidemic and the disease that underpins SACBC programmatic and project initiatives.

The Projects

Briefly, the 29 projects in this study reflect SACBC orphan related initiatives in seven of South Africa's nine provinces and in one province in Swaziland (See Appendix). While some of the initiatives spring from the Catholic Church's care for children and adults in need that dates as far back as the last century, the focus on HIV and AIDS is relatively new. Ten projects began working on HIV and AIDS in the early to middle 1990s. They are pioneers in the field and can be expected to have a wealth of experience. The remainder were initiated in the five years 1999-2003, with the exception of two which began in the year of the study (2004). This means that although the majority are fairly new they too have already accumulated several years of experience in a field that changes rapidly.

Projects range in scope, scale and impact. Some concentrate on emergency needs, others try to address both immediate and longer term issues of child care, while others seek to address challenges of HIV and AIDS and child care in a more holistic way. All the projects focus, in the first instance, on delivering their programmes to communities and individuals in their locality (loosely understood). In this sense, they are both local and community based, operating in

Sarah Vorsteen and grandaughter Elsa – Good Shepherd, Middelburg especially poor communities and working with marginalized people. They also all seem to have adopted more or less similar principles in their approach to children's needs and the epidemic.

1.1 Project Representatives

Educational Background, Responsibility and Experience

Who project representatives are and how they have come to AIDS work arguably is as important to the interventions as the context in which the programmes are operating.

There were 24 women and 17 men interviewed as project representatives.

Generally projects are led or are staffed by women and men who have completed matric or tertiary education.

Of respondents whose level of education was reported (n=24) all but one person has completed matric. More than three fifths (62% or n=15) have tertiary education – specifically degrees in nursing, social work or teaching.

Project representatives all hold some level of management or supervisory function, with most describing their position as manager or coordinator of the project or a division of the project.

Three fifths (n=15) had been appointed into their present position on joining their respective organisations. The remainder entered their organisations at a different level and had been with them any where between one and 25 years prior.

Most have been working in their present position for three years or less. Of those whose year of appointment is reported (n=25) only one had been in her current position for more than ten years. The rest took up their present responsibilities in or after 2000. Twelve had between two and three years experience in their present jobs, six had a year (more or less) and seven were only appointed in 2004.

Education, Training and Experience of Working with Children

The extent of education and training or experience with children that project representatives have is instructive. All but one report some form of formal training and a similar number report personal experience with children. While the kind of formal training received was not always stated, that which was specified seems to be a mix of workshops and short courses with fewer mentioning modules within more systematic, formal higher education.

Education and training mentioned includes running holiday camps, children's rights and entitlements, orphans and vulnerable children, mother craft, AIDS and babies, student and lecturer placements in schools, trauma debriefing, play therapy, educare, memory work, HIV care, counselling, sexual abuse, children with disabilities, early childhood learning, children's voices, as well as formal teaching and training degrees.

Respondents experiential background with children is somewhat less defined, but nevertheless important. Apart from the three who say they have no or not much experience in this regard, most describe their personal exposure to children as part of their working life experience. In this sense they have learnt how to engage with and manage children's issues on the job.

> *"I have worked with orphaned children and have had to deal with the developmental needs of young people, as well as children's issues regarding foster families. Children's issues are mainly emotional and therefore, they have to be helped to learn to cope with their emotional development. This is not always easy as there are varieties of issues affecting different children."* Project Representatives

The few who mention adopting or fostering children themselves have crossed the divide between their personal and working lives.

How come HIV/AIDS?

Like many other people who work with people infected or affected by the pandemic, for the most part working in AIDS came to project representatives rather than it being a career choice that they'd envisaged or planned. The details of each person's experience are always specific.

> *"The suffering and neglect of children pushed me to ask myself how I could help; I met PLWAs when I worked at the clinic; I saw the need and wanted to work in the community; There were many deaths in the community, meeting women at church I listened to their needs; Young people are dying and they can't speak for themselves; I saw many orphans and the work I was doing encouraged me to take this job; I was retired, I agreed to look after four children living with AIDS, I saw the rate the disease was killing families."*
> Project Representatives

Some respondents saw it as a calling or in fact, it was something they were specifically asked to do.

> *"It's God's calling; The bishop asked me to become involved."* Project Representatives

A few project representatives chose AIDS work. Some came into it as a direct consequence of their exposure to HIV/AIDS personally or within their families.

> *"I was sick and I felt that it would be better if I came out and talked about it; A close family member died and I wanted to overcome fear and care for children; My brother died of AIDS, there was strong family denial, even rejection. (This experience) made me want to work with marginalised people.*
> Project Representatives

For others it was where their sense of mission directed them.

> *"I wanted to work and educate people to live positively with AIDS; I wanted to conscientise people, to assist the church and the community where I live; This is the biggest human crisis, you've got to be there, you can't miss it, it is the church's responsibility to the world."*
> Project Representatives

And for a few, it was what they had been trained for.

> *"Working with orphans and vulnerable children is part of social work; It comes with working for child relief."* Project Representatives

HIV/AIDS – Knowledge, Education and Training

Given the way most project representatives have come into working with the pandemic, like their knowledge of children's issues, their exposure to HIV and AIDS appears to be largely work derived. When it comes to HIV and AIDS, all say they know the basics about the disease, while a handful (n=4) describe themselves as experts.

Most project representatives have been educated in this field through workshops, short courses or modules.

One respondent describes herself as being exposed to the issues through her adopted children and to have no AIDS train-

Sr Deliwe Maria Luthuli – St Francis Care Centre, Boksburg ing. The remainder have done one or more courses covering various aspects of the disease syndrome. Amongst others these include: home based care, counselling, HIV/ AIDS basics, behaviour change, AIDS and medication, prevention, disclosure, voluntary counselling and testing, signs and symptoms, ARV administration and monitoring, palliative care, teachers' response to HIV/AIDS, advanced counselling, grief counselling, proposal writing, project management, lifeline courses, support systems.

Several respondents describe having done a long list of courses whilst others only mention one or two. Whatever the case, it would seem that beyond basics, it would appear that knowledge levels are uneven and there does not seem to be systemic, formal continuous education and training on the rapidly changing, multiple dimensions of HIV and AIDS across the programmes. There are some individuals who do have vast formal knowledge and/or experience, but they are the exception, rather than the rule.

Perhaps of greatest importance to the projects and their representatives is that most report limited systematic formal child-focused AIDS education or training.

Six respondents (of 24) say that none of their training covered issues relating to children. One person remarks that the issue only arose out of a debate in the group but it wasn't in the course outline.

With one exception, the remainder report being exposed to more limited and sporadic child focused components in their training. Amongst others topics mentioned include mother to child transmission, bereavement counselling for children, disclosure, awareness and identification of children infected and affected by HIV/AIDS, children's rights, discrimination and poverty.

There is only one report of a respondent completing a medical short course on paediatric ARVS and drug management. However, as this is a new area of learning it is to be expected that it will become an area for broader, rapid knowledge and skills development.

Given that most project representatives are exposed only to intermittent formal education and training in the course of their work, they need to and do draw on other resources for ideas. A few simply base their practices on experience. However, these are the exception. It is particularly noteworthy that most actively seek out information and new knowledge from various sources.

Most respondents report getting ideas and information for their work from relevant literature (be they popular, official and scientific literature), the media, networking with other organisations, people (especially fellow staff, professionals, church leaders, and friends) and workshops (which combine information and knowledge sharing with networking and interacting with people in the same or similar fields).

HIV/AIDS is transforming. Everyone who is exposed to it gets to see the world through a different lens. Their understanding of their places in life and their roles and responsibilities are profoundly changed. Project respondents are no exception.

Direct exposure to the disease and the epidemic in the course of their daily work, coupled with their growth in knowledge and understanding through training, education and networking generally has deepened respondents' individual involvement with and commitment to the issues and challenges that are thrown at them. As they put it:

> *"I have become more involved, there is a greater sense of urgency. At first I knew nothing, now every day people die; I've got better and better – when I think of quitting, I just see the children around me; With every new bit of information I become more involved, but it is depressing; I am gaining knowledge and hope, it gives me a positive outlook and makes me feel optimistic; I see much more of a need to work with children and AIDS; I have become*

> *attached to the reality side, less to the theory; Its about focusing on needs; I understand the disease a bit better and I am becoming more passionate; I used to feel at the periphery, now I feel at the centre; I have become deeply involved with the disease as it brings out many issues; As we witness most deaths, children take us as part of their families, they confide in us."* Project Representatives

Others have changed their role in the organisation and in the field.

> *Initially I ran the project, now the community is more involved. I will be replaced; less hands on, more at a national policy level where the impact is broader; numbers are big, involvement has increased and (we) have become involved with the affected not only infected; Workshops have generated new ideas."* Project Representatives

Equally, just as the lives of respondents are being transformed, the disease syndrome and the epidemic are also transforming individual and collective life in the communities where they work.

Perhaps the most significant change that many respondents observe is the growing acceptance of HIV and AIDS.

> *"There is lots of acceptance by the families and communities. People are no longer afraid to talk about it; People are beginning to realise that AIDS is like any other disease; before people were hiding, now they are coming out, accepting their status; There has been a change from blame to acceptance. It is no longer a sin. AIDS is manageable and care is part of it. Its become our problem – we have to have a positive goal and outreach; People no longer discriminate, more people are coming out and there is less fear; People are beginning to wake up. Prevention is being used more."* Project Representatives

1.2 Caregivers and Children

The caregivers and children who participated in this study shed some light on who in the community is responding to initiatives to deliver community based care needs and who they are caring for, without in any way being representative of these groups.

Caregivers interviewed tend to be young adults or the elderly rather than middle aged. In this study the average age of those whose ages are known (n=24) was 37 years old, with a range in age from between 19 to 70 years. However, with the exception of three, all are below 45 and most (n=19) are in their twenties and early thirties.

Also, all but three are women.

The educational profile of caregivers interviewed looks very different from that of project representatives. Nearly all caregivers (n=19) have matric or less, with only four reporting a post school diploma (n=2) or a degree (n=2).

Most caregivers in the study are unemployed. In terms of income, they therefore depend on others – individuals and systems to survive themselves. Three have no source of income. Eleven depend on mostly old age pensions and other state grants – their

Orphans at Naledi Créche – Good Samaritan Hospice, Bethulie own or others. Nine depend on incentives from projects in the SACBC programmes. And three depend on relatives (husband and children) in formal employment.

> *"We are five in the house, my grandparents receive pensions; I am unemployed, there are 10 in the house; I depend on my mother's pension- there are 10 in the family; This job – I am the only earner at home; I work as a care giver; I get income from the day care centre run by my family; None. We are orphans, I have three siblings to look after."*

Caregivers

The 21 caregivers who provided information about household income live on between R50 and R6,500 a month, with most (n=14) having incomes of R1,000 or less. They are all poor and, for the most part, in search of sustainable livelihoods.

Between them they look after or look out for 367 children. The story of the children in their care can be told in many ways. The table below, depicting the barest details of only 1% of the children of caregivers in the study, captures these childrens' circumstances most starkly. The children range in ages from babies to teenagers. It shows that their parents are deceased or their whereabouts are unknown. In their present care arrangements sometimes they live with siblings and other relatives, at other times they live with other children who are not related. All have been or are in the care someone other than their parents for varying but substantial parts of their young lives.

Care Giver	Thebe	Gladys	Helen	Beatrice
Age	28	35	40	29
Sex	Male	Female	Female	Female
Child One				
Name	Vuyani	Venolia	Gontse Tl.	Mbali M.
Age	15	13	4	3
Parent name	Mmabatho	Mokgadi	Sinah	Don't Know
Mother Where	deceased	deceased	deceased	deceased
Father where	Don't Know	deceased	don't know	Don't know
In your care	5 years	2 years	2 years	2 years
School grade	10	8	not at school	crèche
Child Two				
Name	Rethabile	Clement	Biotemelo Tl.	Lucky R.
Age	12	15	10	7
Parent name	Pauline	Mosina	Sinah	Don't Know
Mother where	deceased	deceased	deceased	deceased
Father where	Don't know	don't know	don't know	don't know
In your care	1 year	2 years	2 years	6 years
School grade	7	9	6	2
Child Three				
Name		Nkele	Kenneth Tl.	Fezile B.
Age		9	15	9
Parent Name		Maria	Sinah	Mantombi
Mother where		deceased	deceased	dead
Father Where		don't know	don't know	don't know
In your care		Six months	2 years	6 years
School grade		5	8	3

The children map their world somewhat differently – articulating the bonds that bind, the relationships they miss, the ones they are building and the ones that they find hard to establish.

Thandi – *My mother, she passed away*

Busi – *My cousin in Dobsonville. She is at crèche. She likes to play. I enjoy playing with her.*

Sipho – *My cousin in Dobsonville.*

Nomathemba – *My sister, she stays in Zola. She goes to school.*

Nomini – *Grandmother on my fathers side. She is not working. She likes to send us around when we were staying at her place.*

Sandile – *My cousin, she is in Zola, Soweto. She is not working. I can't remember much about her.*

Zanele – *My aunt, she went to work. She works in town and stays in Zola. She likes to cook for us when we visit her place.*

Xoli – *My uncle, he went to work. He works in town and stays with us here. He likes to watch soccer on TV. I like watching TV with him. He prepares lunch boxes for me before he goes t work. I go to the shops and buy him things that he has sent me for.*

Thoko – *My grandmother on my mother's side. She is around the house. She likes to go to church. She also likes to tell us stories about my mother- like how she grew up and what she was doing. I like to talk to her. For example, we talk about school and what I want to become when I grow up. She washes our uniforms and she cooks for us when our aunts are not around. I make tea for her when I come back from school.*

Mandla – My uncle – *he is around. He is not working. He likes to move around the location with his friends. He gives us money to buy sweets sometimes*.

Winnie – *My Aunt, she stays in Zola in our house where we used to stay with my parents. She likes to take us to town when we visit her. I like to be around her.*

Solomon – *My father, he passed away*

Ntombizodwa – *My sister, she is in the house. She goes to the school which I attend as well. She likes to be on her own. I like to play games with her. She helps me to wash the dishes every evening. I help her wash dishes and accompany her to the spaza whenever our uncles send her.*

Zee – *My aunt who stays with us. She goes to high school. She likes to sing for us in the house. I like to help her when she is cleaning my grandmother's house.*

Kono – *My aunt, she stays with us here. She is not working. She likes to send us to bring things for her. I don't want to be around her. She washes our uniforms when my grandmother is not around. I help her to wash our clothes.*

Both descriptions tell a difficult story filled with challenges for the children, in the first instance and for everyone interested in theirs and society's well-being in the second.

2. Children's Needs

A generalised HIV and AIDS epidemic significantly impacts on the shape and scale of need of children. This is especially the case when they live in resource poor contexts where there are huge material and social demands on the adult women, and to a lesser extent men, who are their primary protectors and care givers.

Project respondents variously describe children as being robbed of their families, their childhood and their futures. They also consider the epidemic to be disempowering. For some, the enormity of this is summed up in their status. Simply put

> *"AIDS creates orphans".* **Project Representative**

Generally, children and those trying to care for them are confronted by a myriad of problems, often all at the same time. There is the trauma of children watching a parent who is in their care, die in front of them.

> *"Children are traumatized watching their parents die, becoming orphans; Home visits are the most painful, when children have to face seeing their sick parents; To lose a mother is an unbearable experience."* **Project Representative**

> *"Three girls – Nelisiwe (6), Precious (4) and baby Ramona (10 months) were found by a family friend in a small farm outhouse with the corpse of their mother. They had been alone with her for an unknown time. Nelisiwe had been taking care of the younger girls."* **Caregiver – Love of Christ Ministries TLC**

> *"They ask lots of questions, they lose sense of their family and belonging. They wonder 'will my life ever be normal?'"* **Project Representative**

In their own ways, the children express a great sense of loss and of missing.

> *"I used to stay with my mom but now I have to make friends. ...Whenever I begin to talk about it hurts a lot."* **Boy Aged 9**

> *"I feel sad because I miss my parents everyday."* **Boy Aged 5**

> *"The hardest thing is the fact that I can't forget about my mother's death."* **Girl Aged 13**

Then there are the issues of food and shelter, which often become more acute on the death of the care giver.

> *"When their parents die, children are often left without care or food. Sometimes their land and property is stolen by relatives."* **Project Representative**

> *"We did not eat last night and our shack was too cold."* **Boy Aged 5**

Some are simply abandoned. Then they become the carers and breadwinners.

> *"A child of nine takes care of dying parents, then she is forced to become a prostitute as she becomes the breadwinner and head of the house; They become adults before their time; They are subject to abuse and vulnerable to prostitution; A four year old 'mother' was found looking after her two year old brother, because the mother abandoned*

Handicapped orphan, Botshabelo, Free State *them. The two year old called her mom."* **Project Representative**

"T is a young girl of 11 and is in grade 6. She is the first born of six children. She is taking care of her five siblings ranging between the ages of 5 and 10 years old. They are staying in a two roomed house. Each room is about 2 meters. There is very little space for them to move around in the house. Her mother passed away during the first week of April 2004 and her father passed away three weeks after the death of her mother. They both died of AIDS related diseases. When their parents were sick these children had to take care of them. They were taking turns to clean and feed their parents until they passed away. T is now playing a role of mother and father. She is responsible for her siblings. She cooks for them and makes sure they go to school. Field Worker – Research Notes

Sometimes, dying mothers approach projects for help.

"When they are very sick, mothers bring them to us because there are no relatives; There are children from far away places.; (These parents) spoke to the social workers to place their child safely because they were sick – she was also HIV positive. They got better but never came back to check on her." **Project Representative**

Others become dependent on family members after losing parents.

"Their food and education become insecure; They (find themselves) poor, lonely and uncared for. They lose their sense of security, safety and parental care. " **Project Representatives**

Conditions in the homes of relatives and care givers vary. There are always difficulties, even where children are well cared for.

"Sometimes the adults who raise them don't tell them about their parents; There are children who have uncles and aunts who take good care of them; Things are fine for some as long as they are being fed and going to school, but when they might want something else, then it becomes a problem." **Project Representative**

"My uncle buys for me and helps with educational tours." **Boy, Aged 15**

Equally, their circumstances can become harder whether they live in their own homes, with relatives, with caregivers in the community or in children's homes. In the words of the children themselves:

"I always have to go to our neighbours and ask for the wheelbarrow so that I can go and fetch water on my own. ...It is too heavy for me. ...My grandmother always scolds me if I say I am afraid to go to our neighbours in the night to return their wheelbarrow." **Boy, Aged 5**

"Things have changed a lot. We no longer stay at our house. ...Everyday before we go to school my sister and I have to clean the house and (we) wash the dishes in the evening." **Girl Aged 8**

"My grandmother no longer treats us the way she did when my mother was alive. She treats us harshly." **Boy Aged 16**

"Sometimes I go to school without something to eat and now I have to do the cleaning, which I never did when my mother was still alive. I want to live in my own house because the people I stay with do not provide food or take care of me." **Girl Aged 10**

"In the evening I have to go outside and pump water and I am very scared. Every evening I have to go to lock classrooms on my own... . I should not have to go outside at night on my own. Someone should accompany me." **Boy Aged 11**

Children are disoriented by losing their place in the world and especially, when they are separated from their siblings.

> *"I no longer have parents, I no longer live at my own home, but where I'm adopted."* **Girl, 17 years**

> *"I feel bad most of the time – because of my mother's death, because there are no relatives, also being separated from my sisters."* **Girl Aged 17**

For many, whether they live on their own, in the home of relatives or even care givers, schooling and education becomes problematic.

> *"They are forced out of school because of no money; School performance drops; HIV/AIDS affects learning and children's opportunities to develop, dream, school and lead a normal life."* **Project Representatives**

> *"After my father died things changed. Even school, I stayed for some time, not attending. "* **Boy Aged 15**

> *"The children miss their parents and they don't cope well with school."* **Female Caregiver**

> *"I want to go to school. I have been out of school for three years. School is too far and I have to walk a long distance. It is not nice as I left my friends behind."* **Girl Aged 17**

Caregivers, especially point to the problems facing children who are beyond the age of entitlement to child care support and of those who have left or finished school.

> *"They don't get grants because they are over the assistance age. Some are really destitute but they need love, security as well as food. They loiter on the streets. They need to get educated even beyond school."* **Female Caregiver for 65 children**

> *"How long am I going to keep these children in this shack. They will be teenagers and they will ask me lots of questions. What will happen to them when they are bigger? Will I be able to stay with them if they are over age? Will they be well educated?"* **Female Caregiver for six children**

The situation for infected children is often made worse because their own health is often quite fragile.

> *"AIDS is traumatic. The symptoms are vast. Everyday life is a bonus. The children suffer; Some go into isolations wards to protect them from infection; Children living with HIV can't play sports like others."* **Project Representatives**

> *"I've been living here for seven years. When I first came I was sick, unhappy and crying. My family brought me because I was sick and they couldn't look after me. The hardest thing for me is not to see my family."* **Girl Aged 13**

All the children experience profound emotional hurt that manifests in many different ways.

> *"SC is a 5 year old who attends crèche in Orange Farm. He was tearful. He had lost his mother a few days before. He was in the care of his step grandmother, who, on that same day, had thrown him out of the house. He had been sent to his father's grandmother who he did not know at all. SC could not concentrate. Most of the time he*

Caregiver with blind orphan at Siyathokoza – Botshabelo, Free State

> *does not seem to hear when he is spoken to. He does not participate in any activities. And he often just bursts into tears."* **Field Researcher – Notes from Interview**

Several children are fearful, express a loss of trust in adults, and are guarded about what they feel they can ask for or expect.

> *"It is difficult to trust anyone; I don't have trust in them; I worry about things like clothing because I am afraid to ask them. It will be as if I am pushing my luck; I am afraid that they are going to hit."* **Children – various ages**

The fears they have are drawn from their experiences and insecurities, some of which derive from the role that adults, and men in general play in their lives.

> *"Most children are afraid of me. I am the only male."* **Caregiver responsible for five children**

The impact of HIV and AIDS on affected or infected children is overwhelmingly negative. The disease and the epidemic have far reaching physical, material and emotional consequences for them. Generally, project respondents suggest that

> *"There is apathy among (these) children. They have no sense of future, especially among teenagers; Children feel lost and angry; Some resort to alcohol and drugs because of frustration; Others are unruly and very difficult to deal with. You ask them what they want and they tell you straight that (relatives) 'don't want me so I don't know what to do'; The psychological effects are great, even for those children who seem to lead a normal life."* **Project Representatives**

By their own account AIDS affected and infected children find themselves in a variety of circumstances. This differentiation is widely recognised by project representatives.

As one respondent expressed it "you always have to be careful about categorising (them)." Equally, there is a common thread that runs through the experiences of all children – the loss of a parent and the disruption that comes with adult death.

Generally, the trauma of AIDS for children is multiple, massive and long term. In such a context, it is necessary to ask how appropriate are notions of need hierarchies? There might be things that seem to take precedence in time, that seem to need immediate attention because they threaten the very physical survival of individual children – and therefore require priority – but generally, the context is more often one of multiple insults. Because of this complex reality, most project representatives articulate the need for a systematic, holistic response, even when their programmes are only able to respond partially to this need.

Just as working with HIV and AIDS deepens their understanding of the disease and the epidemic, so working with children influences project representatives' perceptions and understanding of children and the problems they face.

Project representatives and caregivers express a general concern about the loss of childhood and all that this loss implies for their present.

> *"Their childhood is lost. They are given big responsibilities at an early age; They are placed at the level of adults in society, as heading families; Normality is taken away from them. Some become sexually active."* **Project Representatives**

The children express this loss with worldliness beyond their years as this account clearly shows.

> *"I stay with other children in the same house. Sisi Sinah is taking care of us as if we are her children. She prepares us every day if we have to go to crèche or to the clinic every Wednesday. Sisi Sinah wakes me up and baths me first while the other children are still sleeping. She gives me soft porridge and tea. ...Here I sleep on a bed. Where I was staying with my parents I did not have my own bed. Sisi Sinah cooks well for us. Each time I get sick and Sisi Sinah takes me to Doctor. I have*

> *lots of sores all over my body. I came here last year. ...Sisi Sinah came to the shack where I was staying with my parents. That time my mother was sick and my father had passed away."* **Girl Aged 5**

A related concern that project representatives and caregivers have centres on the vulnerability that comes with being orphaned.

> *"Children are very vulnerable; There is greater dependence; Children are helpless; Their safety is not guaranteed. They are vulnerable to abuse; They have to deal with abnormal behaviour. They are taught one thing and experience something else; A lot of children suffer; Children are ranked very low by society."* **Project Representatives**

> *"It's difficult. Their guardians physically abuse them. One child came badly burnt – she was made to clean the house and she was only 9."* **Female caregiver responsible for 20 children**

> *"They stay with grandparents or uncles who abuse them or chase them out."* **Female Caregiver responsible for five children**

> *"I don't trust my relatives. They could not help me when my mother beat me."* **Girl aged 17**

Project representatives and care givers also observe changes in their own feelings and behaviours as well as what they see in others.

> *"People destroy children. We tend to judge them...The root of the problem is not the child but our insensitivities to their needs...; Children must be loved; I feel more compassion, I see them as a valuable asset; It has increased my love but I also get stressed and depressed by what I can't do; I worry for my own child."* **Project Representatives**

> *"They don't wash. They don't have food. I really cry but as a man I don't show people around me that I am crying; We are devoted to these children. We become a family. It makes you sad when you see these children die."* **Caregivers**

Certainly, several project representatives are far more aware of the need to talk to children about issues that previously, they might have considered inappropriate.

> *"It is very painful when a baby dies. I sit down and talk to the children; We need to deal more effectively with children rather than focus on dying. Children are traumatised; I educate them about sex from 11 years, whereas in the past I would have done this at about 18."* **Project Representatives**

In general, respondents see AIDS as laying the seeds for future inequality and social instability.

> *"They are being poorly equipped; The gap between children is widening; They will be discriminated against by society; They will become angry adults; I am not optimistic about (these) children's future."* **Project Representatives**

This astute insight into the future implications of the crisis of childhood unleashed by AIDS is perhaps the baseline against which programmatic interventions should be benchmarked.

Nomonde and her sister Ntombizondwa – St Joseph's Ithuteng Campaign

3. Programmatic Responses

The overarching objective of all the SACBC programmes can be summed up simply – to create a decent life and a dignified death for children and adults who are infected with or affected by HIV and AIDS.

> *"Our objective is to bring life to these children so that they can live like other children; We aim to give children hope, love, a chance to play, and to interact without discrimination; The objective is to make the lives of orphans and vulnerable children a fulfilling and enjoyable experience; We focus on rescuing abandoned babies, giving them quality of life, and finding adoptive parents; We want to alleviate hunger and the need for care; Our objective is to look after the well being of the whole child – spiritually, emotionally and psycho-socially; We want to restore children's dignity, humanity and trust and (help then) continue with their education; We care for HIV positive people and their families; We work with people living with AIDS (PLWAs) and orphans and vulnerable children (OVCs) to bring quality of life, to remove the focus on death and (to help them) turn to life; Our objective is to provide professional and holistic care for the homeless and destitute in the Johannesburg inner city."* **Project Representatives**

3.1. Interventions

How programmes set about realising their objectives varies in focus and detail. The greatest concentration of effort seems to be around providing food relief to children in need – either through food parcels that are given to them in their homes as part of home based care, through feeding schemes that are run in the community, in schools and sometimes in shelters or children's homes and to a small degree through school and home garden projects. Invariably, most projects have to access this food – from government, through donations from the private sector or the community and also through direct purchase – and they have to distribute it, unprepared or unprepared.

Caregivers comment that while this food is welcome, there are shortcomings. These include a lack of some essential items, a lack of variety, insufficient quantities and problems with periodicity.

> *"The children get food during the week but not at the weekend. On weekends we bring food from our homes; There is not enough food; I don't have enough food for new intakes. The food parcel has maize, samp, beans, peas, salt, fish oil peanut butter and powder milk – no paraffin, sugar, or tea."*
> **Caregivers**

Caregivers also point out that focusing on food does not accommodate other needs.

> *"They need clothes and toiletries and sanitary pads. I end up giving them mine; We need soap and money for clothes."* **Caregivers**

Many programmes support children's education. They focus variously on getting children into and keeping them in school and supporting their performance. The work here is wide ranging. It includes negotiating over fees and space at local schools, providing fees, school uniforms and books, and helping children with their homework – in their homes, or at aftercare facilities which they run.

A third area of activity in South Africa centres on securing children their statutory entitlements. This work includes getting relevant identification documentation, helping care givers secure child support grants, supporting child placements in foster care or through full adoption and monitoring and preventing abuse by parents or guardians; helping them access primary health care and education; ensuring mother to child transmission prevention.

A few projects directly work through and many actively include recreation as part of their programmatic support for children. Activities include play, arts, drama, dance, sports of various kinds, picnics and other kinds of outings. Recreation is regarded as both a learning as well as a physical and emotional therapeutic medium that makes a very important contribution to children's quality of life.

Several programmes include the provision of shelter for children in their initiatives – envisaged as temporary places of safety, or as permanent homes. Holistic care is usually provided in these homes, with several making considerable effort to integrate children in these institutions into life in the larger community.

Part of the care that programmes offer – whether they are delivered in institutions or through outreach home based care in the communities – focus on child and adult health. Several projects provide medications for people living with AIDS, some provide respite and hospice care, one attends to the health of street children, and several attend to children's primary health care needs. The counselling services provided through numerous projects also seek to address the mental and emotional well being of both children and adults. In this work the focus ranges from HIV and AIDS infection related worries – testing, living with HIV, living with AIDS, death and dying – through to bereavement as well as trauma counselling. Counselling and support is also provided for care givers.

Since caregivers and volunteers also live and work in extremely stressful and distressing environments several programmes try to provide them with structured emotional and spiritual support. Usually termed caring for the carers, it is an essential part of ensuring that people stay with the programmes and are able to respond to the needs and deliver the services expected of them.

All projects do HIV and AIDS awareness work – mostly to try and stem the spread of HIV. Sometimes awareness extends to raising community understanding of children's and adults rights and to encouraging people to become actively involved in community based care. Several projects reinforce their awareness efforts by actively developing the capacity of volunteers, peers and caregivers. Some go even further into development work – setting up or supporting and monitoring community based organisations that generate income (e.g. gardening, spaza, bead making, sewing, bricklaying) or attend to children's needs (e.g. crèches, sports clubs, after school care).

Most of the projects are involved in multiple activities, since the needs of the children and the communities in which they work are many and broad ranging. At the same time and without exception, they all make choices in their priorities and foci. One choice that they make relates to who they will support. Several focus on children – babies, young children, boys initially and now boys and girls, homeless children, HIV/AIDS affected children,

Orphans dancing at Good Shepherd Hospice, Middelburg, Eastern Cape orphans, vulnerable children, infected children etc. Others focus on people living with AIDS and their families.

Thematically, many adopt a needs based approach. They focus on what they describe as “the basics” – food, blankets, sometimes clothes, health and education. These are the needs that they consider to be urgent – understood as requiring immediate attention, and essential – understood in physiological development terms. Others offer specialised services – like the securing of identification documents, the provision of primary health care or adolescent sexual health services- which draw upon the set of specific professional skills. Because they have to make choices they all are aware that there are issues that they have to overlook or find other ways of dealing with. Several actively try to refer the needs that they overlook to other governmental or non-governmental organisations, while others just hope that these will be picked up.

There are project representatives, however, who identify and develop their interventions within a framework of holistic care. By definition, this approach countermands the idea that the needs of AIDS affected children (or people) can be or are ordered in some sort of rigid hierarchy. Since their human and financial resources are inevitably limited, most of these programmes do not try to provide directly for all human needs and requirements. Rather, they choose to directly attend to some aspects of the health and care needs of the children or adults they support, while they also actively network with other organisations to provide for the areas that they can’t address.

Several factors shape these intervention choices and decisions. As already indicated, they are influenced by the paradigmatic framework that guides the programme – be it needs based or holistic.

Another factor that influences interventions is locality. Working in the inner city is very different from rural community based work. It is also different from suburban, township life where settled and new migrant populations intermingle.

The presence or absence of other organisations – government and NGOs – working in the field of AIDS and children in the areas where they operate also shapes the kind of work they do. Some organisations are forced to take on a multitude of activities because there is little alternative organisational response and the communities where they work are weakly connected. Others are able to be more selective because there are greater levels of organisational support and higher levels of social organisation in their areas.

Programme activities are visibly influenced by government policy. Swaziland and South Africa differ in child care policy. The Swaziland government does not have a social security system. However, in the face of a state declared HIV/AIDS national crisis, draft policy on children, including those who are vulnerable or orphaned[6] has been formulated. At present the social security needs of children are provided by the extended family, which by all accounts is overstretched as HIV and AIDS, combined with endemic poverty, social inequality and drought, has seen deterioration in the circumstances of the majority of the population. Approximately 40% of children under five show signs of chronic malnutrition and 60% of the total population are food poor.

The South African government provides for statutory entitlements through the Child Care Act for poor children up to the age of 11 (the child care grant = R170 pm in 2004) and a special needs grant (R530pm in 2004) to caregivers who look after orphaned children up to the age of 18 (the foster care grant).The constitution and in it, the Bill of Rights provides for children’s rights to shelter, education, protection from harm and appropriate care. As a consequence, a lot of effort goes into securing orphans and vulnerable children their statutory entitlements as South African citizens, as well as trying to fill the gaps where these are delayed or unmet. There are also some efforts to help secure them their human rights as children.

The choices that are made around interventions are also dictated by the availability of resources, both financial and human. Many project representatives recognise that their interventions are constrained by limits in infrastructure, money and skills – at times with far reaching consequences. Transport could be described as the Achilles heal of community based family care. It is costly and intermittent, if not absent (especially at night). As a consequence, it is often hard to provide sufficient skilled routine care and support to families in their homes; it is difficult or impossible for adults or children to get the timeous attention they need when they become sick; and it inhibits the participation of children in educare and other initiatives when they stay beyond a safe walking distance.

Equally, as several respondents point out, the challenges of delivering programmes through the voluntary labour of young and old people who themselves live in poverty and are in need of livelihood, constrains and even negatively impacts on the kinds of care and the systems of support that are necessary to make community based family care work. It also contributes to the perverse uses of the system.

Lastly, programmes are influenced by assumptions about children, family and community – assumptions that will be looked at in some detail below.

3.2 The role of children

For the most part, children have played little or no part in determining the foci of the programmes in the study. This is not unusual. In fact it is in keeping with societal notions of children's competencies, entitlements and responsibilities.

This said, because most programmes involve children in their practice, the content of what they do is influenced by the children they work with, to varying degrees.

At one end of the spectrum, there are programmes with no or very little involvement from children, mostly because they deal with babies and infants and rightly regard such children as being too young.

> *"The children are not involved much. The children we deal with are too young; None, sadly so. They are too young; None."* **Project Representatives**

However, there are some which have not thought of involving children or doubt the reliability of children's information.

> *"We go door to door interviewing parents about their children's needs; We listen to the children's needs, share their worries and difficulties, but mostly go to their homes to get the real information. It is difficult to listen to a child coming to tell you that they need grants."* **Project Representatives**

For the majority of programmes the involvement of children occurs through specific activities. In several instances, however, what they learn from the children is more

Velaphi Khumalo
–Sithand'Izingane
Care Group

of a by-product of the activity that they are focusing on and is regarded as incidental rather than integral to shaping their activities and interventions.

> *"We involve the children in the food garden project – each has a patch. Life skills have helped them understand their status. There is an improvement in their lives. They feel a sense of belonging and ownership; We took the children to the car park at Spar and to do door-to-door campaigning. We wanted (the community) to learn more about AIDS and about being an orphan. It gave the children a chance to express themselves; We normally have a session with children to talk about HIV/AIDS. We engage them around the issues of sex; We call them to the parish once a month. We organise activities and find out about their needs; We do drama with the children when we go camping. They communicate their feelings and problems."* Project Representatives

In other programmes, children's responses – what they say and what they do- and their involvement is regarded as critical information and feedback to the success of activities or even the programme as a whole.

> *"We ask them what they need. This way children help with assessing viability, responsibility and sustainability of the intervention or programme; We try to bring children in from school. They help us identify other orphans and they also express their needs; We involve children – choice is a tool for them. Making them drug literate helps them take their drugs on their own. It makes them independent. It gives them a sense of purpose and responsibility."* Project Representatives

> *"Eight year old ZM does not come back if she is taken to school, so we have established a school in the home to safeguard those children who we are not sure of."* Project Representatives

> *"We ask them what they want, what they are happy with and then try to respond. I want these children to be happy since they have experienced pain; We study what the children say in the class room. Listening to the needs of children, observing them in classrooms has improved the methodology of teaching life skills."* Project Representatives

And then there are programmes where the involvement of children is such that it shapes, and even sometimes determines the direction and focus of programme activities.

> *"We involve them in decision making, encourage them to develop their own projects, train them to handle problems; We try to get into children's shoes to understand their trauma and suffering; We have lots of discussions with street children and support groups. We run two information and education camps a year. Street children are difficult to keep track of, it places trust in them and helps them stay in touch with peers."* Project Representatives

> *"We ask the children what they want to do, on the weekend for example. Based on their choices we decide how feasible that is. Older children have influenced us tremendously in forming sports teams and the sports committee. At the moment the Sports Committee is made up of two boys, three caregivers and a social worker. They can either invite schools or have other (children's) homes come and play with them."* Project Representatives

Most programmes are very responsive to children's needs. At the same time, the potential value of children's involvement in programmes designed to assist and support them has yet to be fully realised across the organisations. As much as children themselves may have limitations of age and experience, assumptions about these limitations may themselves inhibit the kinds of contributions children can make to their own and others lives.

Certainly, just asking children what they wish for reveals their immediate worries and concerns as well as their dreams and hopes. It also reveals just how much the epidemic has intruded on their well being and sense of security. They talk about being cared for and caring for those who look after them. They also worry about their siblings and friends as well as other children who find themselves in similar circumstance. They want to help make sure they and others are looked after.

> *"I wish to look after the family, to help people who are suffering; I want to get my grandmother better so she can take care of us."* Boys Aged 15

They talk about their homes, their wish to find comfort and to have everything they need. They wish for little things – a toy, a ball, a doll, a dress – that are personal and special, things that may be outside the realm of 'basic need' thinking.

> *"I wish for a bicycle, toys and chips ...and some proper clothes, and that we have a big and proper house."* Boy Aged 5

All worry about their education – they want to stay in and finish school. This is not surprising since in both South Africa and Swaziland, schools and schooling are the social spaces specifically designated for children. These children also all wish for a 'normal' future – to become an adult, to work, to have a profession. They mention, amongst others, their desire to become a nurse, a doctor, a social worker, a business man, a mechanical or chemical engineer, a soccer star or just plain famous.

> *"I wish to find a job and live a decent life."* Girl Aged 14

Most of the children hanker after a sense of certainty about their place in the world. They express this in their wishes to stop worrying and having to care so much, of wanting to be younger or older than they are – simply of just being able to be a child.

> *"To (stop) thinking too much about my mother and my problems; I would love to change the way I live now; I would love to live free like any other children; I want to grow up; I want to be young; I wish that there weren't orphans in the world."* Children Various Ages

Children need to be heard and responded to.

Clayton Meyers – Good Shepherd, Middelburg

3.3. Institutions, family and community

Programme activities are significantly shaped by ideas about family, community and institutions and the policies that inform them.

By custom and law, parents are deemed to be the naturally and socially obliged protectors of children in the societies in which we live. Children who are orphaned, by definition, have lost the person or people who are their protectors. In such a context, the challenge for any society is to find a way of replacing the loss of a 'natural adult authority' with a guardian or system of protection that secures the rights, entitlements and needs of children affected in this way.

Historically, there has been one of two kinds of societal responses to the social crisis of being orphaned. Either adult kin – grandparents, aunts, uncles or older children – have been called upon to take up the responsibilities of parenting where their deceased relatives left off; or societies have created systems for surrogate parenting – through fostering and adoption to 'stranger' families or through the creation of institutions for collective child care – commonly known as Children's Homes (or formerly, orphanages).

Lessons of history, combined with contemporary economic thinking, and an idealised notion of both 'the family' and 'the community' greatly favour extended family absorption or in-community surrogate parenting for children affected or orphaned by AIDS. Generally there is a strong disinclination to support the creation of residential child care institutions.

As programmes in this study grapple with making the preferred model work, what comes through is a much more nuanced and subtle understanding of its limits and the challenges that this model poses to securing the well being of children.

The statement that orphanages are not an option for HIV/AIDS orphans is rather categorical. Project respondents appear more or less evenly divided between those who agree and those who disagree with it. Yet on closer examination, the divide is far less clear cut. Many express a distinct preference for a community based, surrogate family model because it keeps children socially and culturally connected and because they feel that institutions are inherently not good places for children to grow up in.

> *"Personally I don't think it is a good idea to put children in institutions. I promote community adoptions; Institutions should be the last option. I feel very strongly about community models, orphanages can't cope."* Project Representatives

Equally, those who support the existence of institutional care, regard institutions as one of several options rather than as the model of preferred care. Their argument centres on the existing limits of family and community as well as the weaknesses of the state social work system, where it exists. While most would like children to remain with relatives or in surrogate families in their communities, the majority recognise that circumstances vary significantly and that, therefore, there will always be children needing institution based care.

> *"Institutions should be seen as an option; There are not enough foster parents, and grandparents are dying; A lot of children are going to lack protection and care; Institutional care has a place, subject to changes in size and structure; I don't agree with government because it does not feel the difficulty we face in the community; We lack resources to support scattered orphans in the community."* Project Representatives

While the preference is for children to be raised in a system of community based, surrogate family care, all project respondents point to its challenges and limitations.

There is a common concern across South Africa about the child support grants provided by the state. These are often difficult to obtain, because children don't have birth certificates and they may live with grandparents, relatives or others who don't know or can't remember when or where they were born. Equally the adults caring for them may not have documentation.

> *"When I began I thought it was an easy job. But it is difficult to get documents and therefore difficult to help."* Project Representative

Also, care grants are differentially age prescribed. Presently, caregivers are eligible for child support grants for children of 11 years of age or younger, whereas foster care grants are awarded to caregivers until the children in their care are 18. As a consequence, children who are not in foster care – the majority of affected children – face an insecure future in their teen years.

And there is a problem of abuse of grants. Child support grants have stimulated a form of rack renting of children in many communities.

> *"Families fight over adoption in order to get the grants; People are guardians of seven children. They get the grants but they abuse them and don't take care of the children; The grants are not used for the children's needs."* **Project Representatives**

> *"When we start grant processing, new relatives come forward to claim the child. They were not there when the mother was sick."* **Female Caregiver responsible for six children**

It can be argued that such abuse is actively stimulated by the state, because while it is willing to put some child protection mechanisms in place, it has not responded similarly to generalised poverty, so that the care grants for children inevitably are conflated with poverty alleviation (Bouille and Meintjies *M&G* Aug 27-Sept 2, 2004).

The problem of poverty also influences the abuse of food parcels and other supports offered children.

> *"Some children live in overcrowded homes – we give them food parcels but they don't get to eat them; Families have their own burdens. You can anticipate hesitancy; Foster parents take children's belongings. The community based care model can be abused by volunteers; Food parcels tempt those who are distributing them to steal as they are also hungry."* **Project Representatives**

Misuse of resources is not simply a matter of poverty. It is also about the challenges of neglect and abuse. One of the widely acknowledged problems of institutional child care is the absence of love and care and the risk of abuse. These are not simply institutional phenomena however – they are also typical of the family even before the crises of family life induced by AIDS. Simply put, children do and can find themselves neglected and abused in families.

> *"Yes, children are in homes but what happens when they are neglected? We need to be concerned about their treatment at home. Children are not stimulated or loved."* **Project Representatives**

> *"The way they live at home. They smell bad. They don't wash when they wake up. They come with dirty clothes."* **Male Caregiver looking after five children**

Neglect can be both wilful or unintentional. The community based home care model and the focus on family in itself, places an enormous burden on already overstretched women, and increasingly children who are the central pillars of everyday family life. It should not be surprising, therefore, that project respondents raise concerns about the burden of care that the model places on care givers.

> *"Caregivers are poorly trained, they lack supervision and direction. They become stressed and burdened and suffer from burnout; It relies entirely on volunteers; They can't cope with terminal illness, transportation and they are financially constrained."* **Project Representatives**

Katlheso and Sabelo at Little Feet Créche – Inkanyezi HIV/AIDS Organisation

Given their own circumstances, where most caregivers mostly depend on state grants (especially the old age pensions of their parents or grandparents) or project related incentives and activities, many wish that they could be paid or rewarded in some way for their care giving.

> *"(You) need to think of volunteers as people who need to eat; We need advice on how to use our volunteer skills to earn a living; I would appreciate it if we could be paid; We need incentives, we work very hard – we need something like R1000 a month, not just R500."* **Project Representative**

Concern about abuse of resources can itself lead to perverse responses. This is reflected in narrow interpretation of bureaucratic criteria, or even illegitimate withholding of entitlements. A caregiver who lives in the house her mother built reports that

> *"The social workers would not leave food parcels because they said my house was too big. This house was built by my mother. Should I break it down to get food parcels?"* **Female Caregiver responsible for four children**

Listening to the children themselves, they talk about being loved and cared for.

> *"I feel as if I have parents because I live a normal life again."* **Boy Aged 15**

> *"I wish that Sisi Sinah will take care of me because my mother has passed away and I do not know any one this side."* **Girl Aged 5**

And they talk frankly when they find themselves in uncaring and unloving situations.

> *"They are not good to us. They are not kind. They don't talk nicely. We eat bad food. They could try and be more caring. The sisters are cruel and they make us work too hard."* **Girl Aged 14**

Abuse arises out of the inequality of power between adults and children and, as is well known, it occurs in all contexts of child care.

Some people believe that the propensity to abuse increases in institutional settings, but there is no evidence of that. In fact, perhaps the opposite is the case. Children's homes often create safe places for children who are abused in their homes.

> *"Perhaps as we speak my mother is drunk. My mother was selling me off to older men to sleep with me. She was always drunk and so she could not look after my younger sisters."* **Girl Aged 14**

> *"My brothers and sisters are at home. My mother used to beat me up and say that I slept with her boyfriend. Later she asked other men to sleep with me."* **Girl Aged 17**

Although not intentional, the model of community based home care creates dependency. On the one hand vulnerable families at times become dependent on care givers. In the worst case scenario, for example,

> *"They have a 'patient' and they do nothing for her until the caregiver comes."* **Project Representative**

On the other hand, the caregivers themselves come to depend on the model to help them with livelihood. This is an inherently positive feature of community based home care in so far as it provides for some income and resources relief, but like subsistence agriculture, it is presently simply a survival strategy that will do little to lift caregivers and their families out of poverty unless it is built into the functioning of the formal economy.

Project respondents point to family and community concerns that the system is intrusive and pries into their private lives.

> *"They think that we come to their homes to spy on how they treat the elderly and abuse children. It takes time to motivate them."* **Project Representative**

And there are contexts where the model of community care just can't work, because people live more as a collection of individuals than anything that might resemble notions of community.

> *"Community care in the inner city is very limited. People move a lot, they are difficult to track, there*

> *is generally poor sanitation and there is a lot of crime, including trafficking in people. On the streets, you need small orphanages."* **Project Representative**

All this has a direct impact on the interface between institutional and community based care.

Children in institutional care are more likely to have their physical needs addressed at a higher level than if they were living in the homes of relatives, who themselves are invariably poorer.

> *"In the orphanage they are all treated equally. Despite insufficient resources they are well maintained and catered for."* **Project Representative**

When the focus is on physical resources, not surprisingly children make comparisons between institutions as well as between the institutions they are in and the homes of relatives.

> *"In cluster homes there is competition and children compare the facilities. This makes them less satisfied and they want to leave for the one with better resources; Children don't want to go back home as they feel that the lifestyle is different and there are inadequate resources. They are no longer used to a house with no electricity, hot water or TV. They also say that at home they don't eat food, such as macaroni, instead its just puthu everyday; They feel that they are much better off than those staying in shacks."* **Project Representatives**

These differences make the task of encouraging children to keep contact with family and community that much more difficult. Children also sometimes actively resist placement.

> *"Finding families is always a challenge. Children become funny and uncontrollable when they are with families."*
> **Project Representatives**

Lastly there is the issue of children's sense of themselves and their place in society. Widely recognised to be a problem for children in institutional care, it is not generally acknowledged that many children face a similar challenge in community based care. This, largely, is because of the assumption that self esteem and identity issues will be addressed automatically in family settings. In reality this is not necessarily the case. There are many accounts of orphaned and vulnerable children who struggle for a place in their worlds.

> *"A family member gets scared of the child whose parents died. They are usually not willing to take the child in; Families who were infected are marginalized by their extended family – they accuse each other of witchcraft."*
> **Project Representatives**

3.4 Responding to the challenges

All respondents readily recognise that community based home care for children is a model with many challenges. Programmes in this study are making efforts and have ideas about how to try address some of these weaknesses. The very need for institutional care is a positive and responsible alternative response where community based family care fails.

Grannies and teenagers take care of orphans – Good Shepherd, Middelburg

At the same time, project respondents working in institutionally based, child care programmes are possibly most conscious and proactive about their limitations both because of their disfavoured status in the larger scheme of things, and because ideally, they too support a system that keeps children closely linked to community.

> *"There are a variety of issues affecting different children, especially in this home. As a nurse and a nun, I have been fortunate to not only heal children physically, but to understand the need for children to be loved and cared for. This is what we try to do here."* Project Representative

> *"We realise that we are not treating children in a way that is the norm in society. This usually creates problems of adjusting for children when they have to leave the home. So we now bring both boys and girls into the home. Children from the community attend classes in the home. We enrol (them) in early childhood development classes. We look after sick children. And we encourage visits to families and friends in the community."* Project Representative

> *"Our motto is to care for children holistically as individuals and in groups."* Project Representative

When it comes to community based child care, which succinctly put, requires "ensur(ing) that children are safe in their homes, that they get responsible adult care and that the structures are in place to make it work" a variety of things need to occur in order to get it to work properly. According to project representatives these include:

- interventions with families – surrogate or kin – to provide them with the necessary support and guidance, and to raise their knowledge and understanding of the issues involved in fulfilling their undertaking to the children in their care;
- interventions with caregivers that capacitate, support and supervise them on an ongoing basis
- active engagements with communities, to raise their awareness and understanding of community based care for children;
- communication and networking strategies with all stakeholders including parish structures, crèches, ward counsellors and other non-governmental and governmental organisations
- strategic interventions to get communities to take full responsibility for programmes and initiatives so that they are independent and self sustaining;
- making inroads into the challenges of transport on which so much of the success of community based care hinges
- strategies to address the issues of livelihoods

For the most part, programmes in this study have tried to address one or even several aspects of these concerns. For optimal realisation of the model, however, there is a need for structural and organisational changes to occur together. These need and can be catalysed and supported by the organisations involved in the care of vulnerable and orphaned children, but they have to be driven collectively by all parts of the system.

4. Impacts


Nompumi Sitsi, Naledi Créche – Good Samaritan Hospice, Bethulie, Free State

The challenges of child care for orphans and vulnerable children, many of which have already been described, need to be read against the positive impacts of these programmes. These can be quantified in terms of the number of food parcels distributed, feeding schemes run, children placed in families or in institutions, child care and other grants secured, counselling sessions held, awareness campaigns run, school placements secured or paid for, uniforms and school materials bought; crèches run etc. These numbers matter and they are kept by many projects, often for accounting and monitoring purposes. They certainly can usefully be used for planning and strategic management decision making although the extent to which they are used in this way was not explored in the study.

Equally, it is important to recognise that numbers only account for part of the impact of these programmes. The qualitative stories give us insight into how these numbers translate into individual, family and collective life. In many programmes qualitative information is collected informally rather than formally, which suggests that it is likely to be used in an ad hoc and unsystematic way, if at all.

Drawing from their responses to questions, respondents are generally very positive about the impacts these programmes are having on the children, families and communities they serve.

The emergency food relief schemes run by many programmes address the crisis of hunger that confronts children and adults affected by HIV and AIDS. Although these interventions especially target children, more often than not, they are channelled and supplied through families.

> *"The feeding scheme has meant that there is no more malnutrition, there is personal growth and children are opening up to us and each other. Feeding schemes are received very positively because old people no longer feel left out; We give them a decent meal, keep them off the streets, give them a sense of belonging; Children and family are integrated in a more holistic way – concern is shown for all (the family) not just the one who is lying (sick); People are helped by us with food, counselling and education; They say they can survive because they have food."* **Project Representatives**

> *"The project pays for my school fees and trips and they provide me and my younger brother and sisters with clothes."* **Girl child aged 15.**

> *"At crèche, they get healthy food. We cook fresh food and teach them to do it at weekends."* **Female Caregiver**

Similarly, education related interventions – be they payment or negotiation of school fees with local schools or the provision of uniforms, books or other materials, keeps children in school.

> *"Families are proud to say the child is theirs because they are able to send their children to school; We address*

> *their educational needs and help financially; Children and their families are going to bed with food and they can go to a place where they can be heard. Children can also go to school."* **Project Representatives**

Helping families access child care grants has a similarly positive effect in respect of their food, educational and other needs in the short and medium term.

> *"When they have ids, they get grants and these give them access to income and entitlements; I see happiness when they get the grant – they can buy food and go to school."* **Project Representatives**

The impacts of providing children with shelter and care, be it in institutions or in surrogate families, are also evidently positive.

> *"We save the lives of about 400 babies each month; We have been able to give children a place to be themselves; Children are placed in closely monitored families. They are given space to love and to grow; We see an improved life style because they are cared for."* **Project Representatives**

> *"They help us take care of these children, to give them love and protect them from bad people; Taking children from the streets and putting them with families gives them hope."* **Caregivers**

Generally, project representatives talk of the relief that their programmes provide from the burden of care that poverty and AIDS impose as well as the hope and dignity that they are able to bring to affected individuals, families and communities.

> *"We have been able to help unload the burden these families are experiencing; We are able to restore individual and family dignity; We give a lot of hope to children and families; We offer people a dignified way to die. (Recalling the words of a woman on her death bed) She said that it was the happiest day of her life because she had been treated with dignity."* **Project Representatives**

The notion of community is complex. It is used inter alia as a reference to people in a specific locality, to black people, to the Catholic Church, or to everyone outside the programme itself. Furthermore, most programmes don't have systematic ways of assessing and determining community responses to their initiatives. In the absence of a common definition as well as clear indicators and systems to assess these, they therefore rely on uptake and feedback from the people who use their services or who respond to their requests for assistance and support to understand community perceptions.

All project representatives believe that the communities they serve are positive and supportive of their programmes. This is reflected in the requests for and offers of help that they receive and in the responses of the children and caregivers who they interact with.

> *"The community encourages and assists us; The community is coming in large numbers to ask for help, for food and clothes; People in the community send others to us. They are volunteering to work with us and more are disclosing their status; The larger community is waking up. There is interest, curiosity, offers of help, local churches bring clothes; The parish is supportive, schools make donations; The perceive the project as a place of sustenance even for the hungry. They also think that it is a place that can help protect their children and they are ready to drop off abandoned children at the home because they trust and believe in it. Mothers who cannot look after their children bring them to us."* **Project Representatives**

It is also reflected in the impacts that go beyond any specific interventions.

> *"The community impact of this programme is wider – 'Education for Life' is sought after by the principal at the local school, and headmen encourage young people to attend behaviour change (courses); There is more of a coordinated effort. We are raising awareness;"* **Project Representatives**

> *"I was a client, now I am caregiver. I have grown; If (this) centre stops I will personally suffer. It alleviates my stress and I don't dwell on frustrations."* **Caregivers**

There are significant livelihood dimensions of these programmes which project representatives but especially caregivers and volunteers recognise.

> *"There has been livelihood created for the volunteers who feel that R400 is better than nothing for their families as there are no jobs."* P**Project Representatives**

> *"(If the programme stopped) I'd have no job; We would starve because there are no jobs out there; Who would help the children? Who would help our families?"* **Project Representatives**

All impacts are not necessarily easily achieved, however. Several respondents talk of the difficulties of getting people to come forward as volunteers or caregivers, suggesting that responses have been slower than they anticipated. Several project respondents also suggest that at times, there have been negative responses from people in the communities, although none of these appear to have involved any kind of collective negative reaction from communities as a whole. These arise for various reasons, including fear, misunderstanding, unmet expectations, parochial jealousies, or bad personal experiences.

> *"People associate Sizanani with the hospice, so they are afraid because they think of death; Some families don't want us to come to their homes because people will think that they are HIV positive; the community believed that anyone who came to the project was living with AIDS; They complain that we don't cover all areas, but we are very few; There is jealousy but we try to educate people and show them that we mean business."* **Project Representatives**

Sometimes negative responses come from within institutions or care centres or from other groups.

> *"There has been a negative response from older residents who feel children are not entitled to be here; the negative responses come from inside the care centre; other groups compete but we try to ignore them."* **Project Representatives**

Generally, such responses are to be expected. The critical point is that project respondents have actively worked to overcome negative responses as they have arisen or become aware of them or they have tried to ignore those that they felt to be petty or irrelevant to their programmatic objectives.

Project respondents readily acknowledge that a better understanding of the impact of their programmes would assist them with their work. They point to the need for:

- developing the skills sets needed by general staff and managers
- guidance on how to develop a more systematic approach
- regular stakeholder/user surveys
- more information for caregivers
- a review of the manual – in respect of content and language
- monitoring and evaluation
- more structure
- more infrastructure (computers, physical space, transport)

Orphans at Naledi Créche – Good Samaritan Hospice, Bethulie, Free State

5. Lessons from Experience

Project respondents, caregivers and children all provide us with valuable insights into programmatic efforts by SACBC partners to address the needs of orphaned and vulnerable children in resource poor communities in South Africa and Swaziland.

Child care in a complex context of poverty, inequality, family breakdown and a generalised HIV/AIDS pandemic requires a spectrum of responses rather than an either/or approach. Across this spectrum, all approaches require strategic thinking followed by practical responses to make them work in the best interest of the children that they serve.

It needs to be reiterated that these programmes have developed because children find themselves unprotected and uncared for in society. They are, by definition, a response to system failure that is caused, especially in southern Africa, by the impact of HIV and AIDS on individuals and their families and therefore the communities in which they live.

Programmes invariably seek to fill gaps and respond to needs in a way that addresses these immediately. However, many are also trying to find systemic solutions for the medium and longer term. A lot of what they can and want to do depends on the policy and social environment in which the programmes are operating.

The programmes in this study have numerous lessons to share based on their experiences of and engagement with the many challenges that face interventions to support children in need. To make sense of these, they have been grouped by what they have to say about the model and the who, what, where, when and how of intervention.

The Model

Community-based surrogate family care is the preferred model for intervening to care for orphaned and vulnerable children. There are real integrative and normalising benefits of attending to the needs of children through kin or surrogate family based care. And it is an approach that can be sustained into the medium and long term.

This said, the model has limitations, which include the potential for the abuse of children and the misuse of resources. These are serious issues that have to be planned for, not least of all because they already occur in families that are not surrogate. Programmes can anticipate them by having plans for their active management through prevention and remedial action.

Community based surrogate family care may also not be able to cope with the scale of orphanhood that AIDS is generating in South Africa and Swaziland. There already is a shortage of foster care placements and other forms of surrogate care may too become saturated. Also the model responds weakly to the needs of teenage children affected by AIDS or domestic disintegration. Both caregivers and children identify shelter as a large and desired need. There is a need to develop interventions that will respond to the specific concerns and requirements of the growing number of adolescent and teenage children who find themselves out of home and out of place.

The preference for community based family care for orphaned and vulnerable children does and should not preclude institutional based child care options be they homes, shelters or hospices. Institutional based care is an appropriate response to family based care that fails, is absent or is unable to meet specialised needs – especially where children are chronically sick or severely disabled.

There is agreement that institutional care works best where it is contained in size, is physically and socially integrated into local community life, empowers children to become sociable, independent and responsible and is systematically monitored by organisations that are not involved in its routine daily functioning.

Who to serve

Thinking through who should or ought to be served by the intervention is critical. The general sentiment is that it is important to concentrate on all children be they orphaned, vulnerable, abused or disabled, rather than on orphans only. Inclusivity means that children are not identified by their problems but by their status as children. This approach works for some kinds of interventions like those that supplement food and clothing as well as school materials and school placements. However, it can be difficult to achieve in holistic programmes because it requires a complex skills set that can deal appropriately with the needs of children of various ages and statuses.

Surrogate family care in community presumes that many interventions to support children and their needs are mediated by adults. Several programmes recognise, therefore, that the best and most effective way of supporting children is to ensure that the adults who care for them get the necessary support. This means that interventions, by definition, need to include adult carers in their focus whether they are AIDS sick parents or caregivers who have taken over the parenting of affected or infected children.

What to do

There is a need to make provision for children's special needs. South Africa already does this by law and Swaziland is in the process of creating a policy on children. However, where there is generalised poverty – as is the case in both countries in the communities served by these programmes and beyond – interventions to attend to the special needs of children inevitably conflate children's needs with efforts to relieve poverty, mostly because there is little in place to specifically address adult and child poverty. In designing interventions, therefore it is important to engage with the challenges of poverty and of policy in a way that does not countermand efforts to assist and support children in need.

Orphaned and vulnerable children have multiple needs and there is no formulaic answer that can meet these adequately and at all times. While some programmes are very focused in what they do, most argue for and some are able to offer more holistic care. Whatever service they deliver or need they attend to, all recognise that their effect is greatest when they actively network with other organisations.

Many programmes focus on alleviating

Alona Finiza, 5 years old, HIV+ – Good Shepherd, Middelburg immediate physical needs, especially where children are hungry and without adequate clothing to keep them warm. At the same time, there is widespread recognition that children who have been exposed to parental death, family disruption and looming or actual disintegration also need emotional support as they are often profoundly traumatised. Psychological and emotional interventions are not seen as being urgent in the same way as those responding to physical needs. Yet, by their accounts from experience, is this really the case? Can or should emotional trauma be seen as a second order need that may or may not be attended to down the line? Or should it be something that is understood as integral to the experience of being affected by AIDS, and therefore integral to programmes that intervene to help children? Obviously, to adopt this approach requires professionally supported interventions so that volunteers and caregivers are equipped to address this need. But this requirement is no different from providing ARV and other medications to HIV positive people who progress to AIDS.

Approaches to Intervention

Experience shows that there are better and there are worse ways of conceptualising and developing programmes and interventions. Drawing from the knowledge gained in these programmes there are some critical ideas that need consideration. These are not presented in any order of priority.

i) The role of children

Various project respondents recognise that children can and do make very valuable inputs into both the conceptualisation of programmes and the implementation of interventions. In other words, they should not be treated merely as the end recipients of interventions but rather they should be involved as active participants in them, age and capacity considerations obviously withstanding. Children's experiences of interventions also provide valuable feedback that can assist programmes to effectively meet their own objectives.

ii) Community involvement

Community based child care, almost by definition, requires the active participation of community members as individuals and in their organisational capacity in order to take root. The strength and sustainability of programmes and interventions depends considerably on the extent to which the community is included in them, either by helping conceptualise them from the outset, or through their involvement in their implementation, or just by raising their understanding of the issues that the needs of orphan and vulnerable children raise. Community involvement creates opportunities for people, builds partnerships and creates spaces for others to respond to the inevitable gaps that arise. These all are critical to the sustainability of programmes or particular interventions. As programmes strengthen networks between people and organisations they also build citizenship, which in turn contributes to people's sense of belonging and responsibility towards each other.

iii) Financial Resourcing

Experience suggests that it is important to raise financial resources in advance and in a way that ensures consistency and continuity. This means that is important to have enough resources in place to start any imitative. And while all programmes can and do continuously seek donations to enhance their functioning, these should not be relied on to sustain them unless they have been regularised into long term commitments.

iv) *Sustainability*

In addition to securing finance two critical and related issues need to be addressed in order to ensure the sustainability of these programmes in resource poor, livelihood constrained environments. The one relates to retaining and developing volunteer and caregiver capacity through some form of regularised incentive system. Not all programmes pay volunteers. To survive, volunteer carers are forced to look for ways of getting resources which often distract and reduce the kinds of inputs they are able or willing to make. The very success of creating supports services for a system of community based family care for people living with and affected by AIDS demands reliability and consistency – especially as we enter into it an antiretroviral treatment phase. This, in turn, requires finding ways of linking livelihood security to volunteerism.

The second relates to embedding child care programmes in community life in ways that translate into livelihood generation activities other than through direct employment in the interventions themselves. With the right supports from government, faith based organisations and relevant professional and non-governmental services, child care, aged care and care for the disabled and chronically ill are all potential services that can be developed at local community level. There are already some examples in operation in the form of crèches for preschoolers and aftercare centres for scholars in the communities. Such initiatives need to become integral to all dimensions of programme activity and in all geographical areas.

v) *Planning*

Planning is about conceptualising what the organisation or initiative wants to do – setting goals and objectives – and then developing a clear set of activities and processes that will make them realisable. Planning makes it possible to identify the resources needed – financial, personnel, infrastructure etc. It makes it clear to others – be they implementing partners or intended beneficiaries – where the focus of activity will be and therefore what can and can't be expected from the programme or intervention. And it makes clear the parameters of engagement to the organisation itself.

Creating and implementing plans require information. There is a wealth of data already in the programmes that presently either is unused or poorly used by them. Equally, there is information that is needed by programmes that is missing because it is not collected systematically. These are present weaknesses that need to be addressed since both strategic planning and operational management of these programmes need to be informed by quantitative and qualitative data. If

Orphan at Good Shepherd, Middelburg

they are collected systematically and used purposively they will help these initiatives achieve their specific programmatic objectives, engage in the larger issues of policy and resourcing and assist with practical day to day management.

vi) Personnel

The level of education of project respondents interviewed is high. They also bring to their work considerable experience and especially a desire to learn and grow. This is evidenced by the fact that most of their learning about children and HIV and AIDS interventions has been 'on the job'. This is a huge resource in the SACBC programmes that needs to be tapped and channelled effectively.

The knowledge required to work in AIDS is both vast and fast moving. It is inappropriate to imagine or expect that any one individual will have all the requisite skills or be up to date in information and practices in all aspects in the field. This means that expertise has to be built continuously and it has to be complemented through team work. Furthermore, and perhaps most critical to these programmes, dealing as they do with children in complex adult and community contexts, there is a need to grow and deepen the organisational and management skills of all personnel.

This means that in addition to the need for staff to be properly selected it really is important that programmes build continuous education and training into their plans and practices for personnel.

Equally, ongoing education and training need to be integral to their intervention strategy with volunteer caregivers and children since they are key implementing partners and beneficiaries respectively. Everyone needs to be bought into a continuous learning framework.

The role of the Southern African Catholic Bishops' Conference.

While this study has not looked at the SACBC directly in terms of its objectives and functioning, from the programmes' perspective, it is seen as a coordinating and integrating partner that has a key role to play in the development and ultimate success of church driven initiatives to support orphans and vulnerable children. Especially it is felt that it should concentrate on

1. procurement or assistance with the provision of funding to help projects meet their objectives;
2. education and training in order to develop project and stakeholder capacity and skills in the areas of their work;
3. networking to encourage sharing of experiences and resources;
4. information provision and sharing in order to ensure that projects and programmes keep up to date with developments in their specific areas as well as in the larger policy environment, and
5. creating a platform for innovative thinking and strategic planning.

Conclusion

HIV and AIDS transforms the lives of everyone who is touched by the disease and epidemic. Sparked by the evident and ongoing crisis of care for children caused by AIDS related deaths, the programmes in this study show just how important grass roots initiatives are to the lives of people marginalised by poverty and disease. They are the kernel of a response system to this epidemic that will help present and future generations survive the epidemic. With the right support and commitment from governments and other partners, they have the potential to give millions of children the chance to live a decent life and to create a decent future.

Orphan at Naledi Créche, Good Samaritan Hospice, Bethulie, Free State

Endnotes

1. Children Affected by HIV and AIDS Consultation and Reflection with SACBC partner programmes in South Africa and Swaziland – March -September 2004.
2. Anthony Ambrose, Emmanuel Modikwane, Sr Ouma Nakedi, Hector Rakhetsi were from the SACBC. Nelisiwe Zondi, and independent consultant assisted with field work in KwaZulu Natal.
3. Tessa Marcus (Phd) – Principal Investigator.
4. SACBC Study Workshop and SACBC Study Mind-Map.
5. National Policy on Children including Orphans and Vulnerable Children in Swaziland October 2003.

Appendix

SACBC Projects and Programmes in the CAFOD Partner Study					
Diocese	**Province**	**Project**	**Project Type**	**Date Initiated**	**Beneficiaries**
Ingwavuma Diocese	KwaZulu-Natal – South Africa	1. Nkulunkulu Unathi HIV/AIDS Project	Community based home care to AIDS sick, vulnerable and orphaned children	2001	1420 HBC and 900 clinic patients
		2. Ndumo School Orphan Project	School based support to orphans and vulnerable children	2000	491 orphans in nine schools
		3. Malusi Omuhle HIV/AIDS Project	Community based home care to AIDS sick	2002	639 AIDS and other chronically sick
Archdiocese of Durban	KwaZulu Natal-South Africa	4. St Theresa's Children's Home	Residential care and support to children	Est. 1925	15 children in residence, 80 in community
Dundee Diocese	KwaZulu Natal – South Africa	5. Damesfontein Home Based Care	Community based home care to AIDS sick and orphans and vulnerable children	2003	390 AIDS affected families
		6. Philisa Orphan Care	Community based home care to AIDS sick and orphans and vulnerable children	1998	306 children of whom 60% HIV positive in eMzinyoni township, Bethal
		7. St Anthony's Home	Residential home care and outreach	1953	Presently 8 children in residence – number fluctuate due to death, a further 40 supported in community
Diocese of Eshowe	KwaZulu-Natal – South Africa	8. Holy Cross Hospice	Hospice, Day Care, Community based family care, outreach, youth, traditional healing	2000	1067 orphaned children in and around Gingindlovu, including 80 child headed families
		9. Brotherhood of Blessed Gerard	Hospice with 46 beds and 4 cots, community based home care	1992	Serves a population of poor people – services delivered through 550 volunteers, nurses, doctors and other professionals

Diocese	Province	Project	Project Type	Date Initiated	Beneficiaries
Diocese of Mariannhill	KwaZulu-Natal – South Africa	10. Assissi Cluster Homes (commonly known as Thembalethu)	Temporary /foster care for HIV and AIDS affected and other vulnerable children	2001	Four staff and six caregivers serving a variable number of children
Manzini Diocese	Manzini – Swaziland	11. Orphanaid Project	Orphans and vulnerable children in community based home care	1999	1900 orphans and vulnerable children
Witbank Diocese	Mpumalanga – South Africa	12. Thembalethu Home Based Care	Psychological social interventions with caregivers, children, and educators	1999	3500 orphans in 12 villages in Nkomazi Region
		13. Malelane Catholic Parish	Food relief to orphans and vulnerable children; community based home care	2004	1400 children Mozambiquan and Swaziland children/ refugees
		14. St Kizito (Glen-Cowie)	Care and counselling for children made vulnerable by AIDS	2002	100 orphans
Johannesburg Diocese	Gauteng – South Africa	15. The Love of Christ Ministries	Care for new born and abandoned babies	1993	50 babies at present – total of 289 since establishment
		16. St Joseph Ithuteng Campaign	Support group and income generation for OVCs and people living with AIDS	2000	20 orphans and 126 people living with HIV and AIDS in Meadowlands, Soweto
		17. Sithand'Izingane Care Project	Drop in after care centre for orphans and vulnerable children, income generation, support to carers	2001	30 orphan children in Brakpan and surrounds
		18. St Francis Care Centre	Hospice, palliative care, care for children 0-7; ARV treatment	1992	48 adults and 30 children from Boksburg and surrounds
		19. Inkanyezi HIV/AIDS Organization	Emergency food, self help, outreach to orphans and vulnerable children	2001	Unspecified number of children and their families in Orange Farm, Johannesburg

Diocese	Province	Project	Project Type	Date Initiated	Beneficiaries
		20. Maforonation Home Based Care	Community based family care, drop in centre, outreach	1993	70 children in Etwatwa Daveyton informal settlement
		21. Nazareth House	Specialised care for the elderly, abandoned babies, mentally challenged, HIV and AIDS orphans- ARV treatment	Est. 1864. Special unit for AIDS in 1997	Specialised HIV/ AIDS unit looks after 33 babies and infants; total staff 75 for all services; service
Archdiocese of Pretoria	Gauteng – South Africa	22. St Joseph's Care and Support Trust	Hospice and Palliative care; food relief, community based family care, ARVs, food relief	1999	600 patients,150 orphans and vulnerable children, 40 foster parents, nutritional assistance to 500 children, ARV treatment and support to 200 people
		23. Solofelang Botshelo Care Centre	Educare centres for of 0-18 year olds, homework support, meal a day to service 20 villages	2004?	Service to unspecified number of children in St Kizito Parish, Marapyane and surrounding villages
Diocese of Pietersburg	Limpopo – South Africa	24. Bela Bela HIV/ AIDS Prevention Group	Community based family care, ARV, outreach, income generation	1996	Over 296 orphans in Warmbaths and surrounds
Diocese of Rustenburg	North West Province- South Africa	25. Tapologo HIV/ AIDS Programme	Outreach, counselling and adherence to TB and ARV medications	1994	Unspecified number of patients in Freedom Park informal settlement
Diocese of Kimberley	Northern Cape – South Africa	26. Zenzeleni Wellness Centre	Crèche to support children living with HIV, assist caregivers generate income	1999	60 children
		27. Ntime o mphele ngwana	Community based home care, food and state grant support, awareness for guardians and parents	2001	Unspecified numbers supported in Taung

Diocese	Province	Project	Project Type	Date Initiated	Beneficiaries
Diocese of Tzaneen		28. Kurisanani HIV/AIDS Orphans and Vulnerable Children's Project	Various programmes to support HIV infected and AIDS affected children	2001	Identified 288 orphans and vulnerable children, 25 children in direct care of whom 23 HIV positive
Johannesburg Diocese	Gauteng	29. Impilo Health Care Programme – Hillbrow; Johannesburg	Care services to the homeless and destitute community within the inner city of Johannesburg.	1997	450 Orphans per year
		30. Family Community Services (Catholic Women's League)	Statutory intervention with orphans and vulnerable children Develop strategies for placement / foster care / adoption	2001	170 Children
National		31. Catholic Institute of Education – HIV/AIDS and Gender Unit	Assists schools in policies; life skills training. Pastoral Care; Education Access Programme	1985	350 Schools around South Africa
Archdiocese of Bloemfontein	Free State	32. Siyathokoza, Botshabelo	HBC, ARV Treatment, Feeding Scheme; Day Care Centre	2000	160 Adults are under HBC; Children are 55 taken care
De Aar Diocese	Eastern Cape	33. Good Shepherd Hospice, Middleburg	Main focus on Community Home Based Care and OVCs	1994	50 orphans and 163 Adults under HBC supervision
Aliwal Diocese	Free State	34. Good Samaritan Hospice – Bethulie	Focuses on HBC and OVC with strong emphasis on Child Therapy and Education	2002	120 children
16 Dioceses	8 Provinces in South Africa and 1 in Swaziland	34 Projects			

Lesetho, 6 months old, and blind – Siyathokoza, Botshabelo, Middelburg

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