

**ENHANCING THE AGENCY OF FAMILIES AFFECTED BY AIDS:
STRATEGIES FOR THE CHURCH AT Ilinge TOWNSHIP,
QUEENSTOWN**

BY

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ABSTRACT

HIV/AIDS is a challenge that African society will have to contend with for a number of years to come. Sub-Saharan Africa is the region most affected by HIV/AIDS in the world. The combination of poverty, natural disasters, violence, abuse of women and children, social and political chaos, and mass migration to cities, all accelerate the spread of HIV. Equally, HIV/AIDS increases the risk of a household or individual becoming more impoverished and makes communities vulnerable to other infectious and poverty-related diseases such as tuberculosis. It presents a huge challenge to the church.

South Africa's HIV/AIDS statistics are alarming and the nation is beginning to feel the impact through the loss of economically active people, increasing demand on health care, child headed households and increasing mortality rate due to AIDS. AIDS undermines life and the great possibilities that our new democracy could bring.

Faced with the devastating impact of AIDS, families and communities seek ways and means of surviving and carry on with life. They utilise every resource at their disposal to make a living. Making use of the sustainable livelihoods approach, this study recognises this fact and investigates how people survive, what resources or assets they have, how they utilise these, the constraints they are faced with both in

accessing and in utilising resources, and how the culmination of these efforts impacts upon them. Building on these insights this study focused on how the church at Ilinge Township in Queenstown could enhance the agency of families affected by AIDS.

The study argues that the church can contribute by (i) addressing the underlying factors that contribute to the vulnerability context; (ii) building the asset portfolio of households affected by AIDS; (iii) challenging the policies and structures which inhibit the livelihood options of such households; and (iv) enhancing the existing livelihood strategies. Examples of each of these actions, drawn from the context of Ilinge, are provided.

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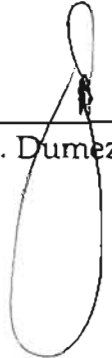
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DECLARATION

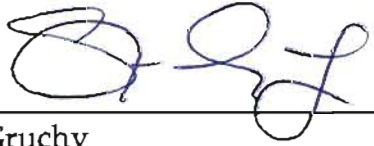
This is to declare that this dissertation, unless specifically indicated to the contrary in the text, is my own original work.



B. M. Dumezweni

21-10-2004
Date

As supervisor, I agree to the submission of this thesis.



Dr S. De Gruchy

21-10-04
Date

CHAPTER 1

Raison d'être for this research study

1. Introduction

Any study that has a particular reference to HIV/AIDS demands a presentation of the current state of the epidemic. This is done to highlight the urgency for effective responses to curbing the further spread of HIV and controlling the overall impact of AIDS on human life. It has been said that AIDS is a major catastrophe that African society has had to face. There have been other catastrophes like malaria, *Ebola*, wars, famines, floods, earthquakes and these have happened at different places in different times, but AIDS is sweeping the world and Sub-Saharan Africa in particular, at the same time, and the impact is enormous.

South Africa has one of the fastest growing HIV/AIDS epidemics in the world. The estimate of the national HIV prevalence for 2001 was that 2,65 million women and 2,09 million men between the ages of 15-49 were living with AIDS. The estimate of the total population infected was 4,70 million in 2002.¹ The rate of infection is said to be stabilising, however the impact of the disease continues to be frightening. The estimated figures can be challenged because people are still reluctant to test for HIV as a result of fear and the stigma attached to the disease. Therefore these figures estimated might be far less than the actual infections and that means we might be in a bigger crisis than we care to admit. For example, the Actuarial Society of South Africa estimates that 6,5 million people were infected with HIV by July 2002.² These figures are significantly different from the government statistics and that leaves a sensitive case for debate.

¹ Avert.Org. "South Africa HIV/AIDS Statistics", 1 October 2003 at <http://www.avert.org/safricastats.htm>

² Rob Dorrington, Debbie Bradshaw and Debbie Budlender. *HIV/AIDS Profile in the Provinces of South Africa: Indicators for 2002* at <http://www.petech.ac.za/aids/documents/hiv-aids%20in%20south%20africa.pdf>

At the South African AIDS Conference held in Durban, August 2003 researchers noted that of the 14,000 people who are infected with HIV everyday worldwide, 600 are in South Africa. These scientists reported that the mortality rate due to HIV is beginning to surpass the infection rate. For males between 20-40 years it has increased by more than 150 % since 1998 and for females it has risen even more. Quarrusha Abdool Karim of the University of Natal said, "even though the increasing death rates could stabilise the country's overall AIDS prevalence, it would be premature and foolish to believe that AIDS was under control in South Africa". She adds, "along with a rising number of deaths, there will continue to be a high rate of infection and more AIDS orphans will be stranded. A rising mortality rate should not be allowed to mask the fact that many people are still being infected".³

It is disturbing that our President Thabo Mbeki in an interview with the South African Broadcasting Corporation on the 08 February 2004 retorted that there are no statistics for AIDS deaths in South Africa, meaning that the anxiety about AIDS is not founded on facts. Secondly, he said that AIDS is similar to other pandemics like diabetes that are not often talked about so it unfairly dominates the health-care debates. I felt a tinge of annoyance as he said this wondering if he is not aware of the research that has been done by state institutions; Statistics South Africa and the Medical Research Council. His stance on AIDS is terrifying and continues to cause a lot of confusion and despair.

On the 21 November 2002, Statistics South Africa published a report of the study done on the causes of death in South Africa. The sample of the study was 12% of death certificates for the period 1997-2001. The findings of the study showed increasing cases of TB, HIV, influenza and pneumonia (all of which are AIDS related) as the major causes of death and it is said that during the period studied, the proportions of unnatural deaths were decreasing. The Medical Research

³ The Body: An AIDS and HIV Information Resource: HIV/AIDS Newsroom. *Gloomy HIV/AIDS Statistics Cited at South African AIDS Conference, 5 August 2003 at http://www.thebody.com/kaiser/2003/aug5_03/south_africa_conference.html*

Council also released a report in 2002 in which it estimated that about 25% of all deaths in South Africa were due to HIV/ AIDS, whilst the Statistics South Africa's report showed a lower percentage of 9%. Dr Debbie Bradshaw of the MRC Burden of Disease Research Unit, argues that this difference was a result of the Statistics South Africa's study depending on the causes of death as per death certificates and the MRC on the other hand, assessed the 'impact of HIV/ AIDS as an underlying cause of death based on the observed excess mortality among young adults'.⁴

It is against this background that this research seeks to investigate how families survive and cope with the distressing HIV diagnosis with a view to enabling the church to make an appropriate intervention. Using the Sustainable Livelihoods Framework, the study seeks to identify the assets and coping strategies that people employ to survive, as opposed to a "client-based" approach whose entry point is to identify problems and hope to come up with solutions to address those.

Development approaches have exploited communities and nations making them believe that they are dependent on the outsiders for their development. The capacity or asset focused approach on the other hand, seeks to develop policies that recognise the capacities, skills and assets of the community. The work that the community is already doing and people's own contribution to their lives and livelihoods are recognised, and the people set the tone for their development.

John Kretzman and John McKnight in their work, *Building Communities From The Inside Out: A Path Toward Finding And Mobilising A Community's Assets* present a framework for community mobilisation: the mapping of assets, relationship building, mobilising for economic development and information sharing, developing vision and leveraging for outside resources.⁵ The mapping of assets recognises the need to invite everyone into the development process. This therefore

⁴ Debbie Bradshaw of MRC Burden of Disease Research. *Causes of Death in South Africa 1997-2001* at <http://www.afroaidsinfo.org/content/research/epidemiology/statssa.htm>

⁵ John P. Kretzman and John L. McKnight. *Building Communities From The Inside Out: A path toward finding and mobilizing a Community's Assets* (Chicago: ACTA Publications, 1993)

involves all the parties that have been marginalised and “decided for”. In our context this would mean black people, women, the youth, the elderly, the disabled and people infected and affected with AIDS.

The one developmental approach of the South African democratic government in this regard was the Reconstruction and Development Programme. The RDP’s fundamental objective was to involve people at grass roots level in the development of their communities and policy issues thereof. I am not sure if the current macro-economic policy, GEAR, encourages the same, considering the initial conception of the policy and its implementation.

In a country characterised by xenophobia, pockets of racism, discrimination against people who are ‘different’ and tribalism, relationship building should be a priority in the debate. Recognising the contribution of people living with AIDS in local development would take a paradigm shift for many South Africans because the common idea is that “they take from us”. People living with AIDS are *buried* whilst they are still alive and treated as if there is nothing they can offer.

Mobilising for economic development and information sharing is appropriate for all communities. However, the questions that need to be asked are, is there any economic potential to be mobilised in our poor rural communities? Are there outside agencies that need to be linked to the community? Who should lead the process and what should motivate them? This is a process that will lead to leveraging for outside resources to support local development. Leveraging for outside resources cannot be ignored at this stage in our country because of the increasing levels of poverty, the heavy burden of apartheid debt, the devastating impact of AIDS and the thriving process of reconciliation and democracy. Unfortunately, foreign aid often comes with attachments and conditions that enslave the recipients. Developing a vision then charts a way forward for development with the community involved at the very onset of the process.

Development is defined as “a process, which enables human beings to realise their potential, build self-confidence and lead lives of dignity and fulfilment. It is a process of self-reliant growth, achieved through the participation of the people acting in their own interests and under their own control. Its first objective must be to end poverty, provide productive employment, and satisfy the basic needs of all the people”.⁶

From this framework of development, and as articulated in the Sustainable Livelihoods Framework, the purpose of this study is to propose strategies to be employed by the church at Ilinge, a township outside Queenstown in the Eastern Cape Province, in enhancing people’s survival strategies and livelihoods. The word church is used generically referring not to a specific denomination but to the whole body of Christ at Ilinge even though there are areas where generalizations are made for the larger church in South Africa. I also recognize the fact that there are churches that are actively involved in addressing social concerns and therefore some of the generalizations made would not apply to those. The church is one institution that does not or should not exist for its own sake. It is called out of the world and sent back into the world. The high calling of the church is to servanthood, and being an asset in the community means being a servant to the community.

The church should be a place where Jesus’ assertion in Luke 4: 18-19 is lived out. A place where good news is preached to the poor, the marginalized, those infected and affected by HIV/ AIDS; where the broken hearted are healed and given hope; where a struggle for liberation of those held captive is pursued; where those who are bound are set at liberty; where the blind recover their sight and a place where jubilee is pronounced.

⁶ Report of the South Commission, 1990, p. 13 quoted by Margaret Snyder. *Transforming Development: Women, Poverty and Politics* (London: IT Publications, 1995)

Kretzman and McKnight argue that the church, amongst other organizations, makes up the most visible and formal part of the community's fabric. It is called to be compassionate. This means full immersion in the condition of being human which calls the church to respond to the needs of humanity and thus the needs of our communities. Henri Nouwen, Donald McNeil and Douglas Morrison say that the church should act as a mediator in the suffering of our communities.⁷ Indeed a suffering community is a suffering church.

The church in essence is an asset for the betterment of the community that should struggle against sin in its practical, structural and institutional manifestations. It is a vital resource without which the community lacks something important, and this truth is even recognised by government.⁸

2. Description of the community

Ilinge is a small township on the outskirts of Queenstown in the Eastern Cape Province. Queenstown was founded in 1853 and named after Queen Victoria. The town was intended to be a military station designed to protect the British settlers from attack during the Frontier wars. In the late 19th century the town grew and the big sandstone public buildings were built such as the town hall and the Methodist, Anglican and the Dutch Reformed Churches.

⁷ Henri J.M Nouwen, Donald P. McNeill and Douglas A. Morrison. *Compassion: A Reflection on the Christian Life* (USA: Doubleday, 1982)

⁸ The Eastern Cape Department of Social Welfare and Development- Rapid Appraisal Report on the study on home community based care programs recommends that FBO's or Church organisations and Hospices need to be increased in capacity and strength.



According to the 2001 census, the estimated population of the Eastern Cape Province was 6,4 million.⁹ The province's non-urban population is 63% and it has a greater percentage of females as a result of migrant labour.¹⁰ The level of unemployment is greater than 40% and it is rated as the poorest of the provinces. ASSA estimates that of the 6,5 million people infected with HIV in South Africa, the Eastern Cape accounts for 12,4% among adults. The HIV infection rate in the province is said to be taking its toll. Part of the reason is the effect of migrant labour and the high unemployment and poverty levels in the province. The following table indicates the 2003 statistics for the Eastern Cape presented by ASSA:¹¹

Population	HIV +	Cumulative AIDS Deaths	Total AIDS Sick	Mortality rates of children and adults			
				Infant	Child	Male	Female
7,244,554	900,000	98,942	62,381	72	116	55	44
Maternal orphans less than 15 years							
AIDS orphans		Non-AIDS orphans		Total orphans			
38,653		62,479		101,133			

In the study conducted by the Eastern Cape Department of Social Development and Population on home-community based care programs, it is highlighted that the

⁹ Health Systems Trust. *Census shows 10% growth*, 05 April 2004 at <http://new.hst.org.za/news/index.php/20030713/>

¹⁰ Eastern Cape Department of Social Welfare and Development at <http://population.pwv.gov.za/research/hcbc/Echcbc2001.htm>

¹¹ Dorrington, Bradshaw and Budlender. *HIV/AIDS Profile*.

HIV/AIDS care programs are limited and not meeting the great need in communities. If the ASSA statistics are anything to go by, then it means that the province is in a serious crisis that demands urgent intervention. It is with regret that at Ilinge there are none of these care programs and there seems to be no plans for interventions of this nature.

The government study shows that in the whole of the Eastern Cape, less than 5% of the organisations that render HIV/AIDS services are faith-based organisations.¹² This raises an urgent need for the church to respond by providing the most needed services and for the many other initiatives not formally known by the government to be registered and capacitated. The challenge for this study is to identify strategies that the church could pursue in its seeking to being salt and light in the community.

Ilinge community has seen young and old die due to AIDS related illnesses yet as argued earlier, there is no concerted effort by government, NGO's or the church in engaging effective prevention and caring strategies. The sick and dying have been attended to by volunteers who take their time and limited resources to conduct home-based care services. Due to the increasing rate of deaths, helplessness and even hopelessness, people have decided to feel nothing.¹³

The HIV/AIDS struggle should not only be to monitor how the statistics have gone up or are stabilising, but to be reminded of the fact that behind these figures are people who are struggling with the disease every day and are seeking a means to live. Indeed the story of AIDS is one of fear, pain, despair, anger, neglect and poverty. The pertinent questions to ask as we analyse statistics are; how do people

¹² Eastern Cape Department of Social Welfare and Development.

¹³ When I was home for 2003 Easter, there was a young adult woman who boarded a taxi, she did not have the money to pay, and she did not tell the driver until she was about to get off. She looked very ill and frail, and the women who were in the taxi did not make it any easier for her. They went on talking about people who go off to cities and only come home when they are dying, they started to mock her. I sat there feeling so numb and angry, yet helpless. The most painful and disappointing thing was that these were actually church people.

cope with this enormous challenge? How do they live and continue with life? This is the reason why this study seeks to investigate broad-based strategies that communities adopt to survive in the face of what the Sustainable Livelihoods Framework calls the vulnerability context comprised of 'stresses'¹⁴ and 'shocks'.¹⁵

In this study, I have looked at the human, social, natural, physical and financial capital that families rely on in the face of the challenging HIV diagnosis and its impact on the family's livelihoods, and explored how the church could enhance this asset portfolio. I have also sought to explore the religious and/or theological belief systems as well as community structures that families rely on in the face of this vulnerability context characterised by the prevalence of AIDS, poverty, unemployment, abuse of women and children, migrant labour, and many other factors that accelerate the spread of AIDS.

3. Research Methodology

Qualitative research methodology was used for this study because it seeks to explore and investigate people's life stories and everyday behaviour.¹⁶ It is often defined as the study about people's lives, their stories and behaviour. This approach was relevant for this study because I was particularly interested in people's stories about their everyday means of survival. As a means of data collection, interviews with six people living with AIDS and their families were conducted, three church ministers were interviewed, a focus group discussion with the home-based care volunteers and a meeting with community leaders was undertaken. The rationale behind the use of interviews was that it would give the

¹⁴ Stresses are pressures, which are typically continuous and cumulative, predictable and distressing; such as seasonal shortages, rising populations or declining resources (Conway 1987: Conway and Barbier 1990 quoted by Robert Chambers and Gordon Conway. *Sustainable Rural Livelihoods: Practical Concepts for the 21st Century*. Institute of Development Studies Discussion Paper 296 (University of Sussex, Brighton: IDS Publications, 1992)

¹⁵ Shocks are impacts, which are typically sudden, unpredictable and traumatic, such as fires, floods, and epidemics (Conway 1987: Conway and Barbier 1990 quoted by Chambers and Conway. *Sustainable Rural Livelihoods*. p. 14

¹⁶ Daniel Silverman. *Doing Qualitative Research: A Practical Handbook* (London: SAGE Publications, 2000)

CHAPTER II

The church's response to HIV/AIDS

1. Introduction

The church has often been accused of not responding relevantly and timely to social problems.¹⁷ Unfortunately this accusation is often true and results in the church's credibility being questioned or viewed with suspicion when it does respond. HIV/ AIDS is one challenge that the church initially refused to even talk about, and time was wasted in discussions of whether or not it should interfere when God punishes sinners. These arguments have not been helpful and have contributed and sustained the stigma attached to AIDS.

Sr Alison Munro OP welcoming delegates to the Southern African Catholic Bishops' Conference AIDS Office Conference held on 05 February 2003 said,

AIDS is arguably the greatest crisis the human family has yet to confront on a global scale, it affects every sector of society, not least the church itself. Theology and theological reflection have not always kept pace with the realities exploding around us. Often enough it is ordinary Christians responding to AIDS, those with no training in theology, who ask the difficult-to-answer questions, and who sometimes do not receive the encouragement and support they need to continue in their own commitment to providing a Christian response to suffering and death around them.¹⁸

The church generally has always lagged behind in responding to social, political and economic struggles that people face. This could be because the church is not involved with the world and it is believed that what touches the world does not touch the church. This is fatalistic theology because before and after anyone is a Christian they are people and that is why 'the rain falls for everyone, Christian and non-Christian alike'. And certainly, AIDS is no respecter of any person and

¹⁷ Church as defined in Chapter I

¹⁸ Alison Munro Op. "Welcome to the Conference from Coordinator of ASCBC AIDS Office" in Stuart, C. Bate (ed) *Responsibility in a Time of AIDS: A Pastoral Response by Catholic Theologians and AIDS Activists in Southern Africa* (South Africa: Cluster Publications, 2003)

Christians are starting to realise that. But most importantly, it is challenging the church to ask questions of its vocation to be the church in our time today.

2. The church responding to HIV/AIDS?

The reality of AIDS and its impact on individual and community life is one that the communities need to be alerted to and the church challenged to start doing something significant, other than just conducting burials every week. HIV/AIDS challenges everyone and the church cannot stand by and watch at a distance. The church should be at the cutting edge of making a difference in the fight against HIV/AIDS. The work that individual churches and denominations have done is commendable but there is still more that needs to be accomplished and more churches to be mobilised to get their "hands dirty".

Ten years ago, church leaders at the All Africa Church and AIDS Consultation in Uganda, April 1994 made this declaration;

We speak out not because of good things we have done, but because of the work of Christ and from our oneness with all humanity. We confess that we have not said or done all we could have. We have been given the prophetic voice of a watchman to speak as God does against sin, but sometimes our call to holy living has sounded as if we are blameless. We are not. God has given us a prophetic message of comfort and hope for the world, but we have sometimes only whispered it to ourselves. We have been made priests to pray for and care for those in need. Jesus meets us in our need even when we are in rebellion and reconciles us to God. We ought to have been more like Jesus in the midst of the life and death struggle of those affected by AIDS, but we have not.

We are watchmen standing in the gap and stewards of the hope of God offered in Christ. The pain and alienation of AIDS compel us to show and offer the fullness and wholeness that is found in Him alone. In this, our time of weakness, may the rule of Christ's love in us bring healing to the nations.¹⁹

Megan McKenna echoes the same when saying that the poor is the first group that must be considered when there is a question of meaning or doubt. The second group to be considered are those people who give witness and are martyred for

¹⁹ *AIDS in Africa: The church's Opportunity* (Nairobi, Kenya: MAP International, 1996)

their beliefs and their interpretations. The *poor* because God has a special bias toward them, the Gospel is written with them in mind, for their emancipation and empowerment. The poor are simply those with no options, who have no voice in decision-making, those who lack food, the unemployed, those who lack shelter, access to education, medicine and health care. They are those whose dignity and hope for the future has been stripped away. "They are often simply ignored, not noticed, heard, counted, and so they are poor. But they are the beloved of God, the ones first noticed, heard, and remembered by the poor one of God who became human and dwelled among us".²⁰

In McKenna's assertion we can recognise the faces of the "poor" as those infected and affected by HIV/ AIDS the majority of whom are indeed poor.²¹ Certainly the link between poverty and AIDS in Africa continues to be a great threat to life. Indeed, HIV breeds hunger and hunger breeds HIV. Alex de Waal in his paper "What AIDS Means in a Famine" argues, "hunger and disease have begun reinforcing each other". He says that African people have always found the means of coping under the worst of famines. "This is changing...in societies hurt by AIDS, famine is more deadly and less susceptible to existing treatments. The reason is that AIDS attacks exactly those capacities that enable people to resist famine".²²

The second group that McKenna refers to might just mean the activist groups and individuals who advocate for justice. In our day and age they might not literally be martyred to death but they are often misunderstood and misrepresented and especially by the church.

²⁰ Megan McKenna. *Not counting women and children: Neglected stories from the Bible* (Maryknoll Orbis: 1994)

²¹ McKenna defines the poor as "those in jeopardy of life, those lacking the basic necessities for human living- food, clothing, shelter, education, medicine and health care, jobs, human dignity and hope for the future. They live without security, without much possibility of change or hope for themselves and their children. They are often simply ignored, not noticed, heard, counted, and so they are poor".

²² Alex De Waal. "What AIDS Means in a Famine" in *New York Times*: 19 November 2002.

It is imperative that the church begins to reconsider what it does year in and year out. It has been so concerned with what is spiritual as if people are only “souls”, yet it has the richness of assets that when effectively utilised, can make a better life to all people it touches. Christ dealt with people where they were- he touched and healed the leper, fed the hungry, and challenged the Pharisees. If the church has any resemblance to Christ, it should be concerned with what he was and is concerned about. We do not have much time to be debating about *whether or not* we should respond to AIDS, instead we need to ask *how* we should respond.

Tinyiko Maluleke notes the urgency to respond when saying, “the HIV/ AIDS pandemic has ushered in a new kairos for the world in general and for the African continent in particular. But that is one dimension of the kairos. The other dimension is that it is a kairos for and of the church- the local church as well as the worldwide church. While we in the church may not all be infected, we all can be affected and once one member of the body is infected we are certainly all infected”.²³ He continues to argue that HIV/ AIDS is not only an ethical issue or merely a pastoral one but a deeply theological issue raising questions about life and its meaning, our understanding of church, our concept of God, human interdependence, human frailty, human failure, human sinfulness and community.

The statement by South African theologians intended for the apartheid government in South Africa was relevant then as it is relevant for today’s AIDS crisis. In the *Kairos Document* theologians made this assertion;

The time has come. The moment of truth has arrived. South Africa has been plunged into a crisis that is shaking the foundations and there is every indication that the crisis has only just begun and that it will deepen and become even more threatening in the months, years to come. It is the kairos or moment of truth not only for secular institutions but also for the church and all other faiths and religions. We as a group of theologians have been trying to understand the theological significance of this moment in our history. It is serious, very serious. For very many Christians in South Africa this is the kairos, the moment of grace and opportunity, the favourable time in which God issues a challenge to decisive action. It is a dangerous time because, if this opportunity is missed and allowed

²³ Tinyiko Sam Maluleke. Editorial, *Missionalia* 29:2, August 2001, 125-143

to pass by, the loss for the Church, for the Gospel and for all the people of South Africa will be immeasurable. A crisis is a judgment that brings out the best in some people and the worst in others. A crisis is a moment of truth that shows us up for what we really are. There will be no place to hide and no way of pretending to be what we are not in fact. At this moment in South Africa the church is about to be shown up for what it really is and no cover up will be possible.²⁴

This statement from the Kairos Document could be said again as we face the HIV/AIDS crisis, and be referred not only to South Africa but to the whole of the African continent. The people of faith are unfortunately caught up in unconstructive debates of whether or not they should be involved in AIDS work. It is unfortunate that the church has grossly ignored its vocation and indeed this crisis will show us up for what we really are. The question that demands our reflection would be to explore what of our belief systems could help dispel fear and stigma even as we ask how God relates to all this suffering. Does he seem distant and unconcerned or is he moved to tears and action? The Bible is full of accounts of God's involvement in the social as well as the spiritual lives of his people. Christ's life and ministry revolved around the establishment of God's kingdom whose concern was the emancipation of the poor and the marginalised.

The church's involvement in the community and AIDS specifically, is an act of obedience and following the footsteps of Christ. Steve de Gruchy says, "The church is seeking (should seek) to proclaim the whole gospel, to the whole person, in the whole world". He further says that the "church can and must see its role in social development as proclaiming the Gospel of freedom: providing the legitimation and confidence to break the patterns of power, and enabling people to become fully human".²⁵

²⁴ *Kairos Document*, 1986:1

²⁵ Steve de Gruchy. *An Introduction to Theology and Development* at www.hs.unp.ac.za/theology/article01.htm

At the heart of the HIV/AIDS challenge are the following issues- poverty, power, equity, gender, liberation along with the list that Tiblier *et al.* outlines.²⁶ These need to be encompassed by the church's response. The HIV/AIDS challenge is the exposure of injustices that have been dormant in society. AIDS has highlighted economic and social inequalities that we have been living with as more poor people feel the brunt of the epidemic. This is why the church cannot go on with business as usual while people are dying and there is more that it can do to turn things around. Ronald Nicolson asserts:

Our God is the God of life who created men and women in His image with equal dignity and worth. We believe the church is His instrument to proclaim and promote life. As an epidemic of huge magnitude, we recognize that AIDS is the opposite of life. It is destroying lives of people, families and communities and inhibits the very development of our nations...the church's lack of response to the AIDS challenge would mean "God, Jesus and Christianity are irrelevant and offer no saving grace."²⁷

Therefore the church's involvement in the fight against AIDS is an act of worship and being true to its calling- to being the salt and light of the world. Jesus says, "I have come that they might have life and have it more abundantly". As AIDS takes away that life, we need to ask what of our resources we could use to give hope, strength and comfort to the hurting and the bereaved; to combat the life threatening diseases in our continent and the world over; to deconstruct any system and structure that brings life to a few and death to millions and what message of life would Jesus bring to us today.

Nyambura Njoroge arguing from a Kenyan context says that in the face of a challenge of this enormity "one would imagine that all leaders, including religious leaders would be up in arms, working with people to confront this scourge that is

²⁶ Kay B. Tiblier, Gillian Walker, John S. Rolland. "Therapeutic Issues when working with families of persons with AIDS" in Eleanor Macklin (ed). *AIDS and Families* (New York: The Haworth Press, 1989) "adjust to the life threatening diagnosis, deal with fears of contagion, accept sexual orientations of family members, cope with stigma and discrimination, manage conflict among family members and significant others, confront a time limited push for reconciliation, prepare for loss and bereavement, shift family roles, provide necessary care and negotiate with external systems".)

²⁷ Ronald Nicolson. *AIDS; A Christian Response* (Pietermaritzburg: Cluster Publications, 1995)

claiming the lifeblood of society. But the leadership seems to have different priorities; some are busy destabilizing communities with violence and starving people to death while others are busy preaching to people to get saved".²⁸

The church's response should start from prevention strategies through to caring for the sick and dying; challenging traditions and cultures that perpetuate gender inequality and violence, and engaging policy makers on issues of justice and equity. This is at the center of the Gospel of Christ whom we follow.²⁹ The Gospel is about a struggle against sin manifested in different forms and structures and injustices of all kinds, and this should form part of the liturgy and the very life of the church.

3. Eight Key HIV/AIDS challenges to the church

People living with AIDS are often separated from their families, social circles and support structures as a result of disclosure of their status and both they and their families experience tremendous stress and alienation. Kay Tiblier, Gillian Walker and John Rolland say that people living with AIDS and their families need help to "adjust to the life threatening diagnosis, deal with fears of contagion, accept sexual orientations of family members, cope with stigma and discrimination, manage conflict among family members and significant others, confront a time-limited push for reconciliation, prepare for loss and bereavement, shift family roles, provide necessary care and negotiate with external systems".³⁰ AIDS thus impacts on the structure and day-to-day life of the family and families adjust to and cope with this challenge in one way or the other. The church needs to appreciate this, strengthen the healthy strategies and advocate against any structures or attitudes that make this difficult.

²⁸ Nyambura J. Njoroge. "Come Now Let us Reason Together" in *Missionalia* 29:2, August 2001

²⁹ Luke 4: 18-19

³⁰ Tiblier, Gillian and Rolland. "Therapeutic Issues".

The literature suggests that HIV/ AIDS presents eight key challenges to the church, namely: denial, stigma, education, sex and sexuality, gender justice, human rights, caring and livelihoods. Let us briefly examine each one before turning to livelihoods, which is the specific focus of this research.

3.1. Denial

Regardless of HIV/ AIDS awareness in South Africa, many people still deny that AIDS exists or have not personalized the risk of contracting HIV. This was also made evident by the responses of this study's respondents who before they were infected with HIV did not think that they could possibly contract the virus. HIV and AIDS remain distant, unseen and "nonexistent" until it hits closer home. Even when a member of the family has been diagnosed with HIV, people deny it is AIDS, both to themselves and to others. They convince themselves that either they have been bewitched or *bayathwasa* (ancestors are calling them to traditional healing, hence a person will lose weight and get sick often). This presents a challenge as the levels of awareness do not seem to correspond with the levels of infection.

3.2. Stigma

People living with AIDS continue to experience the worst kinds of injustices from their family members and the community in general. Some have been chased out of their homes because they are viewed to have brought shame to the family, others are stoned to death because the community cannot admit that AIDS is real. The church unfortunately has contributed and sustained the stigma attached to AIDS by its teaching and lack of compassionate response to this crisis. This calls for our repentance and asking for God's forgiveness and a re-reading of the scriptures if any life giving messages are to be conveyed and received.

3.3. Education

We need to teach about what HIV/ AIDS is and is *not*, and the need for compassionate responses which are unconditional. The Christian church has been labeled as adamantly negative towards issues of sex and HIV/ AIDS specifically; this resulting from the belief and wrong teaching that AIDS is God's punishment to promiscuous sinners. This defeatist belief has resulted in the church not helping in the prevention of HIV by providing correct teaching and skills for people to protect themselves from contracting the HIV virus, living positively with the virus and caring for those infected. We are presented with a challenge to condemn any behavior that puts self and others at risk, whilst perpetrating injustice against the other, and we need to create an environment where people can unlearn the stereotypes and wrong doctrines engraved in their minds and hearts.

3.4. Sex and sexuality

In the era of HIV/ AIDS, Christian teaching should offer sound biblical teaching on issues of sex and sexuality. However, we witness Christians captured by the fear that more open talk about sex will result in a corresponding increase of promiscuous behavior. Contrary to this, the more informed people are, the better they are equipped to make informed decisions and provided with skills and resources to sustain decisions made.³¹ One of the interesting conversations in the Bible is the Songs of Solomon. It talks about love, intimacy and partnership.³² Unfortunately, this is one book that is gravely ignored or avoided by Christians. We often refer to sexuality as "unspiritual" and I think some of us are embarrassed at how "unspiritual" God is to have allowed the Songs of Solomon into His most holy word, the Bible.

³¹ One of God's charges against Israel with reference to Hosea 4: 6 was that, people are destroyed because they lack knowledge. Can we not say this is true in the era of HIV/ AIDS? Small girls and boys are sexually molested because perpetrators believe that sex with a virgin will cure AIDS. Others continue in the delusion that 'I can sleep around, for it can never happen to me or if I only have sex once I will not catch AIDS'.

³² Songs of Solomon, Chapters 1-9

Judith Balswick & Jack Balswick believe that spirituality is not just relevant but essential to working out an authentic sexuality.³³ Most of us have been taught to think of sexuality and spirituality as separate entities or exact opposites that have nothing to do with each other. Sexual desires are considered as a dangerous temptation that needs to be suppressed especially by single people to an extent that there are Christians who assert that their bodies have been nailed on the cross with Christ. The common confession is that '*inyama ifile*' (the flesh is dead).

Experientially, sexuality and spirituality are meant to be a climactic experience that takes place in a relationship between two people who totally give themselves to each other. A mature relationship with the Creator is crucial to the mature easing of our aloneness- bodily, emotionally and spiritually with other human beings. That inspired longing to connect and ultimately merge with another defines our sexuality. It usually does not involve explicit acts, indeed our genitals are a minor part of our sexual yearning to commune with other human beings.³⁴

Philippe Denis asserts that "the HIV/ AIDS epidemic faces the churches with an unusual challenge... HIV/ AIDS calls on the churches to understand sexuality in all its dimensions: not only as an individual act which can be right or wrong but as a reality determined by social, economic and cultural factors".³⁵

Dominian suggests that AIDS may provide society with a sense of urgency 'about faithfulness and deep commitment in sexual relationships which may assist the church in recalling us to a more sane sexuality than the permissiveness prevailing'.

³⁶ He further argues that AIDS may challenge society to question assumptions that consider sex as merely a pleasure accessory without any commitment necessary. This argument does not ignore the fact that HIV is transmitted in many different ways, but is based on the fact that in Africa it is primarily transmitted through sex, and unless intervention strategies clearly assert this and provide resources to help people change their behaviour patterns, we will not see much progress in this fight.

³³ Judith K. Balswick and Jack O. Balswick. *Authentic Sexuality: An Integrated Approach* (Illinois: Intervarsity Press, 1999)

³⁴ Balswick and Balswick. *Authentic Sexuality*.

³⁵ Philippe Denis. "Sexuality and AIDS in South Africa" in the *Journal of Theology in Southern Africa*, March 2003

³⁶ Dominian (1987) quoted by Nicolson. *AIDS: A Christian Response*

Denis further argues that people can avoid contracting the HIV virus by avoiding or reducing the number of sexual contacts liable to lead to infection or 'when these sexual acts take place, by making sure that the transmission of the virus does not happen'.³⁷ This is not revelatory information but that which has been talked about over and over again; yet a change of risky behaviour patterns has not fully been realised. Denis then argues that this is the result of the breakdown of family structures dating back to colonialism. The invasion of people's cultures and nations was characterised by migrant labour, urbanisation and westernisation, and these and many other factors practically destroyed the stability of families and hence casual sex has become a norm.

3.5. Gender and HIV/AIDS

It is widely documented that gender inequalities fuel the spread of AIDS: therefore, gender cannot be left out in any AIDS discussions and interventions. It is now time that the church be vocal about sex and gender issues and it is of significant importance that women in particular be empowered to gain control within relationships. Gro Harlem Brundtland said that we will not achieve progress against HIV until women gain control of their sexuality.³⁸ It is true that the Christian tradition is embedded in a patriarchal system that views women as subordinates and encourages male leadership and dominance. Yet there is also a more progressive and liberating message for women in the Bible, one that needs to be discovered or re-asserted.

3.6. Human rights and respect of human dignity

Every person is created in the image of God (Genesis 1:26), and has a right to love, life, respect, human dignity, protection and care. Discrimination against people on the basis of their race, color, sex, and even sexual orientation is injustice and sin.

³⁷ Denis. "Sexuality and AIDS in South Africa".

³⁸ Gro Harlem Brundtland of the World Health Organization at the XIII International AIDS Conference (Durban, 2000)

The Bill of Rights of the South African Constitution (1998) outlines the rights of every human being and how these should be respected. It is therefore against God and the law to discriminate on whatever basis and prosecution can follow suit. But many people living with HIV/AIDS face violation of their human rights on a daily basis by: testing for HIV without their informed consent, testing for HIV without receiving any pre-test counseling, breaching of confidentiality and denying them access to life insurance. These are crucial areas that need to be included in discussions about AIDS.

The Medical Schemes Act No 101 of 1998 provides that a medical scheme may not unfairly discriminate directly or indirectly against any person on the basis of his or her health, in accordance with S 24 (e) and S 29 (n) of the Act.

Therefore, Medical Aid Schemes will no longer be able to discriminate against people living with AIDS.³⁹ As Christians we need to speak against any forms of injustice and discrimination against people living with HIV/AIDS and advocate for acceptance, forgiveness, reconciliation with others and with God. The employment equity Act No 55 of 1998, S 5 prohibits unfair discrimination directly or indirectly, against an employee in any employment policy or practice, on one or more grounds, including race, gender, sex, pregnancy, marital status, family responsibility, ethnic or social origin, color, sexual orientation, age, disability, religion, *HIV status*, conscience, belief, political opinion, culture, language and birth.⁴⁰

However, people living with AIDS have often been denied employment or have been fired from work as a result of their disclosure of their HIV status. It is rather weird that an HIV/AIDS Christian activist confidently said that he thinks that people living with AIDS should have their status recorded in their identity documents because they are walking time bombs and cannot be trusted. He further

³⁹ The Medical Schemes Act No 101 of 1998

⁴⁰ The Employment Equity Act No 55 of 1998

argued that as an employer he cannot employ someone who is HIV positive because that will be a very expensive task for his organization- the training of the new employee, the sick leave they will need and their replacement when they die.

3.7. Caring

As more and more people succumb to the devastating impact of AIDS, they need to be cared for. A number of non-governmental organisations, community based organisations, faith-based organisations, relatives as well as concerned neighbours tirelessly care for the sick in communities. The few people who are caring in communities are not coping and more people are needed to get involved as the South African society is observing an acceleration of deaths due to AIDS.

3.8. Livelihoods

AIDS impacts on all aspects of people's lives and their livelihoods. It is vital that any approach to AIDS and/or development should consider the context and the contributing factors to the condition of poor people as well as the fact that poor people still have their dignity as a people and are *living* despite the precarious conditions in which they live. Hence their lives and livelihoods need to be considered and shape development research and agendas. We hope that the work of the Human Sciences Research Council on the social aspects of HIV/ AIDS will lead into this most needed research and intervention. This study recognised that all the above AIDS challenges require some significant attention, but has limited itself to focusing on how people cope and survive as AIDS impact severely on their livelihoods. Let us now focus our attention on this concern.

4. The impact of AIDS on livelihoods

HIV/ AIDS is a challenge to livelihoods that impacts on the many facets of people's lives. Judith Appleton quoted by Seeley and Pringle says, "HIV/ AIDS is not only a

health issue that demands prevention and care for the sick; it is also a livelihoods issue, since, if AIDS depleted households are not the target of particular support, the precarious livelihoods of survivors are likely to collapse under the impact of the epidemic".⁴¹

HIV/AIDS is a traumatic experience for any household. It places an enormous demand on the family's financial, emotional, physical and spiritual resources. For example, the infected individual will need health care and nutritious foods, physical care and nursing, whilst the family might be divided and blaming each other for the infection and also having to struggle with stigma attached to the disease and possible exclusion by the community. Alan Whiteside and Clem Sunter argue that because of the prolonged exhaustion of the said resources as a result of AIDS, households have to endure greater hardship than when faced with other calamities.⁴² They further express that unfortunately there are no studies in South Africa on the effects of AIDS on households and this presents a challenge to the effectiveness and relevancy of interventions to assist families cope with the severe impact of HIV/AIDS.

Janet Seeley and Colin Pringle echo the same sentiments by saying that in their study, they have found no in-depth research on the impact of HIV/AIDS on livelihoods and exploring ways in which people adapt.⁴³ They then recommend that research that builds on people's strength to cope with the wide-ranging impact of HIV/AIDS is required. Seeley and Pringle further argue that "livelihoods approaches offer a holistic way of addressing the HIV/AIDS epidemic which promotes joined-up thinking across sectors and disciplines, that can look not just at the impact on health but also at the impact on social support, finances, housing,

⁴¹ Judith Appleton. "At my age I should be sitting under that tree: the impact of AIDS on Tanzanian lakeshore communities" in Judith, Appleton. *Gender and Development* (2000) quoted by Janet, Seeley and Colin, Pringle. "Sustainable Livelihoods Approaches and the HIV/AIDS epidemic. A preliminary resource paper", 15th December 2001 at <http://www.devserve.co.za/seeley%20and%20pringle202001.pdf>

⁴² Alan Whiteside and Clem Sunter. *AIDS: The Challenge for South Africa* (Cape Town: Human & Rousseau (PTY) Ltd, 2000)

⁴³ Seeley and Pringle. "Sustainable Livelihoods Approaches".

land-use and land tenure. After all a person living with AIDS does not stop being a family or community member, a land holder or a house tenant, a carpenter or a share cropper, or for that matter an educated or illiterate person".⁴⁴ They say that HIV/AIDS is a prolonged illness and people's life-styles may change as a result, but they continue to need to 'earn a living, raise children, and cope with day to day crises'. People adapt or die.

The Sustainable Livelihoods (SL) approach recognises that people, regardless of their class position are whole persons and their dignity and value should be respected. It recognises that poor people are engaged in activities of survival, creativity and development and these need to be recognised. I believe that using the Sustainable Livelihoods Framework (SLF) to understand and enhance the agency of families would contribute towards the churches' response to challenges presented by HIV/AIDS. This would be realised by the church recognising that 'troubled' people are not helpless and therefore prey to her acts of good will that often dehumanise. Sekou Toure is quoted by Nyambura Njoroge saying, "To take part in the African revolution it is not enough to write a revolutionary song; you must fashion the revolution with the people. And if you fashion it with the people, the songs will come by themselves and of themselves".⁴⁵

De Gruchy in his paper "Of Agency, Assets And Appreciation: Seeking Some Commonalities Between Theology And Development" picks up this argument by saying that "poor people are always engaged in strategies and struggles for survival, adaptation and freedom".⁴⁶ He continues to say,

...any vision of Christian involvement in social development cannot have as its assumption, as so much of it unfortunately does, the faith and works of Christians and the Church over and against those who are poor and needy; but has to affirm, enhance and appreciate the faith works of the poor themselves. This is the message of the Gospel for the poor, that they are both made in the image of God and called to be actors in the drama of creation and salvation

⁴⁴ Seeley and Pringle. "Sustainable Livelihoods Approaches".

⁴⁵ Njoroge. "Come Now Let us Reason Together".

⁴⁶ Steve de Gruchy. "Of Agency, Assets And Appreciation: Seeking Some Commonalities Between Theology And Development" in the *Journal of Theology for Southern Africa*. 117, November 2003

itself. They are not, and cannot be, simply passive objects of history, but are invited to be the subjects of their own history.⁴⁷

The SL approach is an approach to development that seeks to humanise, and is an alternative to conservative development approaches that regarded people as clients. The SLF also considers the impact of policies and institutional structures either on local, national and global levels that have a bearing on people's lives and forms part of the vulnerability context. An ideal approach to development is one that adopts a bottom-up approach and lets people define or according to Paulo Freire, name their world. "It is not our role to speak to the people about our view of the world, nor to attempt to impose that view on them, but rather to dialogue with the people about their view and ours," he says.⁴⁸

He further argues that the naming of the world is an act of creation and re-creation possible where there is love for people and for the world. He says, "If I do not love the world- if I do not love life- if I do not love people- I cannot enter into dialogue." Freire asserts that the naming of the world should not be an act of arrogance; "it requires faith in humankind, faith in their power to make and remake, to create and re-create, faith in their vocation to be more fully human".⁴⁹

Reflecting on the South African context making use of Freire's theory of action, one can identify with his discussion. The apartheid government, for example, engaged in anti-dialogical action in its relations with South African Black people. First, there was a strong desire to conquer that was carried out at grievous costs to the people. Second, it stood on the divide and rule principle. It removed people from their birthplaces and placed them in areas of their own choice. Ilinge Township is a result of removing political leaders and prisoners from their birthplaces and placing them in an area where they could be monitored and not be 'out of control'.

⁴⁷ De Gruchy. "Of Agency, Assets and Appreciation".

⁴⁸ Paulo Freire. *Pedagogy of the Oppressed* translated by Myra Bergman Ramos (England: Penguin Books, 1996)

⁴⁹ Freire. *Pedagogy of the Oppressed*.

The meaning of the word *ilinge* means a trial. In Soweto for example, people were grouped according to their ethnic backgrounds so that they would remain suspicious of each other and thus remain divided. Any organising and unity of people was a threat to this regime hence the abolishment of political movements and imprisonment of political leaders.

Third, because of being manipulated and even brainwashed by the apartheid regime, there are still South Africans today who say that it was “better when white people led us because there were jobs”. This is a result of many years of oppression and brainwashing to believe that our salvation as black people lies with the white person. This frame of thought is the same that development approaches embraced, namely, that people’s freedom relies on the development agencies from outside the community. Fourth, the cultures of Black South Africans were invaded and undermined. They were not regarded as fully human and were manipulated, enslaved and killed if they showed any kind of resistance. The western culture became superior and living like a westerner was and is considered the best thing to do and is the evidence of ‘development’.

This is why Amartya Sen argues that development is a process of expanding freedoms that people enjoy.⁵⁰ He points out that ‘freedoms are not only the primary ends of development; they are also among its primary means’. The process of development cannot be done in oppressive ways with the hope that the end result will be liberating to the poor.⁵¹ Sen further argues that the challenge is to fully understand the process of development as a liberating process for the oppressed not just a ‘hand-out’ parade that further cripples people with a hope that the end

⁵⁰ Amartya Sen. *Development As Freedom*. (New York: Anchor Books, 1999)

⁵¹ Amartya Sen argues, “The ends and means of development require examination and scrutiny for a fuller understanding of the development process, it is simply not adequate to take as our basic objective just the maximisation of income and wealth, which is, as Aristotle noted, ‘merely useful and for the sake of something else’. For the same reason, economic growth cannot sensibly be treated as an end in itself. Development has to be more concerned with enhancing the lives we lead and the freedoms we enjoy. Expanding the freedoms we have reason to value not only makes our lives richer and more unfettered, but also allows us to be fuller social persons, exercising our own volitions and interacting with and influencing the world in which we live”.

will bring about their emancipation. He argues “the ends and means of development call for placing the perspective of freedom at the centre stage. The people have to be seen, in this perspective, as being actively involved –given the opportunity in shaping their own destiny and not just passive recipients of the fruits of cunning development programs”.⁵²

AIDS limits the ‘freedoms that people have reason to enjoy’. The diagnosis of the virus brings about emotional and psychological strain and possible alienation from family and friends. The financial resources of the family are directed towards health care and possible loss of employment and that means further strain on the family’s income. Faced with this challenge, families still live and struggle through life, and therefore AIDS should not reduce them to helpless victims and clients to services. Human beings are created with an amazing ability to cope with bad situations and that means however poor or sick people are, they still survive and no one has a right of coming up with pre-packaged ideas of how to take them out of their misery.

Therefore, people infected with and affected by AIDS need to be at the centre of any AIDS debate, should be pioneers of any intervention programs and the church can be a catalyst of this approach. The church should recognise signs of life and enhance these, recognise any injustice and dehumanisation of people and struggle against it, hold a hand of the one crying and bring hope to the hopeless. Because the SLF is built upon these important concerns, it provides us with a helpful way of understating the impact of AIDS in the livelihoods of the poor. A fuller description of the SLF is presented in the next chapter so as to provide a theoretical structure for the analysis of the lives of people living with AIDS at Ilinge.

⁵² Sen. *Development As Freedom*.

CHAPTER III

The Sustainable Livelihoods Framework

1. Introduction

The Sustainable Livelihoods Framework (SLF) is a contemporary approach to development that builds on the approaches that have gone before. It seeks to respect people's gifts and abilities to live and survive the worst of life's circumstances. This is rooted in the basic truth that people however poor, "problemated" or even "diseased", have an agency. One fundamental reason why some of the so called development strategies have failed is because they never took into consideration that people already *live*, and so they have consequently made people's lives miserable and poorer instead of 'developed' as they had hoped. The framework therefore is an approach that if adapted in our context can enable development agents to make a significant turn around for our continent.

2. Analysis of development approaches

Development as defined in page 5 is a process about people- their potential, self-confidence and dignity. This definition implies that people's participation in their development should be central to the development discourse and not only be seen in the implementation of development programmes decided elsewhere by other people. This definition asserts that ideally, development is not about the delivery of goods to a passive citizenry but people themselves are pioneers of their own development. However, as experience has told us and leaning on Arturo Escobar's argument, the point of departure for development was that modernization was the only force to destroy superstitions at whatever social, cultural and political cost. Industrialisation and urbanization were seen as progressive routes to modernization. He continues to argue that the advancement of 'poor' countries was seen from the onset as depending on aid from richer countries to provide for their

infrastructure and improving life through industrialization and the overall modernization of society.

This view claimed that social, cultural and political progress could only be achieved through material advancement. Escobar further argues that this approach “looked at social life as a technical problem, a matter of rational decision and management to be entrusted to experts whose specialized knowledge qualified them for the task”.⁵³ This belief asserts the notion that some ‘already’ developed people identify the “not- so- developed people” and develop them.

Building on such criticism, Pam Simmons argues that development promotes the hegemony of western culture and relegates other cultures to being traditional or exotic.⁵⁴ She further argues that this development ideology established a hierarchy and reinforced exploitation by means of unjust terms of trade and debt so as to control national policies. “It promotes over all other cultures a single culture that has shown itself to be both destructive and unjust”.⁵⁵ Simmons continues to argue that women have been invisible to planners of development, policy makers, governments and foreign experts.

Development came as a top-down approach that treats people and cultures as objects and according to Escobar, as abstract concepts, statistical figures to be moved up and down in the progress charts. “The understanding of development as discourse requires understanding of the systems of relations between institutions, socio-economic processes, forms of knowledge and technological factors. These systems therefore set the rule of the game- who can speak, from what point of view, with what authority and according to what criteria of expertise”.⁵⁶

⁵³ Arturo Escobar. “The making and the unmaking of the Third World through Development” in Ranhema M and Bawtree V. *The Post Development Reader*. (London: Zed Books, 1997)

⁵⁴ Pam Simmons. “ Women in Development”: A Threat to Liberation” in Ranhema M and Bawtree V. *The Post Development Reader* (London: Zed Books, 1997)

⁵⁵ Simmons. “Women in development”.

⁵⁶ Escobar. “The making and the unmaking”

Escobar further argues that development created abnormalities such as illiteracy, underdevelopment, the malnourished, small farmers or the landless peasants, which it would later treat and reform. The earth crisis amongst other things is a result of "development" in that natural resources have been overused and can no longer sustain life. For example the United Nations Environmental Programme has warned that time is running out to stop worldwide environmental damage and it is already too late to prevent irreversible harm to ecosystems like tropical forests. The Programme highlighted a number of emergencies: severe water shortages that will get worse, reduced agricultural productivity through loss of topsoil and unwanted growth of vegetation along sea coasts, algae at sea caused by the heavy use of fertilizers. Industrial pollution speeds up global warming and has health implications for people as well.⁵⁷ Activists have also expressed concern about the effects of genetic engineering both to the environment and to human health.⁵⁸

3. Sustainable Development

The vision for sustainable development is entrenched in the recognition of the ills of development and the threat that as a result of *development* the earth will no longer sustain life in this and the coming generations. The United Nation's Millennium Declaration provides the vision for the world's development. The principles of the declaration are: to see a more peaceful, prosperous and just world; to uphold the principles of human dignity, equality and equity at a global level, to establish a just and lasting peace all over the world, and to ensure that globalisation becomes a positive force for all the world's people. The Heads of State at the Millennium Assembly on September 2000, declared fundamental values considered essential to international relations; freedom, equality, solidarity, tolerance, respect for nature, and shared responsibility.⁵⁹ The *Millennium Declaration* acknowledges

⁵⁷ BBC News, *UN Warns of Earth Crisis*, 15 September 1999 at http://news.bbc.co.uk/1/hi/english/sci/tech/newsid_447000/447767.stm

⁵⁸ Donald and Ann Bruce (eds) *Engineering Genesis: The Ethics of Genetic Engineering in Non-Human Species*. (London: Earthscan, 1999) Extracts

⁵⁹ *The United Nations Millennium Declaration* (New York: September, 2000)

that unless development is done in sustainable ways, resources for future generations will be harmed.

The New Partnership for Africa's Development (NEPAD) also promotes sustainable development. It is a pledge by African leaders,

..based on a common vision and a firm and shared conviction, that they have a pressing duty to eradicate poverty and place their countries, both individually and collectively, on a path of sustainable growth and development, and at the same time to participate actively in the world economy and body politic. The Programme is anchored on the determination of Africans to extricate themselves and the continent from the malaise of underdevelopment and exclusion in a globalising world.⁶⁰

The goals of NEPAD are to promote accelerated growth and sustainable development, eradicate widespread poverty and to halt the marginalisation of Africa in the globalisation process. NEPAD like the Millennium Declaration looks at advancing peace, security, democracy and political governance, economic and corporate governance initiatives, sub-regional and regional approaches to development, bridging the infrastructure gap, human resource development initiatives and reversing the brain drain and mobilising of resources. However, NEPAD's shortfalls include its unconsultative conception, buying into globalisation policies including the World Trade Organisation's rules, omission of biotechnology in its plans for agriculture, and debt-relief instead of debt cancellation.

The weakness of the above visions for development is their emphasis on problems and how these need to be solved instead of recognizing the potential that communities of Africa already have. These visions for development have bought into the dominant development paradigm that viewed development as material advancement to be achieved through industrialization and modernization. Needs are real and cannot be ignored and in fact they urgently need to be addressed, but as de Gruchy asks, "what does sustainable development seek to sustain? Does it

⁶⁰ *The New Partnership for Africa's Development* (Abuja: October, 2001)

seek to sustain development itself? Does it promote development that can be sustained in the face of ecological limits? Is it the environment that is sustained through development? ⁶¹

He further argues that the earth community and our local communities are what need to be sustained. The SL approach to development then becomes the ideal, because it focuses on sustaining livelihoods and dealing with the wider context within which livelihoods exist. It is also ideal because it “immediately does away with the problems, conflicts and disagreements associated with the term development. It reminds us that development is not the goal of our labours, but rather a process by which we may enhance our lives and our livelihoods” ⁶²

The SLF is theologically appropriate in that it acknowledges that people regardless of their class position are whole persons and their dignity and value should be respected. It also recognises that poor people are engaged in activities of survival, creativity and development and these need to be identified and appreciated. De Gruchy reflects on James 2: 26, *As the body without the spirit is dead, so faith without deeds is dead*, and reminds us that:

This is not only a word for the non-poor, a call- as it were- to charitable acts towards the unfortunate poor who have no works of their own (and by implication no faith). It is also a word for the poor. They too gain dignity when addressed by the fullness of the gospel. It is not enough that they have faith. Faith without works is dead. The gospel calls them to engage in the works of love, peace and justice in the struggle for their own humanization.⁶³

4. The Sustainable Livelihoods Framework

Contrary to the conservative approaches to development, the participation of the people in their own development empowers and promotes particularly the poor and the marginalised groups in society. The ideal model of development is the one

⁶¹ Steve de Gruchy. “What do we want to sustain? Development and the Earth Crisis” in Steve, de Gruchy. *An Introduction to Theology and Development*.

⁶² De Gruchy. “The Contribution of Universities to Sustainable Livelihoods”. Draft Paper

⁶³ De Gruchy. “Of Agency, Assets and Appreciation”.

that seeks to work alongside people and not to enforce the “outsider’s” values and agendas on communities in the name of development. Community participation refers to people having the power to influence the decisions that affect their lives. This means decentralization of decision making from the ‘outside experts’ to the local people who are the main players in their development. The SL approach’s recognition of the poor as active agents in their own development is therefore a means of listening to the voice of the poor, decentralising power that has only been the privilege of development experts and respecting their dignity and worth as a people. The community begins to exercise their right to choice and is able to manage their own future.

The Sustainable Livelihoods Framework is a developmental approach that is gaining wide endorsement as an alternative to ‘outsider driven’ approaches to development. The World Commission on Environment and Development (WCED) first promoted this framework in 1987 and it is now supported by the Institute for Development Studies at Sussex University, the Overseas Development Institute (ODI), the Department For International Development (DFID) of the British government, the International Institute for Sustainable Development (IISD), the People Centred Development Forum (PCD Forum), Oxfam and the United Nations Development Programme (UNDP).⁶⁴

Koos Neefjes argues, “the Sustainable Livelihoods Framework is essentially people-centred and aims to explain the relationships between people, their livelihoods and their environments, policies and all kinds of institutions”.⁶⁵ This means that poor people are active agents of their own development as opposed to the client-based development approaches.

The SLF realises that people should be *subjects* of their own development from analysing their situation, planning their development strategies and implementing

⁶⁴ United Nations Development Programme, *Sustainable Livelihoods Unit Home Page* at www.undp.org/sl/Overview/an_overview.htm

⁶⁵ Koos Neefjes. *Environment and Livelihoods: Strategies for Sustainability* (Oxford: Oxfam, 2000) pp58-112

those strategies. This recognition should undergird any development and/or intervention efforts if any humanisation of people is to be realised. The SLF therefore, is an ideal approach and the church could benefit from its principles in her endeavours to enhance the agency of families affected by the AIDS pandemic. God has endowed each human being with the richness of talents, gifts, skills and capabilities to do things beyond one's imagination. These need to be identified, appreciated, developed and released to full potential for the individual's and the community's sake.

SLF starts with an analysis of strengths rather than needs. This implies recognition of everyone's inherent potential whether this derives from their strong social networks, their access to physical resources and infrastructure and their ability to influence institutions or any factor that has poverty-reducing potential.⁶⁶

The SLF recognises a range of assets that households and communities have or do not have. It not only focuses on assets that people utilise to enhance their livelihoods but also on the vulnerability context and how it either constrains or liberates people to exploit opportunities open to them. It builds upon people's definition of these constraints and opportunities and explores what strategies people adopt to live within the said constraints and opportunities. It also recognises that some livelihood strategies can enhance one aspect of life whilst diminishing another either in the short term or long term. The essential aspect of the SLF is its focus on enhancing people's livelihoods rather than "running a development project".

The focus on people's livelihoods is based on the recognition of people's capabilities and means to live, to labour and acquire assets. Building on Sen's definition of capabilities, Robert Chambers and Gordon Conway assert that this

⁶⁶ Mark Butler and Ran Greenstein. *Sustainable Livelihoods: Towards a Research Agenda*. (Community Agency for Social Enquiry, November 1999)

includes the ability to cope with stress and shocks, ability to access and utilise assets and exploit opportunities.⁶⁷ They say,

such capabilities are not just reactive, being able to respond to adverse changes in conditions, they are also proactive and dynamically adaptable. They include gaining access to and using services and information, exercising foresight, experimenting and innovating, competing and collaborating with others and exploiting new conditions and resources. Capabilities are both ends and means of livelihoods: a livelihood provides the support for the enhancement and exercise of capabilities (an end) and capabilities (a means) enable a livelihood to be gained.⁶⁸

The United Nations Development Programme defines Sustainable Livelihoods as the assets, activities and entitlements which people utilise in order to make a living. These assets are human, social, natural, physical, and financial and are often referred to as the asset portfolio. According to the UNDP the sustainability of livelihoods becomes the function of how people utilise asset portfolios on both a short and long term basis.

They give an outline of Sustainable Livelihoods as those that are:

- Able to cope with and recover from shocks and stresses
- Economically effective or able to use minimal inputs to generate a given amount of outputs
- Ecologically sound, ensuring that livelihood activities do not irreversibly degrade natural resources within a given ecosystem
- Socially equitable, which suggests that promotion of livelihood opportunities for one group should not foreclose options for other groups either now or in the future.⁶⁹

⁶⁷ Amartya Sen (1984) refers to capabilities as being able to perform certain basic functionings, to what a person is capable of doing and being. It includes to be adequately nourished, to be comfortably clothed, to avoid escapable morbidity and preventable mortality, to lead a life without shame, to be able to visit and entertain one's friends, to keep track of what is going on and what others are talking about.

⁶⁸ Chambers and Conway. *Sustainable Rural Livelihoods*.

⁶⁹ United Nations Development Programme. "Sustainable Livelihoods: Overview", 10 February 2003 at [http://www.undp.org/sl/Overview/an overview.htm](http://www.undp.org/sl/Overview/an%20overview.htm)

Kretzman and Mc Knight talk about the identification of the community's assets and strengths and how these could be utilized for their development.⁷⁰ This therefore, involves all the parties that have been marginalized. The one developmental approach of the South African government in this regard was the Reconstruction and Development Programme. The RDP's fundamental objective was to involve people at grass roots level in the development of their communities and policy issues thereof. With the introduction of the Growth Employment And Redistribution (GEAR) economic policy, the majority of South Africans started being disillusioned and feeling further marginalised by the government, as their participation and agency became undermined.

The Sustainable Livelihoods approach on the other hand

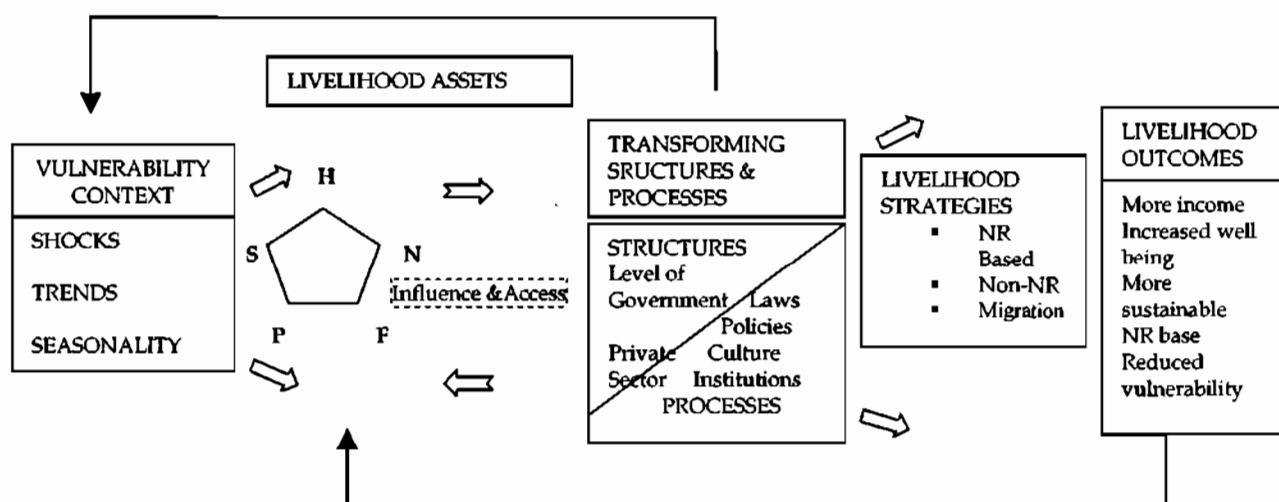
- ❑ starts with an analysis of people's livelihoods and how these have been changing over time
- ❑ fully involves people and respects their views
- ❑ focuses on the impact of different policy and institutional arrangements upon people or households and upon the dimensions of poverty they define
- ❑ stresses the importance of influencing these policies and institutional arrangements so they promote the agenda of the poor
- ❑ works to support people to achieve their own livelihood goals.⁷¹

⁷⁰ Kretzman and Mc Knight. *Building Communities from the Inside Out*.

⁷¹ Department for International Development. *Sustainable Livelihoods Guidance Sheets*, UK Government, London.

5. Analysis of the Sustainable Livelihoods Framework

The following is a graphic representation of the Sustainable Livelihoods Framework with a discussion of each part presented below:



5.1. The Vulnerability context

The vulnerability context comprises of shocks, trends and seasonality. 'Trends are gradual changes partly predictable. Seasonality occurs in the production of crops and food prices, in health and also in employment opportunities. Shocks occur in market prices and in particular in nature and they often destroy assets directly. Other shocks include outbreaks of epidemics of human diseases, livestock diseases and crop pests'.⁷² The SLF looks at the environmental, economic, social and institutional sustainability to address and cope with stress.

According to the Sustainable Livelihoods approach, people live within a vulnerability context. Their use and access to assets is greatly influenced by this context as well as the livelihood strategies they adopt. Butler and Greenstein assert that the vulnerability context is not inherently hostile to livelihoods. "It is important to recognise that the inherent fragility of poor people's livelihoods makes them unable to cope with stress and less able to manipulate their

⁷² Neefjes. *Environments and Livelihoods*.

environment to reduce those stresses".⁷³ According to the UK government's Department for International Development, the vulnerability context lies outside of people's control and any change in this context will be a result of change in policies and structures. They say that other than transforming structures and policies, managing the vulnerability context would mean helping people to be more resilient and capitalise on its positive aspects.

5.2. The asset portfolio⁷⁴

The use of livelihood assets, referred to here as the "asset portfolio", determines the livelihood outcomes. These assets are termed 'capitals' and they include human, social, natural, physical and financial capital.

a) Human capital

"Human capital refers to skills, knowledge, ability and potential to labour, and good health which together enable people to pursue different livelihood strategies".⁷⁵ It is required to make use of any of the other assets. Education and health factors are important indicators relevant to assessing human capital asset stocks. Particular groups often display poorer health or greater degrees of exclusion from knowledge resources.

b) Social capital

This refers to the social resources upon which people draw in pursuit of livelihood objectives, including networks, membership of groups and relationships of trust. Butler and Greenstein argue that social capital is developed through networks and connectedness, formal group membership, trust, reciprocity and exchange. They further point out that this capital can be important in "improving efficiencies in

⁷³ Butler and Greenstein. *Sustainable Livelihoods*.

⁷⁴ Neefjes. *Environment and Livelihoods*.

⁷⁵ Neefes. *Environment and Livelihoods*.

economic relations and in turn improving incomes and rates of return; reducing 'free rider' problems associated with public goods by improving management of common resources (natural capital) and maintenance of shared infrastructure (physical capital); stimulating improvements in human capital where it enables innovation and sharing of knowledge".⁷⁶

c) Natural capital

Natural capital refers to natural resource stocks from which resource flows are derived that are useful for livelihoods. The quality of resources must be taken into consideration when assessing stocks. Butler and Greenstein argue that "it is important to identify what types of natural capital exist as well as to explore questions of access to natural capital, the quality of those resources, and how they are combined over time in relation to livelihood activities".⁷⁷ It is misleading to assess broadly what resources people have without finding out who has access to those resources even within a household. Women, the elderly, the disabled and even people living with AIDS have less or no access to some of natural resources like the land and these are factors that the SLF seeks to explore.

d) Physical capital

This refers to the basic infrastructure and the producer goods used to support livelihoods. It ranges from chemical inputs into production processes to infrastructure such as factories, roads and water-supply systems. This capital is essential in helping people meet their needs and/or utilise other capitals.

⁷⁶ Butler and Greenstein. *Sustainable Livelihoods*.

⁷⁷ Butler and Greenstein. *Sustainable Livelihoods*.

e) **Financial capital**

This refers to financial resources available to people in pursuit of their livelihoods including savings and credit. The financial capital is convertible into other types of capital, it can be used directly for livelihood outcomes (like buying food); it can leverage political influence and free people up for participation in structures and processes.⁷⁸

5.3. Transforming Structures and Processes

According to de Gruchy, Transforming Structures and Processes refers to “the intentional structures, institutions, formations and contracts that are set in place to regulate social and communal life”.⁷⁹ This means that structures are important in making sure that there is law and order and to enforce policies. Unfortunately, it often happens that the policies that are enforced do not favour the poor as we have seen with macro-economic policies. For example, the World Bank and the International Monetary Fund are two major institutions that have undertaken the task of managing the economies of the Third World. Their goal is to make sure that the debt is serviced. Susan George further argues that the ordinary people that are severely affected by this “sacrifice to pay back these loans they never asked for, or which they even fought against and from which they derived no gain”.⁸⁰

Livelihood structures are indeed very complex and revolve not only around the capital income that the family receives, but also involves the skills and services of all members of the family pooled together to making a living as well as national and global structures and processes within which the household is constituted as discussed above.

⁷⁸ Butler and Greenstein. *Sustainable Livelihoods*.

⁷⁹ De Gruchy. “The Contribution of Universities”.

⁸⁰ Susan George. “How the Poor Develop the Rich” in M. Rahnema and V. Bawtree. *The Post Development Reader* (London: Zed Books, 1997).

According to the UNDP,

Poverty is much more than a lack of income but rather a form of deprivation that can be better described as human poverty. Human poverty is multi-dimensional in that it constrains human choices and results in vulnerability and a perpetuation of inequalities. Human poverty is both a condition and a process. It does not imply that poor men and women are passive victims of their plight, but rather that they are constantly coping and adapting to, and more importantly fighting impoverishment processes.⁸¹

This coping and adapting is illustrated by a situation in which a family may survive “by sending its children to sell goods on the streets while the father earns a small wage at a factory and also drives a taxi and the mother grows food in an urban garden”.⁸² Structures and processes function from the household, community, national and global levels and they regulate who has access to what types of capital, livelihood strategies and opportunities, decision-making bodies and sources of influence. Transforming structures and processes would refer to culture, traditional institutions and belief systems, policies from national levels such as economic policies through to international policies, that impact on the lives of ordinary people as well as structures of governance from the local, national and even global levels.

This explains why people within the same family unit or country will have limited or no access to certain capitals or would be constrained from pursuing specific livelihood strategies whilst others enjoy the same. Women for example, have for decades lacked access to financial capital because of their domestic and reproductive responsibilities and this greatly impacted their socio-economic conditions, health and access to health care, their independence and quality of life. “Women are at the bottom of the pay and power scales of agriculture; they are employees not employers, unpaid sowers, reapers and bread makers, not bread earners on the family farm”.⁸³

⁸¹ United Nations Development Programme. “Sustainable Livelihoods: Overview”.

⁸² The International Institute for Sustainable Development, *Communities and Livelihoods* at <http://www.iisd.org/communities.htm>

⁸³ Seager and Olson (1986) quoted by Raana Haider. *Gender and Development* (Cairo: American University Cairo Press, 1996).

5.4. Livelihood Strategies

Butler and Greenstein define livelihood strategies as the range and combination of activities and choices to achieve livelihood goals. They further say “the Sustainable Livelihoods approach stresses choice, opportunity and diversity since greater choice and flexibility yields greater capacity to survive or adapt to shocks and stresses from the vulnerability context”.⁸⁴

People choose certain livelihood strategies informed by their access to different assets and the vulnerability context in which they find themselves. Limited access to assets especially those critical and basic to life often results in the pursuit of negative strategies, as people strive to survive for each day- stealing and crime might be a means to survive yet another day of hunger. It is therefore important to assess why people choose certain strategies over others so that those that are negative could be discouraged and those that are positive or ‘life giving’ could be enhanced.

5.5. Livelihood Outcomes

Livelihood Outcomes are outputs from livelihood strategies, and for them to be sustainable it is essential that they enhance poor people’s agency and livelihoods. The ultimate end of outcomes is that they should enhance the livelihood assets of the household or community.

Livelihood outcomes could include:

- more income relating to the economic sustainability of livelihoods
- increased well being manifested through healthy self-esteem, self worth and dignity, a sense of inclusion and control, physical security, health status, access to services, maintaining cultural heritage etc.

⁸⁴ Butler and Greenstein. *Sustainable Livelihoods*.

- reduced vulnerability: reducing the precarious and unsustainable character of existence, and building cushions and resilience against shocks and trends.
- improved food security,
- sustainable use of natural resource base.⁸⁵

The Sustainable Livelihoods Framework helps us to recognise assets that communities have, the context within which those assets are utilised, and the livelihood outcomes as a result of strategies that people and communities employ in pursuit of their livelihoods. This brings us back to our basic argument that all people regardless of their colour, geographic location and economic position in society have an agency. They are engaged in activities of survival and have a life. This includes people living with AIDS. In the next chapter we evaluate stories of people's livelihoods as they struggle with the reality of HIV/ AIDS in their families.

⁸⁵ Butler and Greenstein. *Sustainable Livelihoods*. p. 59.

CHAPTER IV

Presentation of research findings

1. Introduction

This chapter is a presentation of the data collected in the study. The findings will not be analysed in this chapter but inconsistencies in the information gathered from different members of families will be highlighted. An analysis of findings using the Sustainable Livelihoods Framework will be in the chapter that follows. The identity of families affected by and individuals infected with AIDS will not be revealed for the respect of their right to confidentiality.

Preliminary to the actual field study with families infected with and affected by HIV/ AIDS, a number of different role-players were interviewed. The researcher held a meeting with community leaders to find out their perception of AIDS in the community, establish their political will to fight the disease, assess what programs there are in the community that are a response to HIV/ AIDS, and ascertain what role they see the church playing. The councillors welcomed the invitation to this meeting.

The researcher also met with one of the home-based care volunteers to give an overview of the research study and assess what was happening in the community. From this meeting it became clear that some of the researcher's hypothesis that there was nothing happening in the community to respond to HIV/ AIDS was inaccurate. Indeed the community is waking up to this challenge. The home-based care program as mentioned earlier in this paper has been going on for quite some time even *before* AIDS and these services are even more invaluable now as many more people are getting sick. Second, *loveLife* has initiated an education program in schools since the beginning of 2003 and they are doing this by engaging the community's young people as volunteers to educate their peers on HIV/ AIDS.

Third, the Lukhanji Municipality launched an HIV/AIDS initiative in October 2003 even though nothing practical has happened since.

A focus group meeting with the home-based care volunteers was held and church ministers were interviewed. The other gap in the study is the fact that data from the funeral parlour on the trend of deaths at Ilinge could not be accessed. The reason for this is that they do not have folders for different communities, meaning that it is not possible to get statistics of a specific community. Trying to get this kind of information will require changing the whole of their filing system.

2. Interviews with Civil Society

2.1. Meeting with Community Leaders

Ilinge is part of the Lukhanji Municipality, which falls under the Chris Hani District Municipality.⁸⁶ The Lukhanji Municipality incorporates Ilinge, Queenstown, Whittlesea, Sada, Ezibeleni, Hewu, Machibini, Zingquthu, Tylden and the surrounding villages.⁸⁷ Ilinge is a township that has no employment facilities or companies except for the Nonkqubela Beadwork Project that has a handful of workers, and a government housing project that has afforded community members with temporary employment. The main means of survival for this community are brick making, taverns and spaza shops. The community has four primary, two higher primary, two junior primary schools and one high school. There are two crèches and two pre-schools. There is only one clinic and two fuel stations.

The community is demarcated into two wards with councillors in each ward. The councillors truly appreciated being consulted about the research that was to be done in their community, saying that other initiatives and NGO's wanting to do work in the community just come and seek to work directly with their target

⁸⁶ Find the district map in the appendices

⁸⁷ Daily Dispatch, "Residents owe Lukhanji Municipality R88m, 22 January 2004 at <http://www.dispatch.co.za/2004/01/22/easterncape/cluk.html>

groups excluding the leaders and this approach always proves ineffective. However, one of the male councillors left before the meeting could start. Apparently he did not quite understand that the meeting was to discuss issues related to HIV/AIDS and that the 'guest' was a young woman. He could not 'waste' his time and sit in that kind of meeting and we continued without him. This unfortunately is the kind of attitude (it was said), most males in the community have against HIV/AIDS. They do not want to engage themselves in any of *this*, are abusive in their relationships and yet are the ones who 'spread' the virus, get sick and are then cared for by women. The meeting then continued with one councillor and three ward committee members (each councillor has a ward committee) - one male and three females.

Asked about their perception of AIDS in the community, the councillors felt that HIV/AIDS is increasing; people are not coming out to disclose their status and those who do not hide are not behaving responsibly. An example was given that men especially continue to be sexually active with different women even though they know their HIV status. One committee member has a relative who is HIV positive and spoke about his irresponsible sexual behaviour.

It was said that parents believe that if their children are HIV positive it is because they have been promiscuous and they then tend to isolate and condemn them. Some parents even vent out their frustration by talking badly about their children, saying *unalento ikhoyo* (she/he has this current thing- a way of referring to HIV/AIDS without even calling it by name). Other parents, because of stress resulting from not talking about AIDS, end up getting sick themselves and they even go to the extent of accusing people of bewitching their children.

Parents are terrified of losing more children. For example, small things like fever scare them. An example was made of a family who had two sick children due to HIV/AIDS and the family was not talking about it and some neighbours were being accused of witchcraft. The children died a few days after each other and it is

said to have been a gloomy and painful experience for all concerned. The leaders observe that people who are allegedly HIV positive start to act out irresponsibly- they start to have multiple sexual partners and start drinking. Some say they were not born with AIDS and that means they got it from somewhere and that is why they are also going to spread it. The community label people living with AIDS and they call them names.

The community is engaged in a few activities as a response to the HIV/ AIDS challenge. There is a Home Based Care programme coordinated by the local clinic. This is formed by volunteers who care for all the sick in the community regardless of the illnesses. The Lukhanji municipality in Queenstown, of which Ilinge is a part, launched a Home Based Care programme in October 2003 but the programme has not taken root in communities. It was said that the initial phase of the program would be to assess the needs of people living with AIDS and plan programs that will respond to those need. This means that it will take a long time before the much-needed services are rendered to the community because the research itself has not yet started. *loveLife* is also running educational programs at schools since the beginning of 2003.

The leaders felt that people need to be educated and families are suffering in silence and caught up in fears such as getting AIDS from spoons used by the infected person in the family. Parents are not trained on how to care and they do this at risk of their own lives, get tired with caring and some even tend to neglect their sick children. It was mentioned that AIDS loves families who are struggling and are poor and the reason for this was not known.

They also said that a community centre is needed where education and awareness, counselling, handwork, taking care of orphans and the sick could take place. It was mentioned that people with AIDS get their disability grant too late (that is, when their CD 4 count is less than 200) and they cannot feed themselves and afford the medication. The clinic was accused of delaying even the grant applications. An

example was given that the clinic demands that someone who already had a positive result should test again to confirm so as to get the grant. Asked what role they see the church playing in this fight, the leaders said the church couldn't do anything because they are not cooperative on anything and are certainly far from talking about AIDS.

2.2. Focus group meeting with Home Based Care volunteers

The focus group meeting was constituted of about twenty two women who are home-based care volunteers. Their ages ranged between 22- 48 years and most of them have primary to secondary education. Asked of their perception of AIDS in the community, the volunteers felt that AIDS is real, infection rates are high and it is a family problem. They mentioned that orphans are on the increase in the community and families are not talking about it. Only when they need grants for the children do they come out. They said that they know people who are HIV positive and who are spreading the virus and they do not feel capacitated to either challenge them or give 'sound' advice. These people start drinking heavily and do not even take heed of the counsel given. Some of the people living with AIDS disclose their status to the volunteer who becomes the only person who knows, and the family is not told for fear of rejection. This increasing abuse of alcohol is related to stress and hopelessness that comes as a result of HIV diagnosis. They do not see the future, for HIV is often seen as a death sentence.

HIV infection is presenting problems not only for the one infected but for the rest of the family. It was mentioned that families are struggling with children who go out to big cities like Cape Town and Johannesburg and are never responsible for the family. When they start getting sick they come home and parents then find it difficult to accept them. They argue that when they were working and well they never thought of helping out in the family and they only come home to be cared for and be a burden to the rest of the family.

Volunteers felt that there is a need for family counselling rather than just counselling for the infected person only. They said that families are traumatised by AIDS and that is why some will hide their sick people and refuse that they be seen because they do not know how to deal with this disease. An example was given of a family who knew that their child was HIV positive but after he died they blamed the neighbour of bewitching the child. Another example was of a girl who refused to tell her family that she was HIV positive but the mother told the volunteer that she was suspecting the child might be HIV positive because of symptoms and feared that they might get the virus through sharing utensils with her. Other families spend a lot of money by taking their children to witchdoctors saying *bayathwasa* or *bafuna intambo* (they are called by ancestors or they need specific cultural rituals).

Most families in the community depend on social welfare grants and many more on old age grants and they are not coping financially to care for the sick. Many of the sick young people are taken care of by old people and they are not coping. They care for the sick at risk of their own lives and it has been observed that some family members get infected through unprotected caring.

The volunteers also expressed their problem with the social worker who never visits families or says people should come the next day. This delays the process of helping people deal with their problem and if there are any grants to be applied for it takes much longer. They also said that the local clinic does not have enough drugs even for minor things like flu and people are turned away. Those who can afford a doctor are better placed, but the majority of people depend on the clinic and that presents a shortfall for them.

Asked of their experiences of home-based care, volunteers said they feel they are making a difference and people are gaining their trust.

- People infected with HIV are able to talk to them about their status

- They also felt they were encountering stressful situations in different families and they have to handle people who are dying
- They are sometimes stressed and tense because of seeing this suffering and feel helpless
- They have learned to care for the sick and how to be patient with their demands
- They have learned how to give hope to someone who feels hopeless
- When they identify symptoms they encourage people to test for HIV and educate families not to conclude that their members are HIV positive because of the symptoms the person presents
- They educate people infected with HIV of their right to be protected and a right to confidentiality as well as counsel them on nutrition, and how they should behave sexually
- Volunteers feel overwhelmed with the amount of work that needs to be done, sometimes they have to even help out with their own money and food, and in desperate situations where a family cannot afford a taxi they carry the sick in wheel barrows to the clinic
- They have also learnt how to protect themselves from contracting the HIV virus
- They also try to engage people to tell their families but it is difficult. In some families it is difficult to even go in and one has to win the trust of at least one member of the family. In others you have to identify with the family through *isiduko* (clan name) and that link allows you in as a “relative”.

Volunteers mentioned that out of twenty-two, only five of them received home-based care training yet they have been asking the clinic to organise training for them for the whole year to no avail. This lack of training makes them feel unable to deal with some of the challenges they are faced with. They do not feel protected from TB, especially when someone is not on treatment. They also raised a concern for their welfare and protection, asking: what happens when one gets hurt whilst on duty? For example, one of the volunteers broke her leg whilst on ‘duty’ and she

is going to doctors and hospitals with her own money without any help from the program. They also said that they do not receive any stipend and only five members received R500 once in August 2003 and there was no explanation. They were only told that it will happen like that and others should just wait for their turn.

The meeting felt that parents should be educated about HIV/ AIDS and helped to accept family members who are HIV positive. Volunteers carry the burden of knowing when people confide in them whilst the rest of the family does not know. They also felt that people need to be educated about the grants they receive after their CD-4 count is below 200 because they use this money to practically “kill” themselves by drinking instead of taking care of themselves. The other problem experienced was of people who know their HIV status but who still fall pregnant. This is evidence of unprotected sex and thus of spreading the virus, but also it means an increasing number of children born with HIV and/or children who will be orphans. As it is, families are struggling to care for orphans as a result of AIDS. Other families do not have any source of income and do not know how to care for these children.

Volunteers thought that the role of the church should be to support families with sick people, pray for them, facilitate education programs and assert that it is not only promiscuous people who get AIDS. It was said that churches isolate themselves from their members with sick people and some cannot talk about AIDS and sex issues because this is seen as “vulgar” language. None of the volunteers felt motivated to care for the sick because of their religious convictions. They said they were motivated by the rate of sick people who need to be cared for and are doing this out of pity especially for those who are rejected and they want to make a difference.

They mentioned that some people who are taken by AIDS are breadwinners and after they die the family is left without any source of income and starving. They

want to help to decrease the level of HIV/ AIDS because they also have families and children, and feel that it could be them who are directly affected the next day.

2.3. Meetings with Ministers

Ilinge is a community that is generally Christian. The majority of people are affiliated to a church and even those who do not attend church would be buried at church because of their relatives. It has a number of churches varying from main line churches to African Indigenous churches. These include the Anglican, Methodist, the Uniting Methodist, Roman Catholic Church, Dutch Reformed, Dutch (split from Dutch Reformed), Baptist, Church of Christ, Bethel, Church of Jesus Christ of the Latter Day Saints, NG Kerk, Emmy, Apostolic Faith Mission with its many branches that split up, Bantu Church of Christ, Full Gospel, Assemblies of God, Twelve Apostles, Eleven Apostles, ZCC and many other Zionist churches, Pentecostal Protestant, Seventh Day Adventist, Jehova's Witnesses and Watch Tower. Indeed Ilinge is a small "churched" community and there are still more groups that are springing up as a result of splits from already established groups. This number of churches could be an indication of unhealthy relationships amongst Christians and may explain why there is no concerted effort or strong voice from the church in matters concerning the community.

Three church ministers were interviewed. The reason for this low number was that some ministers of churches in the community live outside the community in suburbs of Queenstown and the researcher could not get to them. Secondly, there is a huge project of house building going on, and many people are involved and working in this project including some of the ministers the researcher wanted to see. Appointments were never honoured until the time allocated for research was over.

2.3.1. Reverend Xwazi of the Methodist Church of Southern Africa.

Reverend Xwazi is a young minister full of zeal to turn things around in his congregation and to have a significant impact in society. He came to this parish on the 6th of January 2003. For the ten months that he has been in this community he is seeking to familiarise himself with the context within which he is working and involving himself in the lives of his parishioners. He expressed with concern that, "Ilinge is in a crisis as far as AIDS is concerned". Ilinge is stricken by poverty and unemployment and all these are contributing factors to the accelerating rate of AIDS in the community. He said that during the day you wouldn't see 12-14 year old girls because they are sleeping and late afternoon they get up and go to Queenstown for prostitution. He also said alcohol consumption is very high and it puts people more at risk.

He attended a meeting at the clinic in April 2003 where they were trying to establish a support group of people infected with HIV. His first observation in this meeting was that people infected with HIV are fearful of coming out into the open because of stigma attached to the disease. Second, the people who were leading the discussion and making decisions were not the people for whom the support group was to be established but NGO people from outside of the community- ATTIC. There was then no follow-up from this meeting as promised so he does not know what is going on now.

Reverend Xwazi expressed that many people are sick and most symptoms are AIDS related. He said that many people who die are from cities eg. Cape Town and Johannesburg and the cause of death is either TB or pneumonia. In the church he had a family that had two members who were sick and have consequently died. He tried talking to them but they were not willing to discuss the illness of their family members. He said when you try to get close to a family they become secretive, thinking that you might expose their affairs. Families deny that AIDS is real and they associate it with witchcraft. He said some of the families at church were good

families but when they have a sick person they started to fight, became hopeless, stopped coming to church, asked why was it them who are suffering and why God is punishing them. Even some members of the congregation isolate themselves from these families and only about twenty percent would accept and support them.

He said this presents a challenge to educate church members so that they could be able to go out and talk to others outside the congregation. "When it is communion time and there is one member people are suspecting to be HIV positive, they do not want to sit next to her and when its time to share the peace, people avoid the person".

He said, "The church needs to be outward looking, work as a body of Christ and should stop lifting up the names of our denominations. The church is not united and that is why there is nothing effective and impacting on our communities. The church is pretending as if there is nothing happening, AIDS is not our *thing*. Unfortunately, this happens in a context where funerals are happening even during the week and it is mostly young people. In May and June there were about five funerals every Saturday and this drains you physically and spiritually". He said it is time that the church should educate people, be practical and stop being theoretical. This could mean visits to families with sick relatives, care for orphans even if its just one family where one could make a difference.

2.3.2. Mr and Mrs G.S Nqophiso, *Igosa* of the Baptist Church

Mr and Mrs Nqophiso are overseers of the Baptist Church at Ilinge. They do not have a minister and the church has been characterised with break-ups over the past few years. Asked about their perception of AIDS in the community, Mr Nqophiso asserted that AIDS is the main problem at Ilinge and it targets young people and many are dying. The main problem as he sees it is that there is no help and cure for AIDS and it is growing fast. "What this means is that if you get it, you are surely going do die". He said that the number of people infected with HIV who are

starting to be treated for opportunistic illnesses far exceeds the capacity that the local clinic can service. "We are indeed in a crisis".

He also mentioned that AIDS used to come with people who worked in Johannesburg and Cape Town but now even the "local" people have it. Most families in the community have people infected with HIV and they are dying. The community in general has not accepted AIDS, they still see it as a disease to be shameful about and hence those infected and their families are not disclosing their HIV status and because of this secrecy *iyabosela* (it hurts them so bad and deep).

He said that at his church they had three people who have died due to AIDS related illnesses and they deteriorated in front of his eyes, but the families were not willing to talk about it. It was only after they died that the families mentioned that these people were HIV positive. He also said that the number of funerals leaves nothing to be desired. "In the community, we would have about ten funerals every Saturday and on Sundays there would be about four".

Mr Nqophiso emphasised that AIDS should not be taken lightly and regarded as a shameful disease. People can prevent themselves from contracting the virus and that needs to be stressed and the church needs to talk about AIDS in all its programs and sections. They mentioned that the church is slowly trying to respond to this crisis by talking about AIDS. They bought a video cassette with basic facts about AIDS which they have made available for people to borrow. However, no one has ever borrowed the cassette and the reasons ranged from lack of interest to the fact that many people do not have video machines. They also encourage people to test for HIV so they can live responsibly and take care of themselves so as to prolong their lives. They also offer prayers for the sick.

2.3.3. Pastor Dyantyi of the Pentecostal Protestant Church

Pastor Dyantyi has been at this branch of the Pentecostal Protestant Church at Ilunge for the past four years. His church consists of about 18 members. Asked how he perceived AIDS in the community he said, "I see AIDS as a problem but this was after I attended a conference of church leaders in East London and one of the speakers presented on the challenge that AIDS poses for the church. I was challenged as a Christian to respond compassionately to AIDS. The reality of AIDS presented moved me to tears". Pastor Dyantyi asserted that he does not have a doubt that Jesus is the answer to this crisis but unfortunately people do not want to listen. His wish is that people who are HIV positive could accept Jesus' salvation who heals all the diseases. "I don't have anything else to say about AIDS but that *uYesu usisisombululo*" (Jesus untangles, or is the answer).

He mentioned that the fight would be won if people change their behaviour. He also said that families suffer the brunt of AIDS. At his church one family had a sick relative and they visited to pray with them and the sister was hurting terribly; *wayenesingqala* (deep sighs not of relief but of pain) also because they could not really say what the problem was. They have had one funeral at his church, which they suspected was AIDS related, but the family was not open about it and they just said the cause of death was pneumonia. Pastor Dyantyi thinks that families are not coping with this disease. They either condemn the sick saying they have invited the disease upon themselves or hide the sick person from being seen by people. He also said funerals have been steadily increasing in the four years that he has been in this community. "In a month I think four in ten funerals would be AIDS related".

Pastor Dyantyi said that educating people about HIV/ AIDS will help dispel the myths around the disease. He said he thought that AIDS is a disease for the promiscuous but has since realised that that is not true. "My attitude was because I had not been educated and at church I encourage people to take care of

themselves". Since the change of attitude he has counselled a couple where the wife was infected through her husband's unfaithfulness.

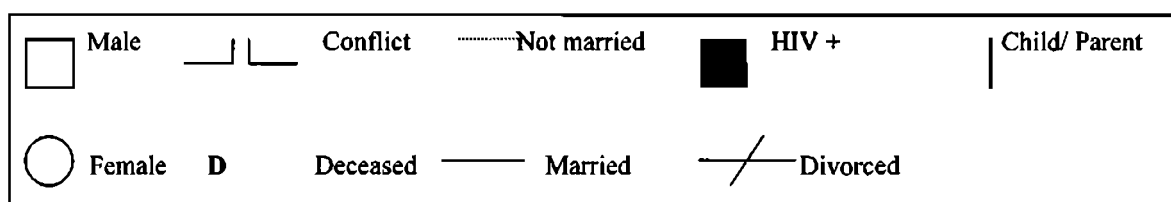
He concluded by saying that people should be told the saving word of God. They should not be condemned and *babethwe ngelizwi* (be bombarded by the Word) but be shown how this decision will impact their lives. He said "church leaders should use their authority to talk about AIDS and educate people because many people have confidence in them. Young people should be encouraged to talk to their peers as well and we need to visit people who are sick to pray and encourage them". He then said, "I don't really know what we can do but I want to seriously think through this. As a Christian I cannot afford not care when people are perishing".

3. Interviews with families infected with and affected by HIV/AIDS

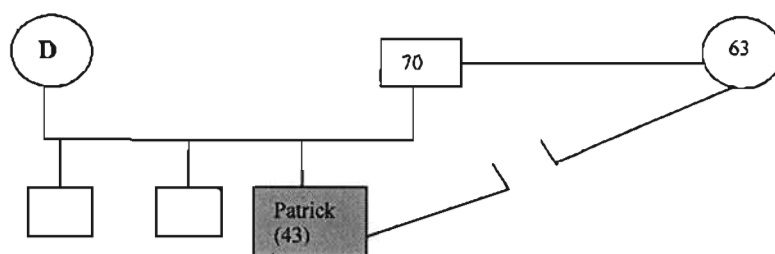
The home-based care volunteers identified the families with an HIV infected member whom they are working with. The criterion used was to identify a family whose member knew their HIV status, are talking about it either to the home based carer and/or the family. An appointment was then set with the family through the volunteer who is known in the family. The researcher then went to the families together with the volunteer so as to be introduced to them and allay any fears or uncertainties they might have. The volunteers would then excuse themselves, though in some cases the families requested the volunteers to remain during the course of the interview. Six families were interviewed and an effort was made to interview all the members of the family who were available.

As I examine these six families, which are large and intergenerational, I will use diagrams to depict the structure of these families. A key to understanding these diagrams is here below:

KEYS



2.1. Family I



This is a family of three adults staying together and the rest of the family members live and work in Johannesburg.

Mother: The first person interviewed was a 63-year-old mother of the home who is a pensioner. She is the second wife taken after the first wife died and has raised the three children she found as her own. She said they have a problem with their 43-year-old son who has not been well since 2001. He started by losing weight and in October 2002 he got very sick with tuberculosis and was admitted in hospital. He has been on TB treatment since. He came from Johannesburg without money and the parents are taking care of him and they are now applying for a grant for him. The only stable source of income in the home is the parent's old age grants.

The mother said that because of health care expenses sometimes she and her husband would go to *oomatshorisa* (loan sharks) because the other two children are not supporting them. They will only give some money when they are asked. She also sells *iintloko* (heads of sheep) to make ends meet. She also mentioned that since the son came home, her blood pressure always rises because it is not easy to have a sick person in the house. She does not go to church anymore because she has to care for her son. He is fussy on what he wants to eat. He does not want to eat what they normally have, *umphokoqo* (mealie meal), but wants to eat meat and wheat bix, which they cannot afford. She also said that apart from the support they receive from the home-based care volunteer, they are on their own.

Father: The father mentioned that there have not been any adjustments the family has had to make due to their son's illness. They are living as they used to and have

not spent a lot of money because his elder brothers are supportive. He also mentioned that they are helping his son apply for a grant. The church is supportive and members visit them to pray and one of the neighbours also visits from time to time.

Patrick: He is 43 and said that he started getting sick in July 2003. He had a swollen foot and he went to the doctor and was diagnosed to be having TB and he was not told about the results of his blood test. He said since he has been taking treatment he is recovering. He worked in Johannesburg as a driver and is now waiting for his pension money. Asked why he left his job. He said he quit because *ebothukile* (he was shocked) and he did not think he would make it through. A follow-up was made as to the shock that made him quit his job but no direct answer was given and he clearly avoided the question.

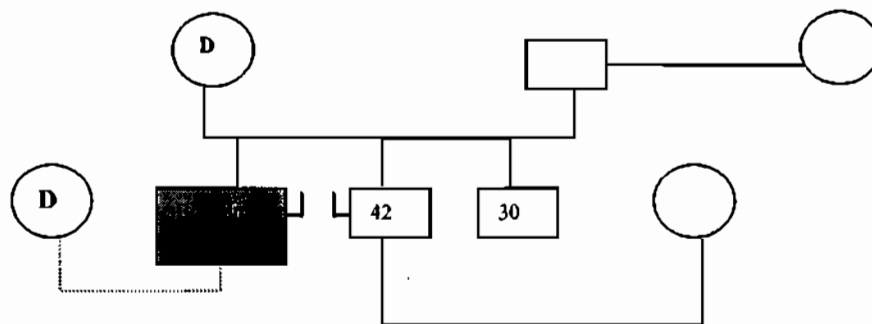
He expressed that he is now struggling financially and he can't even afford to go to the doctor. When he needs something he gets into a fight with his stepmother. His elder brother supports him financially and he wanted him to stay with him in Johannesburg because of their 'not so good' relationship with the stepmother but he decided to come home because he feared that his friends would laugh at him so it was better to come and hide at home.

Researcher's comments:

It is interesting that the mother accused the other two sons of not supporting them whilst the father said they are. The father also seemed not to think that his son's illness is a problem whilst his wife complained. Could it be that he was protecting his sons and the wife spoke the way she did because these are not her real sons? Or could it be that she feels the burden more because she is the one who is physically caring for the sick son?

Patrick said that he started getting sick in July 2003. This was inconsistent with his stepmother's account that he started getting sick in 2001. The researcher could also tell that he did not want to talk about the 'real' reason why he was so shocked that he quit his job and did not think that he was going to live long (after all he was diagnosed with TB which is not incurable). The fact that he ran away from Johannesburg because his friends would laugh at him presents an interesting inquiry. He also did not mention that he was HIV positive to the researcher yet the home-based care worker introduced the researcher to the family because of AIDS.

3.2. Family II



Bongani: The first person to interview in this family was a 47 year old man who is HIV positive and at the very symptomatic stages of the disease. Just as we started our conversation he cried saying that his younger brother who is the only person he is staying with is ill-treating him. When he is drunk he insults him for being "a nothing" and he can't even see *ukuba uyitya ntoni naloombali yakhe* (how he spends his grant, because there is *nothing* to see in him). He has been receiving the grant from 2002. His family knows about his HIV status because he told them. The brother who is accused of ill treatment is married and he and his wife don't even go into his room to clean it. He is now very weak and is practically in bed and he thinks that they are despising him.

He had a building construction firm that was doing well before he fell sick. The First National Bank in Queenstown is one of the places he had worked on, but now

he can't work and he is grateful that when he stopped working he had no debts because that could have been a problem for him. His only source of income now is his social grant. According to him, his family, the neighbours and his church are supportive, not in any tangible ways but through visiting. He last saw his old father early this year and would love to see him when he gets better.

He said that he started getting sick in February 2000 and he decided to test for HIV for which he tested positive. He encouraged his girlfriend to test as well and she also tested positive. She since died in November 2002. He is very ill and with the help of the home-based care volunteer he is on treatment and she dresses his wounds and helps him bathe sometimes.

Brother 1: His 42-year-old brother said that his brother's illness has not affected the family in any way because they all work outside this community and therefore it does not touch them. He is married and he and his wife live in Dimbaza. He himself worked in the textile industry in Dimbaza and he was at home because of problems at work and he will go back in February 2004 but he is also looking for a job. During the time of the interview, he was in his second week at home. He said that his brother was with him in Dimbaza and they both came home in the last two weeks.

He said he is disagreeing with his brother on how he spends his money and he just says he pays people he owes with his grant money. He said that they are not coping financially. If his brother buys a bag of mealie-meal and cabbages that will be all. He said he really does not know what he does with his money and he wants to call on social workers to come and talk to him. He also mentioned that he came to help him with his insurance policies and they could not agree, but he is still to pursue this. His nephew from Cape Town was to come and stay with him.

Brother II: The last interview was with a 30 year old man who is the last-born in the family. He came home in September 2003 from Cofimvaba where he stays with his

relatives. He came and found his brother sick and being helped by a boy from next door who also was sleeping in their home with him. He said that the family is hurting because of his illness but they have all accepted things as they are and are hoping that he recovers. He mentioned that he is grateful to their neighbour and the home-based care volunteer for their support and concern.

Asked how the reality of HIV/ AIDS has impacted on him specifically, he said that since he got to know that his brother is HIV positive he decided to have just one girlfriend. This was probed and it came out that what this means is that he is having one girlfriend in Cofimvaba where he stays and now that he is at Ilinge he also has 'just' one girlfriend. This meant two girls who in turn might be having their old boyfriends, who also have other girlfriends. This network of relationships was explained to him and shown how risky this behaviour was. He then mentioned that he actually realises that he is not safe because he is not sure how faithful these girls are and he was challenged as to why should they be when he isn't himself. He also said that he has been contemplating going for an HIV test. He was encouraged to do this and the meaning of the test was explained to him.

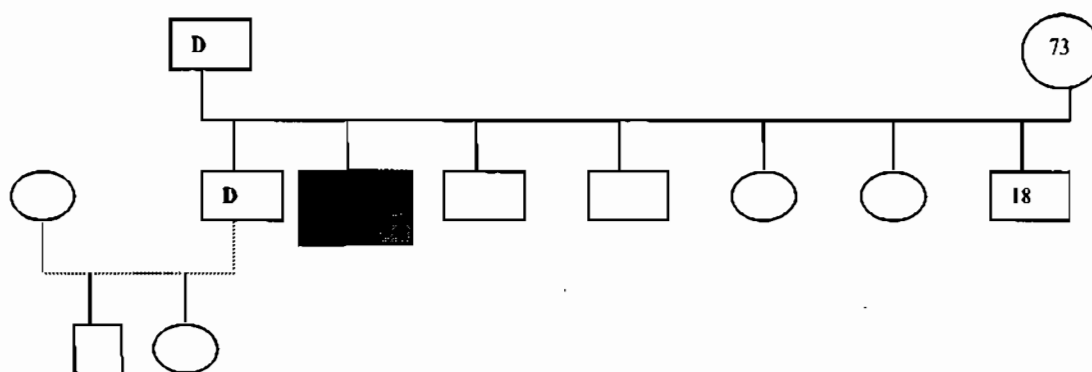
Researcher's comments:

When I got there for this interview at 09h30 Bongani had not had anything to eat and therefore could not be able to take his treatment. He said he does not have an appetite and this has been going on for about a week. Practically speaking, he has not been eating well for a week and thus not taking his medication regularly and there is no one to make sure that he eats and are patient with him.

His younger brother said that Bongani was with him in Dimbaza and they both came home in the last two weeks. This information from the brother was not supported by any of the other members of the family including the home-based care volunteer. He clearly lied and presented himself as one who cares and is looking after his brother.

He also mentioned that he came to help him with his policies and they could not agree, but he is still to pursue this. My sense as the interviewer was that all this brother and his wife are interested in is Bongani's pension and insurance policy returns. He could not be bothered about whether or not he ate and has taken his medication.

3.3. Family III



Mother: The mother of this family is a 73-year-old pensioner who lives with her five adult children, an under 18 and two grandchildren of her deceased son. The son was not married and the children are depending on her for support and at the time of the interview they were then visiting their mother for holidays. The researcher only managed to interview two members of this family because one sells fruit in town and leaves home very early in the morning and gets back late. The other two brothers have their shacks outside the house and they come home to eat, their whereabouts during the day are never known. The 18 year old was busy with his exams and could not be found at home.

The mother said that William started getting sick in 2001 but has been seriously ill this year. He was diagnosed and treated for TB and he later told her that he was HIV positive. She also said that after his son disclosed his status to her he felt better and almost recovered. She then thinks that it is because the load of secrecy was off his shoulders and that she never rejected him. She then said she felt good that her son could trust her. He, together with the mother, then told the other three adults

in the family, but not everyone because they do not know what their reactions would be. To this she said, "I know my children, that is why I told these ones and not the others". When asked to explain the impact of AIDS on her family, she said '*isixinzelele kakhulu ubomi abumnandi*' (meaning it has oppressed/suppressed them heavily and life is not nice).

She continued to say that her deceased son supported the family very consistently and when they have problems like the one they have now, she thinks of her son and how he would be handling things now. "My son's illness has brought back painful memories and opened wounds that have healed". There is no one who has a stable job and food becomes a problem. The four who are still at school need to survive without some necessities- there's one doing second year of college, Grade ten, Grade nine and Grade four.

The only stable source of income for this household is her old age pension and now the grant that her HIV positive son receives. One member of the family sells fruit in the taxi ranks of Queenstown and does not bring much home. She continued to say this disease was oppressing them. "I don't know, I feel I'm in the dark. I know I need help but I don't know what, could you please see what kind of help I need". This was a desperate cry for help that tore my heart and I felt helpless and even useless because there was not much I could do except to just sit there with her and allow her to vent out her pain and frustration.

She then mentioned that the only thing that makes sense to her right now is her hope in God and the strength she receives from him to survive each day. She said her church, the Seventh Day Adventist, is supportive. They visit and give encouragement and hope.

William: is 39 and has never been married and does not have children. He said he started getting sick in 1993. He was told he had TB and was admitted to hospital and it cleared. In 1999 he got sick again and he is being treated for TB. In October

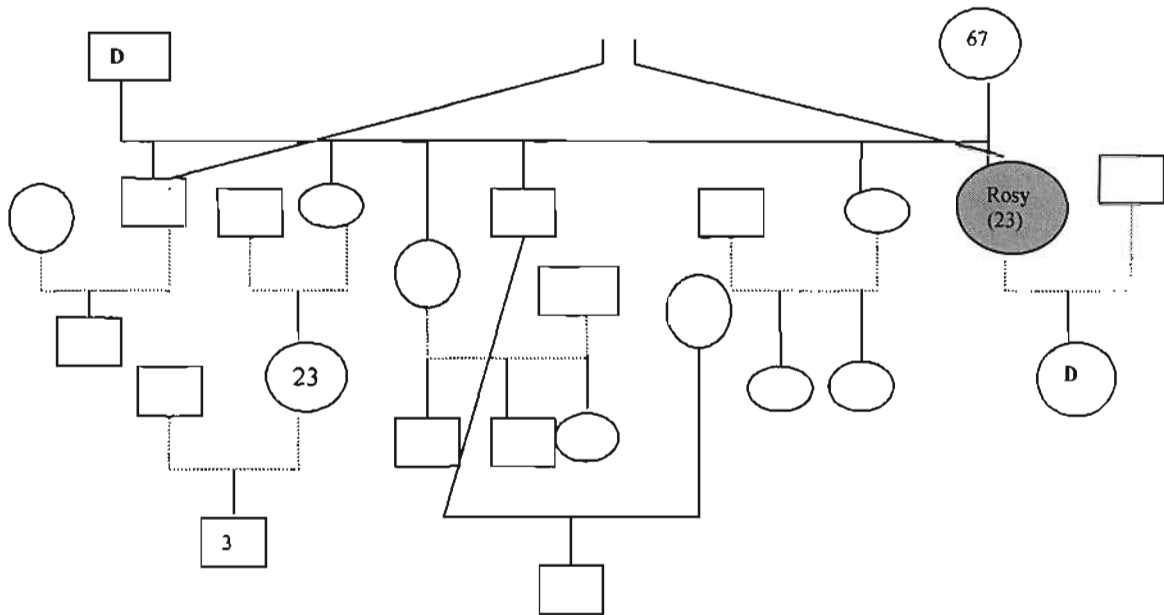
2002 he went for an HIV test because he was always sick and he tested positive. He also mentioned that his church is very supportive of his family. "When I was very sick and had lost hope that I will live, one mother from church visited me at hospital, she prayed for me, gave me hope and I recovered". He later told his family but has never told his girlfriend and he has not noticed any problems with her (referring to AIDS related symptoms).

He worked in Johannesburg as a driver and lost his job in 1990 because the company was rightsizing and has never worked since. When he was told that he tested positive for HIV he was distressed but he then decided to welcome the challenge and is working on treating himself. "I can't blame anyone because I don't even know where I got it from, so that is why I accepted it. I sometimes get anxious but I tell myself that this is life and it has its own challenges. I still want to live, I am young".

Researcher's comments:

William's longing for a *whole* life and dreaming of the future broke my heart and I wondered of how many chances to have a longer life were available to this man. Poverty and lack of access to treatment that could help prolong his lifespan regardless of the HIV virus, clearly did not present much hope. Even though the government has outlined its plan to roll-out anti-retroviral treatment for people living with AIDS, many would have died by the time it actually reaches down to people, and it is unfortunate that William might be one of those who would not have their dream to live realised.

3.4. Family IV



This family consisted of 16 people living together. They live in a one-bedroom home with a kitchen and a sitting room.

Rosy: is a 23 year old who left school at Std 5 and has been staying at home. She tested HIV positive in 2001 and when she got the positive results she did not really care because she felt fine and was not sickly. She is currently frail and on TB treatment. She told the rest of the family and they are hurt but they have accepted it. She never told her boyfriend of the positive result for fear of losing him and eventually they broke up in March 2003 because she had lost weight enormously and could not handle the sexual 'demands' of the relationship. She also said that she is not sure whether the boyfriend is also HIV positive because they have never used any condoms.

She said that she struggles getting money to go to the doctor because the only source of income in the family is her mother's old age pension and her sister's wages as a domestic worker. One of the neighbours gives food when they do not have and the only support they receive from their church is that they visit when she is sick and pray for her. Asked how she would live her life differently, she said there is absolutely nothing she would change. She would still do the things she had

done and the choices she had made and as far as she is concerned, nothing worries her. This girl presented with a sense of hopelessness, an 'I don't know any better' attitude. She looked like a very angry person but she was not willing to say anything much. Even when probed she would just give a short, uninterested response. She also did not mention anything about her daughter who died because of AIDS.

Mother: Her mother is a 67-year-old pensioner. She lives with her six adult children and nine grandchildren who are all at school. Her other daughter works as a domestic worker and supports the family and her employer is quite supportive to the family as well. She said the family is struggling to make ends meet and sometimes they are forced to go to *oomatshonisa* (loan sharks) to loan money to buy food and this becomes a vicious cycle, because after they had paid the loan they are left with not enough money to last them a month and they are then forced to loan again. This is a cycle of poverty that they are struggling to break out of. She then said that she is now working on getting the grant for her child who is sick with AIDS.

Sister: One of the sisters has three children and is unmarried and not working. She worked for a while as a domestic worker where she was earning R150 a month. She then gave up this job because she felt she was being exploited. She expressed that she receives R160 for child support and her other sister gets R150 for her child as well. She said that her sister Rose has been very sick especially after she got a child who was also HIV positive and died at three months, three years ago.

She said that they all depend on their mother's grant and sometimes they get *piece* jobs (casual one or two day jobs). The sister also mentioned that she is amazed at Rose's resiliency. Many people who were insulting her because of her HIV status have since died of AIDS related illnesses and they insulted and labelled her not knowing about their own statuses. She said she has not been in a relationship since June this year because she fears AIDS. She has never tested for HIV but she wants

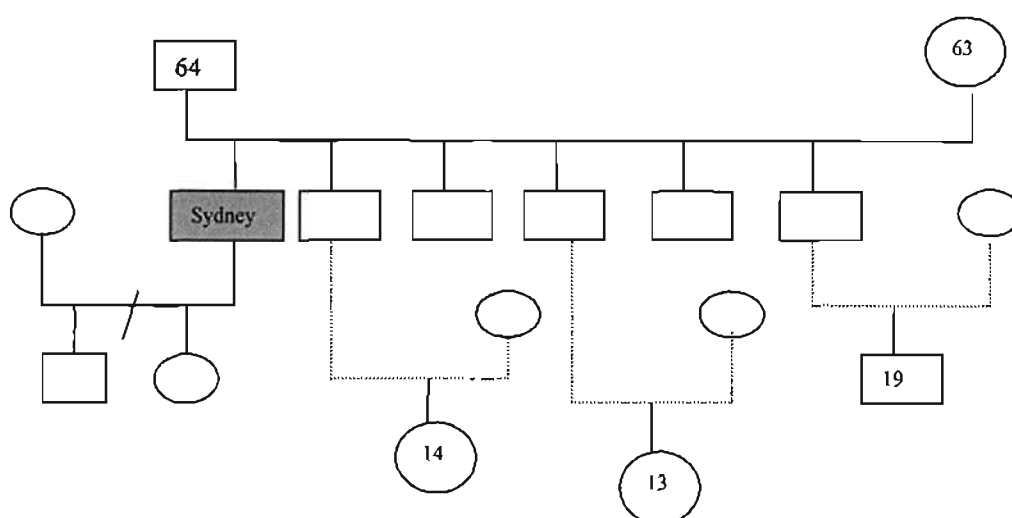
to go for a test but gets discouraged because the clinic is always full and one has to be in a queue for the whole day. She also said that Rose is always in tears but she refuses to talk about whatever is worrying her and her older brother insults her because of her 'AIDS'. She sometimes has *isingqala* (deep short sighs) even when they have not seen her crying.

Grandchild I: The researcher also met a 23-year-old grandchild of the family who is in Grade 11. She has a three-year-old son and receives a R150 grant for him. She said that the news of her aunt being HIV positive has not affected her in any way. They are relating well with her aunt but sometimes some of the family members fight and insult each other. She sometimes worries about things but does not have anyone to talk to. She is in a sexual relationship not with her son's father. They have never tested for HIV and are not using condoms. Asked if she considers herself at risk of contracting HIV, she emphatically said she is not at risk because she only has one boyfriend. This discussion was extended to explore possibilities and to help her perceive her risk of contracting of HIV. She could not be certain that her boyfriend is not involved sexually with other girls and she was then encouraged to reflect on what she wants in life and make sound and responsible decisions.

Researcher's comments:

One of the sisters said that Rose, has been very sick especially after she got a child who was also HIV positive and died at three months, three years ago. Now, Rose did not reveal this information and she actually said she went for HIV/ AIDS out of her own decision and it came out that she tested whilst she was pregnant. She only told the family about her status after the child was born and was consistently sick. This could explain why the researcher's observations were that she looked like a very angry person. She had a lot to deal with and there was no counselling received and she does not belong to any support group.

3.5. Family V



The family has four adults staying together with two children. They live in a one-bedroom home with a kitchen. Sydney said that he has been sick since October 2003. He had diarrhoea and was coughing. He was then told he had TB and he was also tested for HIV for which he got a positive result. He is worried about his status and has told the adults, but the children have not been told because they fear that they will talk about it in the community. He said when they ask he just says it is chest problems. He said that he receives encouragement from his family. He said he worries a lot when he thinks about his health status and the fact that he has AIDS and that it is never going away. The fact that he has to hide what he is sick about is unsettling but he said he is fine that his family knows. He said, “the local clinic does not give support, you can die there”.

He mentioned that there is no one working in the family and his parents are both on old-age grants and he himself has not applied for the grant yet. He said that he has never been married and has two children who stay with their mother and they do not even know that he is sick. His church members visit and pray for him.

Father: His 64-year-old father said that his son has been sick since 2001 when he was in Johannesburg, contradicting his son’s assertion of October 2003. The son

was married and his wife left him when he got seriously sick. They have two children and they are in their mother's home and the elder child knows that his father is sick because he lived with them in Johannesburg. The parents had to go up to Johannesburg to bring him home in September 2003.

"He is our patient and we feel helpless that we cannot help him. We loan *imali ezalayo* (money with interest) to take him to the hospital and that gives us problems in buying food. I still owe Frontier Hospital R20 for the bed when he was admitted there. We have three more children; two work in Cape Town and the other one in Johannesburg but they are not supporting us. One of the three helps only when we ask him for help". He continued to say, "when we get sick ourselves we can't afford to go to the doctor and when you finally go to the clinic, you stay there the whole day only to be told that there is no medication". He also said that his church the Zion Church in South Africa prays for them and helps in burying people. "When there is no death there is nothing that they do".

Mother: His wife is 63 and she is the main caregiver in the family. She said that after Christmas last year her son in Johannesburg phoned saying Sydney was very sick and later then recovered. In September this year he phoned again saying the parents should send them money so that they could send Sydney home. They then called his brother in Cape Town to help and he sent them R300 and they added to it and went to fetch him from Johannesburg.

Sydney went to the clinic for TB treatment and he was then referred to the hospital. "Whilst still on medication he got worse and we thought we were losing him and we called an ambulance to take him to the hospital and he was admitted for a week. He was then given a card to get treatment from the local clinic but he cannot go himself because he is too weak so the home-based care volunteer does this on his behalf". The mother said that it is only TB that was diagnosed and nothing else. "We are hurting. I was happy *ndizihlelele* (just staying here) without any problems

and he is truly my problem. Sometimes he gets sick and I have to go loan money and I also have to buy food”.

Grandchild I: He is a 19-year-old in Grade 9. He said that his uncle’s illness has made them all sad. He asked him why he was sick and he told him that he was HIV positive. “I felt bad and I cried. I never thought he would die soon and I still believe that he will be ok. I told myself when he needs my help I will give him and I do clean him up even now but I do not feel safe because I am not using gloves”. He himself is in a sexual relationship with one girl. “We do not use any protection but I know that I am negative”. He then took out a medical report of his test for HIV, which was negative. He and his girlfriend went to test for HIV and they were both negative and they are going for a confirmatory test in January. He said that he is faithful to this one girl and he hopes that she is faithful too but he cannot be really sure. They went to test because the girl suddenly lost weight and her parents suspected her to be HIV positive and they pressured her to go and test. She then came and asked him to go along.

Grandchild II: is 14 and is doing Grade 7. Her father is one of the family’s sons and does not stay with them but he is also at Ilinge Township. He is not employed but takes on *piece* jobs and would buy them food and even clothes. She said that her father also pays for her school fees and her mother lives in Cape Town and does not support her. “She said she will visit this December. I had been staying with her in Cape Town but I wanted to come and stay with my grandparents because I wanted to stay with my father. “It is hurting that my uncle is sick and I have never asked why he is sick because they would all swear at me”.

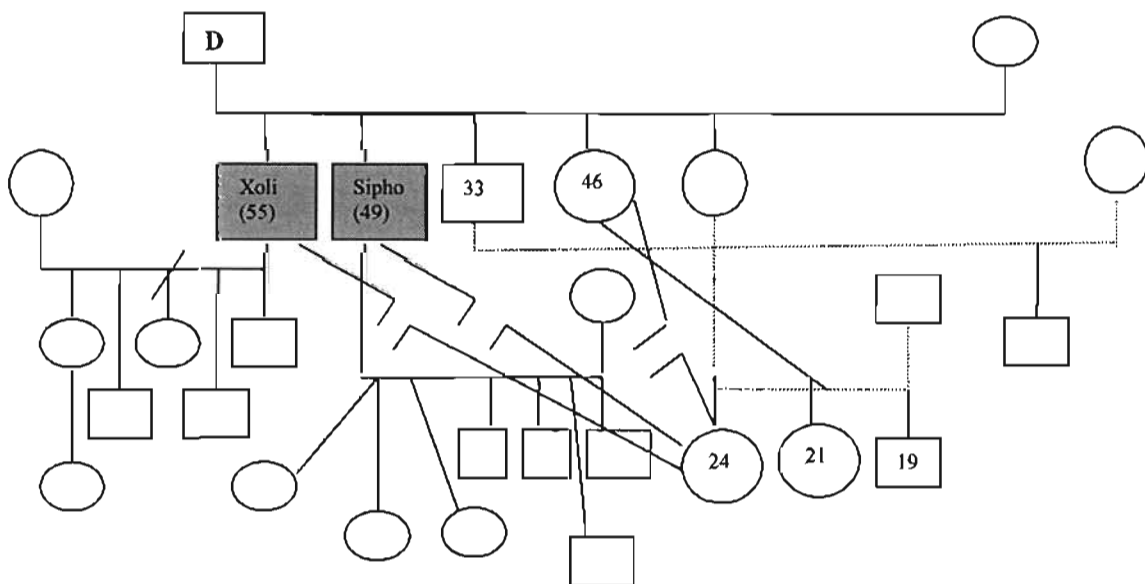
Grandchild III: The other 13 year old in Grade 5 said that her father also takes *piece* jobs but *uyazityela* (he eats the money for himself). Her grandparents pay for her school fees and the grandmother sells milk to make ends meet. She then said that they are not fine that her uncle is sick with TB and she wishes that he recovers soon.

Researcher's comments:

I found it interesting that some of the people infected with HIV interviewed gave a different account of when they started getting sick than that of their family members. They tend to shorten the time of when they have been sick and I could not make out whether they found it much easier and less threatening to say they have been sick just for a short while. This man not only lied about the duration of his sickness but about his disclosure to the family. They do not know that he is HIV positive, yet he said he had told them. He also said he has never been married, yet his father said he was, and has two children.

The home-based care volunteer expressed that the parents have been insulting Sydney saying that he was working in Johannesburg and not caring for them but now that he is sick he is their problem and they have to struggle caring for him. She then thinks this is one of the reasons why he has not told them about his HIV status.

3.6. Family VI



There are nine adults (three of whom are children over 18 years of age) and one child in this home living with their mother. They live in a four-roomed house and

have built a shack in a yard opposite their home to have extra rooms. Three of the children are still at school and the one has completed Grade 12.

Mother: Their mother said that her two sons worked in Johannesburg, moved to Cape Town and then came back from there already sick. They both have TB and are on treatment. She said that both her sons have their own families and have not been staying with her but have come now so that they can be closer to health services because the other clinics where they stay do not have sufficient medication. She mentioned that she sends them to doctors with her own money even though they have their grants they receive because of their illness. "There are no support structures, I do things on my own, and I struggle alone. When I receive my old age pension I have to give money to Siphso who still receives his grant from Cape Town and have to travel every month. My youngest son who has been supporting me and built this house, worked in Johannesburg but was retrenched in February this year and he is now at home".

Grandchild I: Her grandchild who is 24 passed Grade 12 last year and had no money to go further with her studies. She is a *loveLife* volunteer involved in educating learners about HIV/ AIDS. She started in January 2003 when the project started and she said that she did not know anything about AIDS before then and that is why she decided to join. "We encourage kids to delay love affairs because of AIDS. My life has changed since because I did not think that AIDS is a reality and since I joined I decided to abstain. I also went for an HIV test and tested negative but I am not settled yet until I go for a second test".

She said that her uncles are both suffering from TB. Xoli was staying with his wife who rejected him and has extra marital relationships and that is why he came home. She said he does not even want to take his treatment and he drinks a lot. "They all (the brothers) sleep in one room so their TB can easily be transmitted to others and even to the rest of us". She also mentioned that Xoli's first-born daughter is HIV positive as well because she saw the medication she uses and she

fears that the child she is breastfeeding might get the virus from her but she did not know how to confront her. She said that both brothers have grants and they use their money to take care of themselves. She has a cousin sister who is a teacher and she supports her and they also have a food garden that helps them as well.

Mandisa: A 46-year-old woman said her brothers, Xoli and Siphoh, have suffered chest problems since 1983. Xoli and Siphoh were treated and got better but they have since become worse. The family then brought them back from Cape Town in 2001. When Xoli came back, his wife deserted him saying she cannot stay with a sick husband. He then remained with his five children and because the children could not manage caring for him, the family then decided to take him home. He receives his disability grant and does take some money to the children. According to Mandisa, Siphoh stays with his wife and has come home just to change the environment.

Mandisa said that she is epileptic herself and has never had any children. Her younger sister who is mentally ill has three children whom she raised as her own. Mandisa used to work as a domestic worker but could not continue because of her illness. She said Xoli has TB and tested HIV positive and he called the home-based care volunteer to also tell her as well. Xoli has accepted the results as any other illness and yet Xoli did not say this to the researcher. In the house-building project, Xoli has applied for a house since his wife left him so that he can have a home.

The rest of the family knows about his HIV status except the children but Mandisa also told Xoli's first-born daughter. Her reaction was that the family should organise a funeral policy for him. Mandisa also said that they have been all depending on her mother's grant until she got her disability grant and a foster care grant for her sister's children. After she started receiving the foster care grant the children wanted to control how the money was used and she suffered a stroke as a result of their insults. Mandisa then decided to move out and built a shack opposite her mother's house. The elder daughter of her sister who is mentally ill is said to be

ill-treating and insulting everyone and that is why they all stay in the shack now, that is, her and the two sick brothers.

Mandisa mentioned that the family's income is directed to health care for the two brothers and Siphos's wife also has TB and the two have seven children that need to be supported and his first child has TB as well.

Xoli: is a 55 year old man who worked in the mines and started getting sick in 1980. He was told that he had TB and he treated it but has never fully recovered. He later went to look for work in Cape Town where he got sicker with TB again. He came back from Cape Town last year and he continued to go to the doctors because he was not getting any better and he is now being treated for asthma. His blood was taken for an HIV test and the results came saying he was 'clean'. Asked about Mandisa who said that he is HIV positive, he then said his sister says she saw it in his file that he was HIV positive but he was never told this. He has five children he is supporting with his disability grant. He is struggling to take these children to school and some had to leave school because they do not have money for fees. One of them has passed Grade 12 but could not go further because of a lack of money.

Siphos: is 49 years old. He also worked in the gold mines and he started getting sick in 1983. He attributes his and his brother's illness to their mine work. He was diagnosed with TB and it was treated. In 2001 he had TB again and he was treated for eight months and it cleared. Soon after this he had breathing problems and it was said that he had asthma and he is now on asthma treatment. He, like his brother, also moved to Cape Town to look for employment which he did not find. He applied for a disability grant whilst in Cape Town before coming back home. He now has to go up to Cape Town on paydays and depends on his mother for travelling money. He sometimes skips one month and goes to Cape Town the second month so that he receives two payouts. He is still working on transferring the pay to Queenstown.

He is married and they have seven children who are all at school and the eldest child has TB. His wife is not working and is arthritic. They all depend on his disability grant and his younger child's support grant and Siphso sometimes comes to his mother for help. He said he has been at his parent's house for four weeks then because he wanted to change the environment. He also said that blood samples were taken for HIV and they came back negative and he is also cleared of TB as well. There are no support structures that they rely on except their family. According to him, the church's contribution is in burying people.

Brother II: The last person met in this family was a 33-year-old single man who only has one child and is also at home not working. He used to work in Secunda mines and was retrenched in February 2003. He is receiving his UIF and is awaiting payouts from his provident fund and is currently seeking employment. He is worried that his brothers are sick and the family is struggling to cope with this problem. The family worries about his brother's children who need to be supported and cared for and there are not enough means to do this.

Researcher's comments:

All the members of this family never mentioned AIDS, except Mandisa, whose claims of his brother's HIV status were never admitted by Xoli himself. Xoli, who was rejected by his wife, left the children to fend for themselves and supports them with his disability grant. Child-headed households as a result of AIDS and other family disputes are a reality in our communities and this brings an constant panic for the future of these children.

Siphso has TB together with his wife and their first-born son. This could have been passed on from Siphso but he claimed that he has been treating his TB. A hypothesis could be made that Siphso could be HIV positive together with his wife, and then their son and if this hypothesis is true, the family would be faced with a huge and

devastating challenge. Their main source of income is social security grants which is unfortunately directed to health care and therefore not meeting all their needs.

4. Summary

The people of Ilinge are generally poor, the majority of whom depend on social security grants and casual jobs. As a result of poverty; AIDS is mounting, the number of orphans is rising, crime is on the increase, girl children are forced into prostitution, and there is general apathy and a sense of hopelessness.

Community leaders at Ilinge expressed the urgency of responding to the AIDS crisis and showed a willingness to spearhead this process. They recognised the value of collaboration with all stakeholders to make this a reality, but, they did not think that the church can make any contribution to this fight because of its lack of involvement in issues concerning the community. On the other hand, church ministers asserted that it was time that they should wake up and respond to the HIV/AIDS. This is definitely a profound change that needs to be encouraged, shared with others and sustained.

The home-based care volunteers are doing some significant work by caring for the sick and helping them access the much-needed health care services. They work under very difficult circumstances, are not trained and paid for their sacrificial service to the community. It is interesting that some of them received R500 payment and many others did not and were only told to wait for their turn. I feel that something is not going right here.

All through the stories gathered in this research, children are left out in any discussions about AIDS. They are not told of what their parents, uncles or aunts are suffering from. Children suffer the brunt of AIDS in silence, they are left out and nothing is discussed with them. The secrecy around AIDS is enforced by the stigma attached to AIDS, which in turn perpetuates its spread. Children are struggling with questions, pain and grief and they cannot share that with anyone.

The other observation I made was the fact that in most families, people have children outside marriage and most of them remain unmarried. This increases the number of children being cared for by their grandparents who ultimately become their sole caregivers as parents succumb to AIDS. Grandparents are severely impacted by AIDS. They are old and some are sickly, on old age pensions and need to be taken care of by their children, but AIDS has reversed that order.

There was value in interviewing different members of the family to get different perspectives on how they view AIDS and/or sickness of a family member. Different people revealed different pieces of information and that enhanced the richness of the data collected. This also helped to fill in any gaps and/or misinformation that was received from some members of the family.

CHAPTER V

Analysis of data collected

1. Introduction

The research findings will be analysed in this chapter, making use of the principles of the Sustainable Livelihoods Framework. The focus will be on identifying the strengths and survival strategies of families in the midst of the difficulty presented by AIDS. Even though most families interviewed are going through enormous challenges, which made me wonder if they are surviving or just 'breathing', yet the truth is they are living. However, AIDS harshly impacts on people's livelihoods and as much as people learn to cope and survive, the severity of AIDS undermines their very lives, assets, and livelihood strategies resulting in livelihood outcomes that are not sustainable.

The Sustainable Livelihoods Framework has five main elements, namely, vulnerability context, asset portfolio, transforming structures and processes, livelihood strategies and livelihood outcomes. We will make use of this framework examining the situation at Ilinge, taking each element in turn.

2. Vulnerability context

The first element of the SLF is the vulnerability context. This is the wider context in which people's livelihoods function. Four key aspects that form part of this context at Ilinge were identified. These are poverty, migrant labour, HIV/ AIDS, Violence and Culture, and Food insecurity.

□ Poverty

Ilinge Township is generally a poor community characterised by high levels of unemployment, a lack of food, a lack of access to good health care services,

overcrowded homes, high levels of illiteracy and a “brain drain”. The Eastern Cape Province, of which Ilinge is part, has been identified as the poorest province in South Africa. The provinces’ people leave to work in other more *resourced* provinces. The Eastern Cape government together with business are seeking ways and means of addressing the disquieting brain drain in the province. As argued later, the reality of poverty in this community accelerates the spread of AIDS and raises the mortality rates.

□ **Migrant labour**

Dating back to colonisation and gold mining in South Africa, family structure and stability has been gradually destroyed. It is worth mentioning that gold mining in South Africa changed the whole structure of community life and had a dramatic impact on the lives of Black people in particular. Taking away of land and cattle from people not only dehumanised them for a time but it had a life long impact on them, which we are still facing. Fathers, husbands and sons were forced out of their homes and away to work on mines to pay taxes that the government enforced so as to get workers in the mines. This system introduced cohabitation and casual sex relationships, which are still a reality of our society. These fuel the spread of AIDS. Different respondents mentioned that people who work in Cape Town and Johannesburg have been the ones with AIDS and now the “local” people themselves have AIDS.

□ **HIV/AIDS, Violence and Culture**

The prevalence of AIDS itself is a shock that this community has to contend with. HIV is an invisible and silent virus that sweeps through many families. HIV is spread mainly through sex with an infected person, and women and children are more vulnerable to HIV because of violence perpetrated against them. The rape of women and children at Ilinge is said to be increasing. During the course of this

study some of the respondents mentioned that some of the people who test positive to HIV decide to spread the virus “so they will not die alone”.

Even when women know for a fact that their husbands are unfaithful, there is nothing they can do to protect themselves because they are not free to discuss sexual matters with their spouses. The old notion that sex is a man’s right and a woman’s duty is part of the reason why men rape women, and the woman is blamed for it. This *traditional script* also says that if men do not stop a woman on the streets or make comments with sexual undertones as she passes by, then there is something wrong with her. This belief encourages men to pursue and conquer women, whilst women’s value and attractiveness is placed on their bodies and giving of themselves unreservedly to men. Unfortunately this has serious repercussions in the era of AIDS.

□ **Food insecurity**

Forget the anti-retrovirals, the medicine these people need is food. Food, food, food.⁸⁸

These words from an Irish nun in Zambia echoed the same anguish of people at Ilinge. They struggle to have food because many are unemployed. Furthermore, as breadwinners succumb to AIDS, there is no one to plant and care for food gardens. Many of the families interviewed depend on social security grants, which cannot cope with all the demands presented by AIDS. These limited financial resources are directed towards health care, buying food, education of children, funerals and other family needs. Clearly, the amount of money that comes in is not enough and families are forced to go to cash loans to buy their necessities, which then becomes a spiral of poverty, as they have to pay back the loans with interest. Hunger is a daily reality of these people and as a result girl children are forced by this situation into prostitution to feed their families.

⁸⁸ Sister Joan Walsh, an Irish nun who runs a home-based care organisation in Langwe, Zambia in Rory Carroll. *Mail & Guardian*, November 1 to 7 2002. p. 15

3. The asset portfolio

1) Human capital

AIDS strips people of their ability to work and they end up on disability grants. It also denies them of their right to good health and that hinders them pursuing any livelihood strategies. Many skilled and economically active young people are dying due to AIDS related illnesses whilst others are forced to leave school because they cannot afford to pay fees or have to care for the sick relatives.

The lack of prevention programs, compassionate responses from society and treatment that will prolong the years of those infected with HIV thus affording them a chance of living productive lives limits and even distorts this capital. People get sick and have to leave their jobs so their potential to labour is taken away.

However, families derived strength from the support they received from the members of their extended families who as it were, were the human capital that they utilized.

2) Social capital

Home based care volunteers were identified as a vital aspect in the community on which families relied upon for caring and helping them access services that they would otherwise not have access to. They are caring for the sick and getting them access to health care services. They also act as confidants of people living with AIDS as they seem to be the only ones 'trusted' with disclosure of the HIV status. Neighbours continue to be an asset to rely on when life gets tough.

The church has been identified by some of the respondents as a support structure in as far as offering prayers for the sick, visiting them and conducting funerals. Some of the respondents expressed a strong sense of hope that comes about

because of their faith in God. Religion, including both their Christian faith and faith in ancestors was identified as a buffer when times are tough. Other families belong to more organised groups like *oomasiphekisane* or *imigalelo/ stokvels* (let us cook together) in which members assist each other when one of them has a funeral.

3) Natural capital

The community has no access to farming land and only relies on small backyard gardens. Due to a variety of factors including bad weather conditions, deforestation for purposes of firewood and AIDS, there are less trees and vegetable gardens at Ilinge than there used to be. People are sick and do not have the physical energy to plant and care for their food gardens and this in turn increases their poverty levels. However, food gardens still provide food for some people and are often converted to financial capital, as some would sell their vegetables to neighbours.

4) Physical capital

Ilinge has an improved clean water supply and sanitation is improved. The roads are dilapidated, forests are cut off and almost destroyed, one factory that existed has since been closed and there are no employment agencies except for the current housing project that does not offer long-term employment. There are no recreation facilities to keep young people constructively occupied, but taverns are springing up everyday leading to the high levels of alcohol abuse that fuels the further spread of HIV. The high levels of unemployment in this community have a ripple effect in the spread of HIV/ AIDS and the accelerated deaths of those infected as a result of 'already weakened' immune systems even before HIV comes into play.

The local clinic is an asset for health services even though it has been expressed that its capacity is overwhelmed by the current demand for health services. Different respondents and even the home-based care volunteers themselves,

expressed that often the clinic does not have the most needed medication for people.

5) Financial capital

Most people in this community depend on social security grants- old age, disability and child support grants. Some have what they refer to as “piece” jobs- these are temporary casual jobs, others are domestic workers, a small proportion have stable middle class jobs and still others sell fruit and vegetables in taxi ranks or at their *spaza* shops. This explains why most of the young people are in cities like Johannesburg and Cape Town for employment. There is currently a housing project going on and that has created jobs for a number of people either as service providers (through tenders) or as labourers.

Lack of employment and the availability of child support grants has a negative impact on people. It has been expressed time and time again that people prefer to have more babies so that they could access grants. This line of thought is fatal because the money is so small that it can hardly support the whole family, but the reasoning is that it is better than nothing. Secondly, it will only last for a few years after which both the children and the parents will be in a worse off condition than before. Lastly, it also means that people are engaging in unsafe sexual practices that puts them at risk of contracting the HIV virus and hence the increasing number of orphans.

4. Transforming structures and processes

□ Systems of governance

The South African government is divided into three levels: the national level, provincial government and local government. Cabinet at national level having received inputs from the “grass roots” level, gazettes laws and policies and these regulate communal and social life in the country. The national government itself

operates within global influences and pressures. Every policy or law of the country either limits or expands the *freedoms* that people enjoy. Anne Nasimiyu Wasike argues, “globalisation is a form of re-colonisation that does not need military action”.⁸⁹ She says that globalisation benefits the rich and the powerful people within and between countries of the world. The Structural Adjustment Programmes have reduced the power of unions and therefore increased corporate profitability, resulting in increased retrenchments leaving millions of people unemployed, others in temporary jobs with little or no fringe benefits. Ilinge has not been left unscathed by the impact of globalisation, and its euphemisms like privatization, retrenchment or rightsizing.

With HIV/AIDS their plight is worsened as economically active people die of AIDS leaving their families and children to fend for themselves. Therefore it becomes necessary that the focus be on building structures that will represent the poor as well as endorse national policies that will not restrict the advancement of poor people. This will be achieved if the poor majorities of our country are involved in policy formulation processes and they be given a space to make their voice.

The government’s stance on HIV/AIDS has not been very helpful, and our president’s question of whether poverty causes AIDS left many ordinary people confused. The Department of Health’s reluctance on providing treatment also invited uproars from civil society and people living with AIDS specifically. However, of late, government’s awareness programmes and its roll-out plan for antiretroviral drugs are commendable but the process will need to be sped up, as many people like William will die before they access this treatment.⁹⁰ The process of drug treatment will demand that the Eastern Cape health department seriously work to improve its health centers. There have been complaints of lack of medication, ill treatment of patients by staff and long cues at Ilinge Clinic and this

⁸⁹ Wasike Anne Nasimiyu, “Foreword” in Getui Mary N and Theuri Matthew M (eds) *Quests For Abundant Life in Africa* (Nairobi, Kenya: Acton Publishers, 2002)

⁹⁰ William is a 39-year-old man who is HIV positive and has started to be symptomatic. His desire is to live. Refer to interview of family III.

is true of many other communities in the province. The Lukhanji Municipality, of which Ilinge is part, is only starting to think to implement response programmes for its communities.

□ Structures of religion and culture

Religion, with specific reference to Christianity, has been in many instances used to oppress instead of liberating people. For example, the apartheid regime influenced the church to maintain its oppressive and alienating laws by cooperating with them either actively or passively. Today, the institution of the church has been 'isolated' from the world such that the gospel of truth has been compromised and is not life giving. The church hierarchy characterised by male domination continues to relegate women to inferiority. Women are told to be obedient and submissive to their abusing, unfaithful husbands even if their lives are at risk. They are told that God hates divorce and they have to accept their fate as God's will for their lives. This is why married women are more vulnerable to domestic violence and HIV/AIDS and they suffer in silence. This is why Mercy Oduyoye argues, "the pyramids of power that exist in African culture have found companions in Christianity".⁹¹

The patriarchal culture that still prevails in our communities enforces an unhelpful hierarchy within households and the community in general. Generally, men and boys receive bigger and better shares of food and this has nothing to do with the amount of food one can or cannot take, but because they are men- the heads of the household. Many families at Ilinge are poverty stricken and the system does not change. Women and children sacrifice what would be their share for their husbands and fathers. This means that women who already have their immune systems depressed, easily succumb to AIDS. This is also because caring for the sick

⁹¹ Mercy Amba Oduyoye. *Daughters of Anowa; African Women and Patriarchy* (New York, Maryknoll: Orbis Books, 1995)

is their sole responsibility whether they are not feeling well themselves and often at risk of their own lives.

□ **Civil Society**

David Korten asserts that the focus of what he refers to as the fourth generation of development, “is on energising decentralised action toward a people-centred development vision. Social movements have a special quality; they are driven not by budgets or organisational structures but rather by ideas, by a vision of a better world”.⁹² People organise themselves for specific issues that they need addressed in their communities and work towards achieving a better future for themselves and the generations to come. The people will volunteer their time, energies and resources for the sake of the cause with which they believe in.

In South Africa for example, the people’s movement proved its resilience and power in the fight against apartheid. People committed all they had to fight against the system they believed dehumanised them, even at the expense of their lives. Currently, the Treatment Action Campaign and the invasion of pharmaceutical companies by the National Association for People Living with AIDS are putting pressure on the government to adopt a treatment policy that will give access to drugs to poor people of South Africa.

5. Livelihood Strategies

The families interviewed in this research and the community in general utilise a number of strategies to enhance their livelihoods. These are income generating strategies, alcohol abuse, migration to cities to look for employment, denial and silence about AIDS, interdependence amongst families and neighbours and the home-based care programme.

⁹² David Korten. *Getting to the 21st Century: Voluntary Action and the Global Agenda* (West Hartford: Kumarian Press, 1990)

□ **Income generating strategies**

The families interviewed depend on social security grants for their survival. Many of them rely on old-age grants, disability grants as well as child support grants. For child support, people choose not to prevent pregnancy so that they can access the grants. For some families income comes from domestic work, *piece jobs*, food gardens, spaza shops, selling fruit and vegetables, selling sheep heads and the booming business at Ilinge currently, is taverns or shebeens.

□ **Alcohol Consumption**

Alcohol consumption is seen in this study as a strategy used by people to ease and escape their painful realities of poverty, AIDS, unemployment and despair. The alcohol business at Ilinge is flourishing and is the main source of income for some families.

□ **Migration to cities**

Some leave the community to look for employment in cities like Cape Town and Johannesburg. Most if not all, informal settlements in Cape Town and some in Johannesburg are formed of people from the Eastern Cape.

□ **Denial and silence**

Regardless of AIDS awareness in South Africa, some people still deny that AIDS is a reality and still others have a fatalistic belief that it can never happen to them. This is acted out by irresponsible behaviour towards self and others, the silence and stigma surrounding AIDS. Some families turn to traditional healers because they believe that their relatives are either bewitched or they are called to traditional healing when they start getting sick.

□ **Ubuntu- extended family, neighbours and the home-based care volunteers**

The virtue of African society is its extended family and relations with neighbours enforced by *ubuntu*. Even though people are gradually moving towards individualism, the role that neighbours play to support and care for families in need has been identified. Home-Based Care volunteers in the community are caring for people out of concern for human suffering and a drive for making a difference in the lives of others.

6. Livelihood Outcomes

De Gruchy reminds us that “livelihood outcomes are not necessarily positive and sustainable, and that negative outcomes can add to the vulnerability context and further undermine the capital base of the community and household”.⁹³ Some of the strategies employed by people to survive indeed have negative repercussions for livelihoods that people seek to enhance.

□ **Income generating strategies**

The community takes advantage of the social welfare system by giving birth to more children to be able to access support grants. Minimal income does come in but this puts women more at risk of contracting HIV as a result of unprotected sex. It also results in an increased number of children born with HIV and AIDS, who will probably also be orphans. These children end up being cared for by grandparents. Thus, the negative impact of livelihood strategies that people adopt to deal with hunger, for example getting more children to access grants, result in more hunger and more AIDS. Therefore, this strategy is not sustainable and undermines the very livelihoods that people seek to enhance.

⁹³ Steve de Gruchy. “The Contribution of Universities”.

□ **Alcohol Consumption**

Because of unemployment and a sense of hopelessness, people abuse alcohol to ease their worries. Alcohol and drug abuse takes away the small income people have, living families starving and torn apart. It also plays a significant role in the spread of HIV as people engage in unsafe and/or casual sex, as well as violent crimes.

□ **Migration to cities**

Some people relocate to cities to look for employment, access to health care, education and better housing. To a greater extent these needs are met but because of the high levels of unemployment in South Africa, urban life can be very difficult. Many people do not find the employment they were looking for. Some end up in prostitution and others find themselves involved in criminal activities. Migration to cities results in overpopulation of cities and people living in shacks. It is common knowledge that these informal settlements are characterised with high levels of unemployment with corresponding levels of crime, high levels of HIV infection and other diseases. Often, they are victims of fires that break up and leave them homeless and more vulnerable.

□ **Denial and silence**

Denial and silence results in more infections and the isolation of those infected with HIV. At Ilings some families even go to the extent of hiding or chasing out of the home their members who have AIDS. They then pay a lot of money to traditional doctors and end up destroying their relationships with neighbours who are accused of bewitchment. This harms relationships and further undermines the family's asset portfolio particularly the social capital. Home based care volunteers then play the role of mediator in families in dispute, care for the sick and help

people access health care services. As they do this work, they are in turn empowered as individuals and gain more self-confidence and sense of worth.

Despite the long-term negative outcomes that come as a result of livelihood strategies that people choose, these strategies help them survive. People at Ilinge are living, they have livelihoods but the question is, are they sustainable? Are some of the strategies used to survive helpful? These questions present a need for a critical reflection of who gets to define whether or not livelihood strategies that people employ are not helpful. Is it the people themselves or the advocates of the Sustainable Livelihoods approach or a dialogue between insiders and outsiders? Given the sad reality of poverty in our communities and how it leaves people with fewer choices to make, where does the answer lie? Is it in getting the government grants and risk contracting AIDS, or starving to death?

The next chapter is an attempt to recommend strategies that the church can embark on to enhance the agency of families affected by and infected with AIDS at Ilinge. This is so because the community has not been involved in the very last stages of prioritising what they think should be the way forward in addressing their own situation. Their involvement went as far as identifying their coping strategies and experience of AIDS, the constraints and opportunities at their disposal as well as sharing some ideas of how these could be addressed. This work therefore might be accused of not being different from “problem-focused-development approaches” because of this limitation. However, the recommendations presented here are not simply prescriptive to an “outsiders” diagnosis of the community, but a process that the community itself could be engaged in for their own emancipation.

CHAPTER VI

Recommendations for the church's response in enhancing the agency of families affected by HIV/AIDS

1. Introduction

In this chapter, recommendations for the church's involvement in enhancing the agency of families affected by AIDS at Ilinge will be outlined. The list is not exhaustive but a synthesis of areas of involvement that the people themselves have identified and a few others that are relevant for the community and for the church. The chapter will follow the Sustainable Livelihoods Framework as presented in Chapter III with the exception that livelihood outcomes will not be addressed because there is no way of ensuring what livelihood outcomes should be. However, if a context that constrains people from making choices is addressed and more opportunities are presented for people to utilise and have access to assets, then it can be predicted that these would have positive outcomes for their livelihoods. As it has been argued earlier, some of the strategies that people utilise for their livelihoods in a given context, undermine these very livelihoods.

2. Recommendations

2.1. Vulnerability context

The vulnerability context, as argued earlier, is comprised of shocks, trends and seasonality. These could range between what is referred to as natural disasters that are often a result of the exploitation of the environment by humans; wars between nations, and other catastrophes. HIV/AIDS has come as a shock that ravages the nations of the world and South Africa is no exception. The church's response to AIDS should seek to address this context and find ways of either eliminating any causal factors of the diseases or those that tend to sustain it. The following are a few areas that the church could embark on;

❑ **Transforming communities**

The South African community in particular is undergoing a process of transformation and growth. Since the 1994 democratic elections, change and readjustments have been the order of the day. This process calls for reconciliation between nations, families and individuals, hence the Truth and Reconciliation Commission. The church has played and is playing a significant role in this crucial process in both facilitation and ensuring sustainable reconciliation and peace. As a result of political tensions between the African National Congress and the Inkatha Freedom Party for example, families lost their members and breadwinners to senseless killings and were removed from their places of residence, a source of stability. The link between community instability, poverty and AIDS cannot be underestimated in alarming rates of HIV/ AIDS in KwaZulu-Natal and in other parts of the country.

The community's transformation also refers to the complete makeover of the community. This means addressing issues of poverty, unemployment, lack of housing, disease, education, crime etc. The church should be in the forefront of such a movement.

❑ **Leadership and leadership development**

The church has a special competence to provide responsible, accountable and sound leadership for the community. In most communities, church leaders and individuals are known and respected because of their dedicated, sound leadership and the church is almost regarded or expected to be the voice and take a stand on issues pertaining the community. Responsible leadership is a virtue that is disappearing in our nation, and the Eastern Cape in particular has seen leaders who exploit their position and the effect of their corruption in communities is unbearable. As it has been discussed in this paper, abuse of power by those in

leadership and wrong decisions made from the local through to international levels impact on ordinary people's lives negatively.

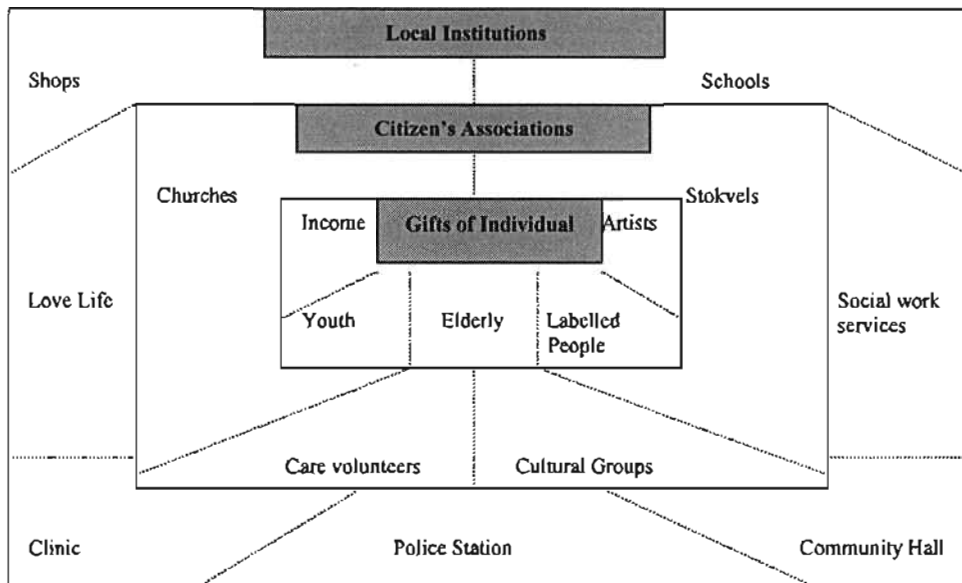
The church is equipped to also provide and create opportunities for leadership training because of its expertise in leadership and can take this opportunity to prepare political leaders of great repute. This obviously is an exaggerated view of the local church's expertise considering the fact that so many ministers are not trained or are under trained. However, this challenges the "educated" church to take on that responsibility of ensuring that leadership training is encouraged in communities.

□ **Research**

Research is a tool that enables one to have a better and deeper understanding of life issues. The church therefore, needs to take on research as part of its job description so as to be able to respond relevantly to issues of concern in the community, and assess the impact of shocks and how to prevent these in the near future. For example, the community might come up with strategies to minimise the impact of floods, fires and even drought and thus lower the level of community devastation that these factors produce. The indigenous knowledge and experiences that are sometimes neglected can be helpful in addressing some of the current problems.

2.2. Asset Portfolio

The Sustainable Livelihoods approach begins by identifying the community's assets and strengths and not their needs and problems, and this enhances the community's self-confidence and empowers them as a people. Using Kretzman and McKnight's map of community's assets I have outlined the assets that are often ignored as problems get magnified leaving the community feeling inferior and "problematized".



The above diagram helps us see the assets and great potential in communities however poor. According to the Sustainable Livelihoods Framework these assets range from human, social, natural, physical and financial and are referred to as the asset portfolio. Families faced with the devastating impact of AIDS draw strength from and utilise their assets to survive. In the previous chapter, strengths of families were identified and the challenge is for the church to encourage those assets and strategies that families use to enhance their livelihoods.

a) Human Capital

□ Awareness

At Ilinge, levels of HIV/AIDS awareness are relatively low and this presents a need for rigorous efforts by the church to continue talking about what AIDS is and is not. "If the Christian church were to limit itself (which it is doing) merely to preaching closed sexual relationships it would be guilty of hypocrisy (even at

church people are not abstaining and faithful to their spouses) and would deserve to be ignored".⁹⁴

Having made efforts for prevention, it is important that those who are already infected access medical care and balanced nutrition to enable them to enjoy good health. The South African government's antiretroviral rollout plan is a breakthrough in fighting and containing AIDS, but the hunger related to poverty remains a problem. The people of Ilinge, many of whom are not employed, will get the drugs but take them on empty stomachs. The church needs to think proactively about how it can respond to this reality. The church can embark on a number of things like food gardens or education about alcohol abuse. It has been documented that children leave school to care for their sick relatives, and from this study it was established that some children leave school because they do not have the money to pay for school fees. This becomes a cycle of poverty as these children will not be able to find employment in a very competitive work place.

The church's contribution might be to take the burden of care off the children, explore possibilities of subsidising children's education (primary to secondary education in local community school is not expensive and I believe that the church can afford to do this if there is a will) and even encourage its members to adopt orphans.

□ Education

There is an urgent need for sound teaching on HIV/AIDS, sexuality, human rights, environmental care and other social concerns at Ilinge. The church, amongst other structures, could play a significant contribution by providing much needed education for its members and leadership as well as for the community in general. Stigmatisation and secrecy about HIV/AIDS continues to be the culprit in the

⁹⁴ Willem Saayman and Jacques Kriel. *AIDS: The Leprosy of our time?* (Johannesburg: Orion Publishers, 1992)

spread of the virus and in the alienation of people living with AIDS. Church property and facilities could be used for meetings, and the pulpit used to convey the message of hope, justice and responsibility in the time of AIDS.

b) Social Capital

The church needs to recognise itself as a social asset in the community. Kretzman and McKnight argue that the church, amongst other organizations, makes up the most visible and formal part of the community's fabric. It is called to be compassionate. This means full immersion in the condition of being human which calls the church to respond to the needs of humanity and thus the needs of our communities.

□ Pastoral counselling

The church needs to help people with the painful impact of AIDS. It could facilitate family counselling, as it is often the case that counselling (if at all available) is done only with people infected with HIV. It was mentioned that families struggle and are imprisoned by fear and shame as a result of a family member contracting HIV. Njoroge argues that the church can be a haven for people struggling with HIV/AIDS- the bereaved, the lonely and alienated, the rejected. The church can provide hope and healing, not being limited to physical healing.⁹⁵

Different governments are also recognising the role that religious institutions, especially the church can play, and are creating opportunities for its involvement. The KwaZulu-Natal Department of Health has established a religious wing in its HIV/AIDS Action Unit and continues to encourage religious leaders to assist not only in caring for the sick but also in taking AIDS seriously and advocating for the Voluntary Counselling and Testing campaign.

⁹⁵ Njoroge, "Come Now, Let us Reason Together".

The church can provide counselling and support for the bereaved, especially for the children who are often left to struggle alone. From this study, children are not told of what is going on and are practically kept away from AIDS. They are not even given space to grieve and the question is, what will happen to these children?

Philippe Denis says:

With AIDS the world has turned upside down. At an age when the elderly expect support from their children, they have to bury them instead, and are forced to take responsibility for the upbringing of their grandchildren... clearly these families need material assistance. But they also need emotional support. The children are directly affected by the death of their mother or father, but they do not know how to talk about it. They do not understand what has happened (and there is none there to tell them). The memories of the dead parent tend to fade. This creates confusion, which prevents them from developing to their full potential.⁹⁶

It has been expressed that many people who test HIV positive tend to drink and live reckless lives putting others at risk. This is amongst other things as a result of hopelessness, and the church can bring hope to the hopeless. T. Adeyemo sums up the response of Christians to the HIV/ AIDS pandemic when he says;

Where people are bruised, the church supplies the balm,
Where people are battered, the church restores with dignity
Where people are broken, the church brings healing
Where people are buffeted by the scourge, the church soothes
Where people are banned by society, the church provides a home.⁹⁷

□ Holistic community-based approach

Njoroge presents a model of responding to HIV/ AIDS for her Kenyan church that with adaptation could be applied in a different context. She proposes Bible study that will offer a journey of self-discovery and healing for the participants. The scripture has often been used to condemn and criticise and these Bible studies could help people rediscover what the gospel is all about as it addresses people at different points in their lives. God has always been at the centre of people's lives and they need to know that he cares in the midst of pain and struggles and the

⁹⁶ Philippe Denis. "Sharing Family Stories in Times of AIDS" in *Missionalia* 29:2, August 2001

⁹⁷ T Adeyemo of the Association of Evangelicals in Africa.

church could help with these reflections. The other asset that the church has and must offer is prayer. People need to be mobilised to pray for the cure, to pray for those infected with HIV and their families, pray for those caring for the sick and most importantly, pray that Christians would start taking social problems and all that concerns life including AIDS as *something* to be concerned about and respond to.

□ **Caring**

Caring for the sick at Iltinge has been left on the shoulders of the home-based care volunteers and the church has abandoned its vocation of caring for the sick, the orphans and widows. AIDS therefore presents an opportunity for the church to truly be the 'church' and be faithful to its call as a caring community. Caring for carers is essential as these volunteers deal with distressing cases everyday without any debriefing made for them. I am not sure that the church is capacitated with counselling expertise to offer this kind of service but it can surely give support, a safe space for volunteers to share their struggles and pray for them and the work that they do. The task of a structured counselling service for volunteers lies with the health centre, which the church can present as a challenge.

□ **Volunteerism**

The church needs to mobilise its members to offer their services to the community. This could be an invaluable resource to the community as there is such a great need for caring, for support, for love and compassion and few workers available. Encouraging volunteerism would involve capacity building and training of those who do volunteer and in turn this will build self-confidence in people as they take responsibility for their lives and that of their neighbour.

c) Natural Capital

□ Concern for natural resources

One of the contributions that the church could give to society is its concern for the environment. The earth and all that is in it is God's (Psalm 24:1) and it needs our care. The church as a community of faith can be a catalyst of change in how the environment is used and exploited. Martin Robra of the World Council of Churches has noted that more and more people are deprived of the resources essential for their survival. Their conditions of living are deteriorating as those who are already impoverished and marginalized suffer most. They have no money and have no access to the market economy and their lives depend on the support the community can give and what nature has to offer. "Defending the earth is not a project. Defending the earth is a way of life".⁹⁸ The church does not live in space, it is here on earth and is obligated to preserve the earth.

The carbon dioxide in the atmosphere acts like a blanket over the earth, trapping heat in, causing the planet to warm up. This is the most abundant gas released by human activities that is implicated in atmospheric warming. It is given off in the burning of forests and fossil fuels like oil, coal and gas. Scientists believe that marine life is at growing risk from a range of diseases whose spread is being hastened by global warming and pollution.⁹⁹ This might have no direct impact on AIDS but a healthy and green environment brings hope and life and that is essential for people's perception of life around them. But also, the drastic weather and environmental changes we observe have a tremendous impact on agriculture resulting in food insecurity, which accelerates the rate of HIV infection and AIDS mortality.

⁹⁸ World Council of Churches, "Defending the earth is not a project. Defending the earth is a way of life". *Ecumenical Team at second Preparatory Committee for the World Summit on Sustainable Development* at <http://www.wcc-coe.org/wcc/news/press/02/04pre.html>

⁹⁹BBC News at http://news.bbc.co.uk/1/hi/english/sci/tech/newsid_436000/436702.stm

From the data gathered during field research, almost all of the respondents were being or had been treated of TB. This raises a concern for people around them who breathe the 'polluted' air especially their family members. The church needs to be up in arms in coordinating health awareness campaign as more often than not, TB patients are not diagnosed early enough so as to prevent spreading it, or they lack emotional support to encourage them to take treatment as it can be very depressing to take a handful of tablets every day.

The Lukhanji Municipal spokesperson in an interview with the Daily Dispatch of the 28 January 2004¹⁰⁰ said that he will be embarking on a clean up campaign at Ilinge, Mlungisi, Ezibeleni and Whittlesea. He said that the municipality wants to keep all open spaces in residential areas clean and environmentally friendly. This campaign will involve business, schools, churches and NGO's.

□ **Concern for recreation**

Ilinge is a community with no recreation facilities except for 'hand' constructed football fields. Young people only find entertainment in taverns and hence the increasing alcohol abuse which in turn accelerates the spread of AIDS. Even church youth are not engaged in any constructive activities that stimulate their minds and creativity. The church needs to attend to this if there are any inroads that will be made in the fight against AIDS.

d) Physical Capital

At Ilinge, church halls and buildings are used for functions, funerals and weddings. Faced with the challenge of HIV/AIDS, church halls could be used as AIDS education centres for the community. This strategy will not only provide the

¹⁰⁰ Daily Dispatch, "Queenstown maintains clean status, 28 January 2004 at <http://www.dispatch.co.za/2004/01/28/Easterncape/eqtown.html>

community with the venue but it will help in destigmatising AIDS because the church is still considered as one institution that is judgemental and has 'nothing' to do with AIDS. I believe this could be a significant turn around for the church and it will mean more involvement in the lives of people. The church halls could also be used as soup kitchens for the many children orphaned by AIDS. The financial resources of the church could also be channelled to address specific needs of the community and AIDS being one.

The other reality of this community is that almost all the public facilities have been vandalised because people do not see it as their responsibility to look after "their" property. Could it be that as the church thinks about the environment, it could also think about stewardship of all that God has given us and educate the community including its members who are not different from the rest of the community?

e) Financial Capital

□ Job Creation

Financial capital is one that poor people do not have or, have a very limited access to and it is often in terms of social security grants and temporary employment. The church might not be in a position to create employment as it is constituted mostly by unemployed people itself. But it could be a link and an advocate between its own links and networks from outside the community. The rich church outside the community could use its influence and resources to make a better life for the poor.

Some of the suggestions thought about by the community leaders were that of an AIDS centre where craftwork and other small jobs could take place. This is a grand idea but it will take some time before it would be realised. The church could therefore use its facilities and the small financial resources at its disposal to initiate projects like these. These could include food garden projects that will encourage

people to plant so as to feed their families. This will in turn give purpose and help occupy people with beneficial efforts.

2.3. Transforming structures and processes

Structures and policies also form part of the vulnerability context as poor people are impacted by national as well as global policies of which they have no control. The SLF considers the household, community, national and global forces that all have a bearing on the people's livelihoods.

□ The prophetic voice of the church

The church's prophetic voice must not be compromised for the sake of being politically correct or holding on to tradition even when it is not helpful.

Transparency and accountability are fast disappearing in our communities, and leadership and the church should tirelessly deal with corruption, all kinds of injustices and the depreciation of morals. The church needs to challenge structures, processes and policies that dehumanise many for the sake of the powerful 'few'. It is said that the very hierarchical structure of the church often 'suppresses' and discriminates against women, young people, the elderly and especially people living with AIDS. These are structures that need to be addressed.

The church needs to challenge the political, economic, social and cultural structures that make closed sexual relationships difficult if not impossible.¹⁰¹ Educational efforts to curb the spread of HIV have made some inroads even though the high level of infection does not correspond with the level of awareness there is about AIDS. Furthermore, the church can contribute in challenging power structures in society which make women subordinate to men and render them powerless to negotiate on matters related to sex and older men taking advantage of younger women.

¹⁰¹ Refer to an earlier argument by Philippe Denis.

It has been mentioned during field research that most sick people in the community do not have access to health care either because they do not have money to pay for these services or the medication needed is not available at the local clinic. These are problems that have continued to exist over the years without being challenged and it is time that the church wakes up and seeks ways of raising and finding solutions for these concerns. Families and the home-based care volunteers expressed their disillusionment with the social worker that serves the area. A collective voice from the church to the department of social welfare could help solve this problem and many others.

The church has an obligation to combat injustices of all forms in the community. The church cuts across many class and geographical lines and Christianity has much to say on social justice. There are forces within it that seek an honest treatment of the issue and challenge the church to take a lead in encouraging remedial change.¹⁰² The church has and is still involved in advocating for justice and equality in our communities. For example, the ecumenical movements for the cancellation of the Third World debt, unjust economic policies, the plight of the unemployed, democracy and racism etc. The church should continue to speak up on unjust laws and practices. Its prophetic voice should be heard on issues of economic justice and policies, all forms of abuse, violence against women and children, exploitation of workers, racism, the role of law, crime, environmental care and development debates.

The Basic Income Grant Campaign is another campaign by citizens of the country to lobby the government to give out a small grant to the unemployed. These are clearly, life-giving movements that need the church's support, and people from "peripheral communities" like Ilinge need to be brought into these movements and encouraged to mobilise themselves to address problems they have in their local areas.

¹⁰² James P. Grant. "Can the Churches Promote Development?" in *The Ecumenical Review* (WCC) Vol 26, No 1 January, 1974

□ **Watchdog of community institutions**

Transparency and accountability are virtues that are disappearing in our communities. The church should tirelessly deal with corruption, injustices and the depreciation of morals and engage in the regeneration process. The Vice-President of South Africa, Jacob Zuma has launched the Moral Regeneration Programme. I am not sure of the effectiveness of this effort observing the activities that have been done. This is one of the processes that the church needs to reflect on and be actively involved in shaping efforts of regenerating morals in society.

2.4. Livelihoods strategies

□ **Income generating strategies**

Some of the respondents accused the local clinic of delaying grant applications for people living with AIDS by demanding that someone with a positive result should test again to confirm so as to get the grant. If this story is true, then it means people are grossly violated and exploited by those in authority. The second problem identified with grants is the fact that people are making money out of their children. The church needs to take these concerns very seriously and seek ways and means of addressing them. People need to be reminded of the value of life and respecting the dignity and worth of people created in God's image.

It has been identified that one of the major income generating efforts in this community is shebeens and taverns. This strategy works well for the sellers but it is destroying lives and families. Unfortunately, there has never been any discussion or voice being made against this. As some respondents mentioned, many people who test HIV positive end up abusing alcohol, which in turn fuels the spread of AIDS. The church's response to AIDS should encompass a reflection of how the problem of alcohol business and abuse is to be addressed if there are any inroads to be made in this fight.

Migration to cities for employment does not help either. The levels of unemployment are as high in cities as they are in rural areas. Living conditions of people in cities have been discussed and how these put people more at risk of contracting HIV. The wider church and the church at Ilinge, needs to seriously consider the issue of unemployment and poverty, as these factors continue to undermine any HIV/ AIDS awareness programmes, because people choose to die of AIDS than of hunger and hence they make choices that put their lives at greater risk of AIDS.

□ **Traditional beliefs and healing**

People in this community believe in ancestors and traditional healing and the church does not have space to talk about this reality. Many people would spend a lot of money consulting with traditional healers for AIDS related symptoms and engage in expensive rituals that often prove ineffective. Unfortunately, any response from the church people tends to condemn and that is why people would not even want to hear what the church has to say. I think that it is time that reflection on traditional religions and healing is included in our Bible study and teaching. The truth is, the African church ministers to and among the people who believe in these things and the church's ambivalence has not helped in bringing people *in* to hear what the Gospel is all about.

The respect of the dead and the process of grieving is one of the reasons why people spend a lot of money in funerals. This is a very complex subject to address but I think one that the church needs to address as a matter of urgency. People in our communities are poor, they are dying in great numbers and have to conduct these expensive funerals. This further impoverishes and making them more vulnerable.

□ Denial and silence

Denial of AIDS has been discussed as one of the strategies that people use to save themselves from facing “head on” the frightening reality of AIDS. However, this strategy is not helpful as it makes matters worse. The church itself continues to ignore AIDS as if it will just go away. The ministers that were interviewed unanimously asserted that it is time that the church should respond and take AIDS very seriously. The church’s teaching should address people holistically and not just as souls without bodies.

□ Ubuntu

The foundation of African life has been built on interdependence of people. But as people are becoming more civilised, we are losing this great virtue of *ubuntu*. I think that the church could lead a process of regenerating the values of African culture that have been discarded as evil in the process of Christianising people. The Bible challenges us to love our neighbour as ourselves and this means that this is not only the African Renaissance’s idea, but the idea of Christ himself for the church.

3. Conclusion

The Sustainable Livelihoods approach starts by identifying people’s or communities’ strengths and builds on those rather than being a ‘client-centred’ approach to development that starts by defining people’s needs and problems and presents itself as the problem solver. The needs driven approach focuses on how to solve problems, making people aware of the nature and extent of their problems and how valuable the services are to help solve those problems. These are development experts who are from outside with little or no knowledge of the community. The experts are thus capable of exploiting the community and making them believe that they are dependent on the outsiders for their livelihoods.

This approach to development obviously undermines the community's intelligence and their rich experience as a people. In contrast this study, leaning on the Sustainable Livelihoods approach, aimed to engage the community in the process of identifying their coping strategies and experiences, the assets they already have and how these are utilised to render intended or unintended livelihood outcomes.

The AIDS epidemic depresses communities that have been struggling already as a result of "development" amongst other problems. Unfortunately, many responses to AIDS have taken on the 'problematic' development approaches and have not proven effective and sometimes have made matters worse. "Throughout history, few crises have presented such a threat to human health and social and economic progress as does the HIV/ AIDS epidemic".¹⁰³ It impacts on livelihoods more severely than any other challenge, and hence the study looking at enhancing people's survival strategies, because people do survive in the midst of it all.

Identifying people's survival strategies was not easy for a number of reasons; people found it difficult to spell out what strategies they have adopted in the face of HIV/ AIDS, because for them life is a whole and adjusting to different and difficult life situations is natural and almost unconsciously done; their lives have always been a day to day struggle even before AIDS- even though it has worsened things. Michael Taylor reflecting on human suffering says,

Poor communities are places of hospitality and culture. Children play. People dance and celebrate. They worship and observe rites of passage. Their faith is strong... A simpler way of living, in stronger and more stable communities may even be gain rather than loss. What you are born into and have always been used to is in any case easier to deal with than what you reluctantly have to adjust down to or fear you might. The very nature of normality is that what from the outside look like dire conditions are from the inside simply everyday realities which do not preclude pleasure and satisfaction.¹⁰⁴

¹⁰³ FAO Report for the 27th Session of the Committee on World Food Security, 2001

¹⁰⁴ Michael Taylor. *Poverty and Christianity: Reflections at the Interface between Faith and Experience* (London: SCM Press, 2000)

People cope and live within what they have, utilising more their social, physical, natural, human and financial capitals.

Poverty and hopelessness remain the biggest culprits in the spread of HIV/ AIDS at Ilunge and this twining link warrants an in-depth study that will help inform response programs in turning the tide of AIDS in this community and the nation in general.

BIBLIOGRAPHY

1. Books, Chapters and Articles

- Adeyemo, T of the Association of Evangelicals in Africa. *AIDS in Africa: The church's Opportunity* (Nairobi, Kenya: MAP International, 1996).
- Appleton, Judith. "At my age I should be sitting under that tree: the impact of AIDS on Tanzanian lakeshore communities", in Appleton, Judith. *Gender and Development* (2000).
- Balswick, Judith K and Balswick, Jack O. *Authentic Sexuality: An Integrated Approach* (Illinois: IVP, 1999).
- Bruce, Donald and Ann (eds). *Engineering Genesis: The Ethics of Genetic Engineering in Non-Human Species* (London: Earthscan, 1999)
- Butler, Mark and Greenstein, Ran. *Sustainable Livelihoods: Towards a Research Agenda*. (Community Agency for Social Enquiry, November 1999).
- Chambers, Robert and Conway, Gordon. *Sustainable Rural Livelihoods: Practical Concepts for the 21st Century*. Institute of Development Studies Discussion Paper 296. (University of Sussex, Brighton: IDS Publications, 1992).
- De Gruchy, Steve. "Of Agency, Assets And Appreciation: Seeking Some Commonalities Between Theology And Development" in the *Journal of Theology for Southern Africa*. 117, November 2003.
- De Gruchy, Steve. "The Contribution of Universities to Sustainable Livelihoods". Draft Paper.
- Denis, Philippe, "Sexuality and AIDS in South Africa" in the *Journal of Theology in Southern Africa*, March 2003.
- Denis, Philippe. "Sharing Family Stories in Times of AIDS" in *Missionalia* 29:2, August 2001.
- Escobar, Arturo, "The making and the unmaking of the Third World through Development" in Ranhema M and Bawtree V. *The Post Development Reader*. (London: Zed Books, 1997).

- Freire Paulo, *Pedagogy of the Oppressed* translated by Myra Bergman Ramos (England: Penguin Books, 1996).
- George, Susan. "How The Poor Develop The Rich" in M. Ranhema and V. Bawtree. *The Post Development Reader*. (London: Zed Books, 1997).
- Grant James, P, "Can the Churches Promote Development?" in *The Ecumenical Review* (WCC) Vol 26, No 1 January 1974.
- Haider, Raana. *Gender and Development* (Cairo: American University Cairo Press, 1996).
- Korten, David. *Getting to the 21st Century: Voluntary Action and the Global Agenda* (West Hartford: Kumarian Press, 1990).
- Kretzman John P and Mc Knight John L, *A path toward finding and mobilizing a Community's Assets* (Chicago: ACTA Publications, 1993).
- Maluleke, Tinyiko. Sam, "Editorial", *Missionalia* 29:2, August 2001, 125-143.
- McKenna, Megan, *Not counting women and children: Neglected stories from the Bible* (Maryknoll Orbis: 1994).
- Munro Op, Sr Alison " Welcome to the Conference from Coordinator of ASCBC AIDS Office" in Stuart, C. Bate (ed) *Responsibility in a Time of AIDS: A Pastoral Response by Catholic Theologians and AIDS Activists in Southern Africa* (South Africa: Cluster Publications, 2003).
- Neefjes, Koos. *Environment and Livelihoods: Strategies for Sustainability* (Oxford: Oxfam, 2000).
- Nicolson, Ronald. *AIDS; A Christian Response* (Pietermaritzburg: Cluster Publications, 1995).
- Njoroge, Nyambura J. "Come Now Let us Reason Together" in *Missionalia* 29:2, August 2001.
- Nouwen, Henri J.M, McNeill, Donald. P, Morrison, Douglas A. *Compassion: A Reflection on the Christian Life* (USA: Doubleday, 1982).
- Oduyoye, Mercy Amba. *Daughters of Anowa; African Women and Patriarchy* (New York, Maryknoll: Orbis Books, 1995).
- Saayman, Willem and Kriel, Jacques. *AIDS: The Leprosy of our time?* (Johannesburg: Orion Publishers, 1992).

- Sen, Amartya. *Development As Freedom*. (New York: Anchor Books, 1999).
- Silverman, Daniel. *Doing Qualitative Research: A Practical Handbook* (London: SAGE Publications, 2000).
- Simmons, Pam. "Women in Development": A Threat to Liberation" in Ranhema M and Bawtree V. *The Post Development Reader* (London: Zed Books, 1997).
- Snyder, Margaret. *Transforming Development: Women, Poverty and Politics* (London: IT Publications, 1995).
- Taylor, Michael. *Poverty and Christianity: Reflections at the Interface between Faith and Experience* (London: SCM Press, 2000).
- Tiblier, Kay B, Walker Gillian, Rolland, John S "Therapeutic Issues when working with families of persons with AIDS" in Macklin, Eleanor (ed). *AIDS and Families* (New York: The Haworth Press, 1989).
- Wasike, Anne Nasimiyu. , "Foreword" in Getui Mary N and Theuri Matthew M (eds) *Quests For Abundant Life in Africa* (Nairobi, Kenya: Acton Publishers, 2002).
- Whiteside, Alan and Sunter, Clem. *AIDS: The Challenge for South Africa* (Cape Town: Human & Rousseau (PTY) Ltd, 2000).

2. Other Documents

- Brundtland, Gro Harlem of the World Health Organization at the XIII International AIDS Conference (Durban: 2000).
- Carroll, Rory. "GM Food Refusal Sets Precedent", *Mail & Guardian*, November 1 to 7, 2002, page 15.
- De Waal, Alex, "What AIDS Means in a Famine". *New York Times*: 19 November 2002.
- Department For International Development, *Sustainable Livelihoods Guidance Sheets*, UK Government, London.
- FAO Report for the 27th Session of the Committee on World Food Security, 2001 *Kairos Document*, 1986:1.
- The Employment Equity Act No 55 of 1998.

The Medical Schemes Act No 101 of 1998.

The New Partnership for Africa's Development (Abuja: October, 2001)

The United Nations Millennium Declaration (New York: September, 2000)

3. Web Pages

Avert.Org, *South Africa HIV/AIDS Statistics*, 01 October 2003 at

<http://www.avert.org/safricastats.htm>

BBC News at

http://news.bbc.co.uk/hi/english/sci/tech/newsid_436000/436702.stm

Daily Dispatch, "Queenstown maintains clean status, 28 January 2004 at

<http://www.dispatch.co.za/2004/01/28/Easterncape/eqtown.html>

Daily Dispatch, "Residents owe Lukhanji Municipality R88m", 22 January 2004 at

<http://www.dispatch.co.za/2004/01/22/easterncape/cluk.html>

De Gruchy, Steve. "An Introduction to Theology and Development at

www.hs.unp.ac.za/theology/article01.htm

De Gruchy, Steve. "What do we want to sustain? Development and the Earth

Crisis" in De Gruchy, Steve. *An Introduction to Theology and Development*
at www.hs.unp.ac.za/theology/article01/htm

Dorrington, Rob, Bradshaw, Debbie and Budlender, Debbie. *HIV/AIDS Profile in the Provinces of South Africa: Indicators for 2002* at

<http://www.petech.ac.za/aids/documents/hiv-aids%20in%20south%20africa.pdf>

Eastern Cape Department of Social Welfare and Development at

<http://population.pwv.gov.za/research/hcbc/Ecchcbc2001.htm>

Health Systems Trust, *Census shows 10 % growth*, 05 April 2004 at

<http://new.hst.org.za/news/index.php/20030713/>

MRC Burden of Disease Research Unit, 22 November 2002 at

<http://www.afroaidsinfo.org/content/research/epidemiology/statssa.htm>

Seeley, Janet and Pringle, Colin. "Sustainable Livelihoods Approaches and the HIV/ AIDS epidemic. A preliminary resource paper" (15th December, 2001) at <http://www.devserve.co.za/seeley%20and%20pringle202001.pdf>

The Body: An AIDS and HIV Information Resource: HIV/ AIDS Newsroom, "Gloomy HIV/ AIDS Statistics Cited at South African AIDS Conference, 05 August 2003 at http://www.thebody.com/kaiser/2003/aug5_03/south_africa_conference.html

The International Institute for Sustainable Development, *Communities and Livelihoods* at <http://www.iisd.org/communities.htm>

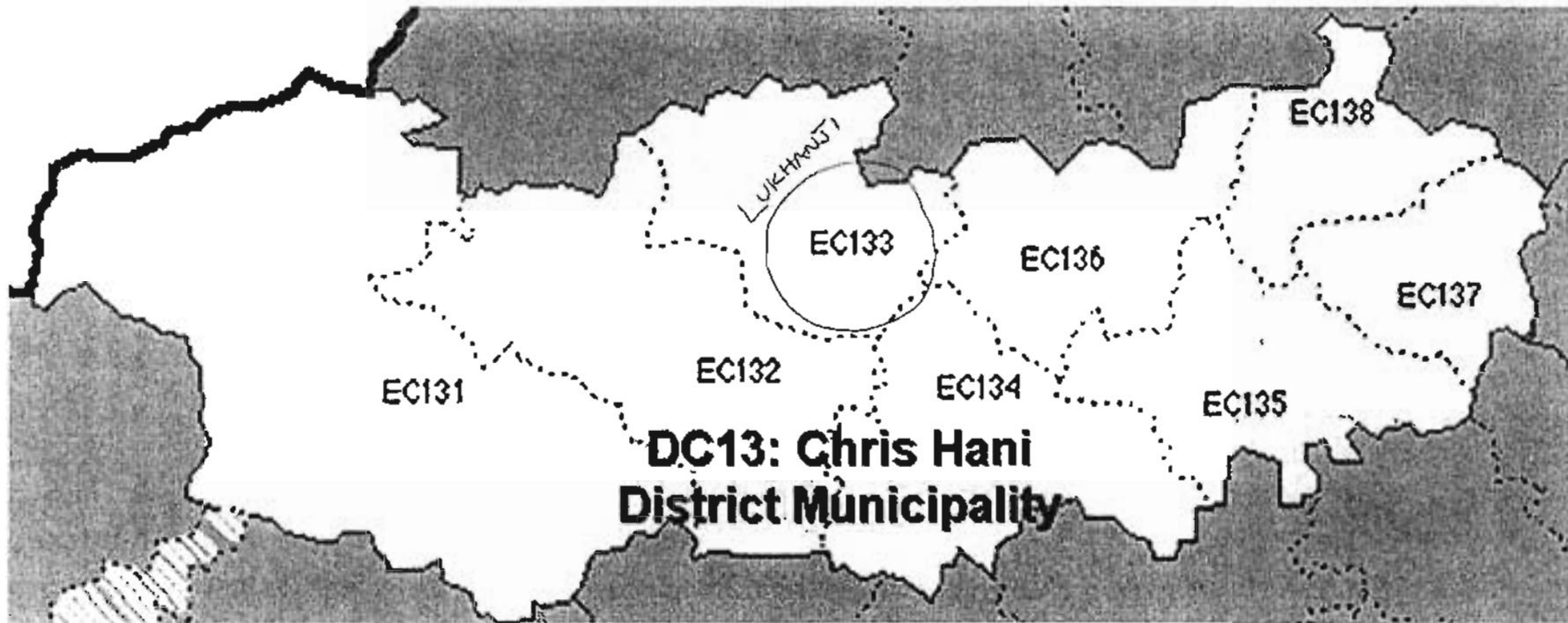
United Nations Development Programme, *Sustainable Livelihoods Unit Home Page*, www.undp.org/sl/Overview/an_overview.htm

United Nations Development Programme. " Sustainable Livelihoods: Overview". At http://www.undp.org/sl/Overview/an_overview.htm (10 February 2003)

World Council of Churches, "Defending the earth is not a project. Defending the earth is a way of life". <http://www.wcc-coe.org/wcc/news/press/02/04pre.htm1>

Situation analysis

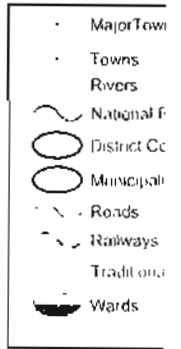
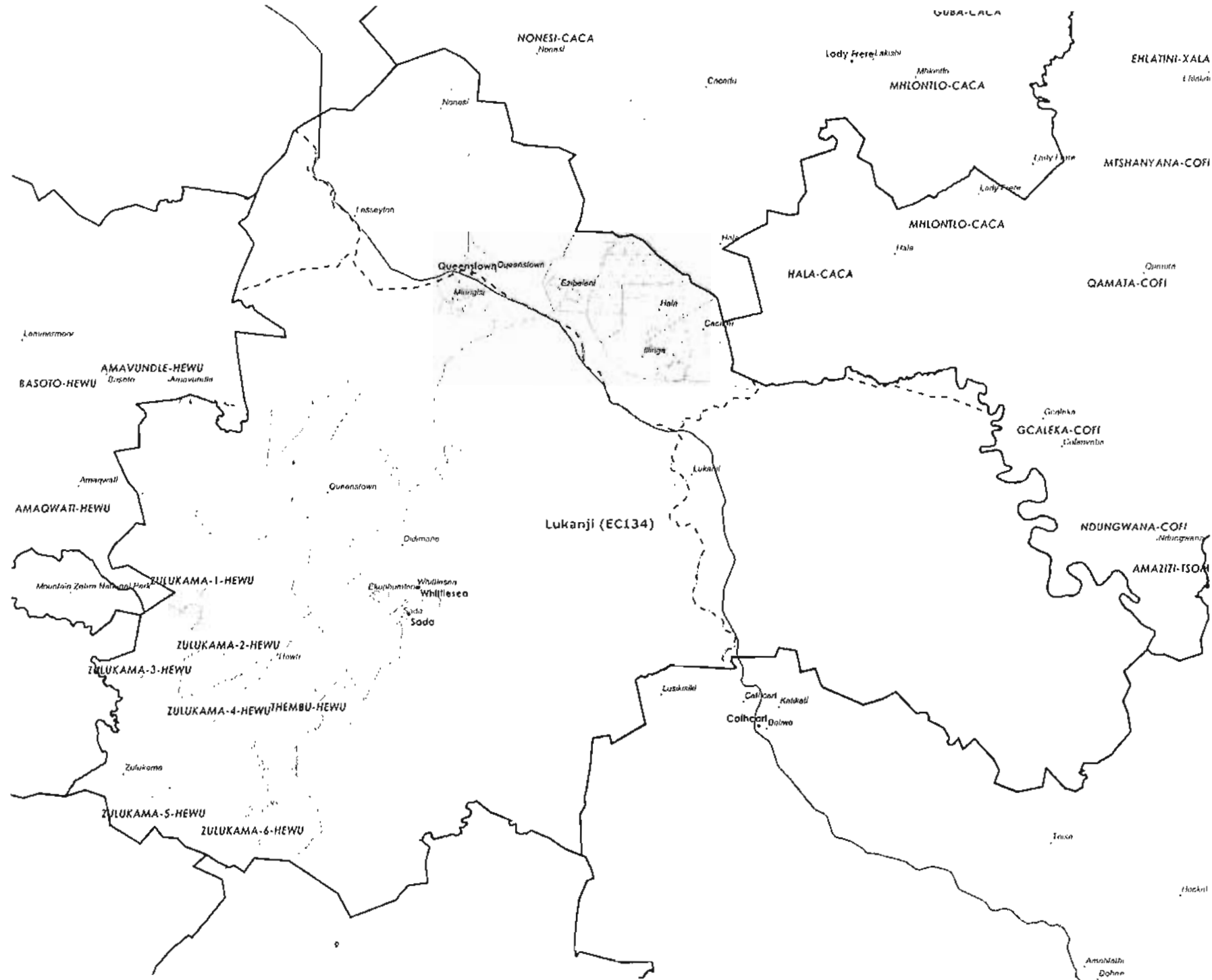
CHRIS HANI DISTRICT MUNICIPALITY EASTERN CAPE



Interim District Management Team of Chris Hani
District Municipality
HST/ISDS (RDHSP/ISRDP)

July 2002

MUNICIPAL
DEMARCAT
LOCAL
MUNICIPAL



Province :
Eastern Cape

District Muni:
Chris Han

Local Municip:
Lukanji



SEMI-STRUCTURED INTERVIEW QUESTIONS

Name: _____ Age: _____ Sex _____

Number of adults (18 and above) _____ Number of children (0-17 years) _____

1. Establish if there is anyone who is chronically ill in the family
2. How long has that person been ill for?
3. Is the person on treatment, what kind of treatment?
4. Do they know what the illness is?
5. How has this illness affected the family: economically, socially, spiritually, and emotionally?
6. How are they coping with this challenge: economically, socially, spiritually, and emotionally?
7. What adjustments or changes the family has undertaken as a result of this illness?
8. Are there any structures the family relies on for support to enhance these changes/ strategies?
9. What kind of support do they need to sustain these strategies?
10. Establish if the church is considered as a support structure and why?