

# **Forgotten people: realities and rights of farm dwellers in the context of HIV and AIDS**

## **A study with and of farm dwellers in the KwaZulu Natal Midlands**

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On behalf of

**The Association for Rural Advancement**

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## EXECUTIVE SUMMARY

In the post 1994 development agenda, farm dwellers are largely invisible, silent and vulnerable. These communities have been dispossessed of their tenure rights pre 1994 and their tenure, status and socio economic rights in general are now not recognised.

AFRA has been concerned about and alerted to the growing impact of HIV and AIDS on farm dwellers by the community themselves. The vulnerability of this community is now being deepened by HIV and AIDS with its many and varied social economic and emotional impacts on individuals, households and communities already in distress. Slowly, the community, lead by the women, is starting to break the silence about the existence and impacts of HIV and AIDS. The experiences and daily realities of farm dwellers in South Africa reflect hardship. Post 1994, farm dwellers are still invisible and vulnerable, and there is a long road ahead for farm dwellers to access socio-economic rights.

The study examines the condition and position of women and men farm dwellers in three areas of KwaZulu Natal in the context of the HIV and AIDS epidemics. Initiated by AFRA, in partnership with the Gender AIDS Forum, the purpose of the study is to inform and shape a strategic response to HIV and AIDS by AFRA. The study design was for us as a team as important as the data itself as we wanted to ensure that farm dwellers themselves as well as activists and workers at the cutting edge of land rights work participated in the design, data collection, analysis and shaping the recommendations. This contributed greatly to the value of the study which was ensuring that those most affected were directly engaged in generating options for confronting the challenges to their access health, health services and other socio economic rights directly or indirectly related to HIV and AIDS. The major limitation may be seen as the fact that the sample was 3 out of 10 communities. This was compensated for by using a deliberate sample.

The term farm dwellers refers to a category of rural women, girls, boys and men, who view the farm as their home, are born on, live on, work on farms without a salary; who consider themselves to have a right to reside on a farm in spite of not having approved documentation to support this; their claims are supported by their history as residents and community of that farm and by the fact that their ancestral graves are located there (AFRA 2005: 8).

The legal and policy vacuum in which farm dwellers have to survive has huge social and economic implications. The need for transformation of both the policy and practice frameworks presents this country with an imperative for action. These realities include:

- Social and economic insecurity Poverty and economic inequality
- High levels of population mobility
- Poor access to social services, particularly health and education
- Low literacy levels as a result of poor access to education
- Social dislocation during forced and 'negotiated' removals. These come with consequences such as loss of assets and livelihood sources such as land, equipment and opportunities for livestock and crop farming; poor nutrition; emotional insecurity due to loss of tenure and home which is strongly linked to identity
- Poor access to water and sanitation and the consequences on hygiene, health and general well-being
- Social (dys) functioning including what has been described by farm dwellers themselves as 'alcohol abuse', crime and violence, including violence against women

The conditions set the scene for amongst other things, the rapid and unchecked spread of HIV and the increased impact of AIDS on the already vulnerable women and girls in particular.

The factors that have and continue to drive the HIV and AIDS epidemics include:

- ✓ Macro economic and political factors
- ✓ socio economic factors
- ✓ behavioural factors
- ✓ biomedical factors

There is also a bi directional relationship between HIV and AIDS and these development factors leading to a vicious cycle where one drives the other. The impacts are felt at the individual, household, community and societal level and are both social, economic and emotional.

Gender inequality also fuels HIV and deepens the impact of AIDS on women and girls. The oppression of women which occurs at the level of women's bodies, in intimate relationships, at the household and community level and in the workplace and in all institutions, further drives the epidemics. Farm dwellers are disadvantaged by various forms of inequality including race, geography and income and women and girls in this patriarchal society, are further oppressed by gender inequality where they do not have *control over their own bodies*; do not have *equal access to services, resources, wealth*; decision making about resources and wealth are compromised by the status quo in terms of the *division of labour*; women's work is unrecognized, unpaid and where often there is a double shift where women work within the household and externally.

The conceptual framework used for the analysis of the data in this study includes intersectionality, gender analysis of HIV/AIDS and a gendered rights based response to HIV and AIDS.

The study highlighted and illuminated a range of key issues that create unacceptable levels of vulnerability and where HIV and AIDS is being allowed to erode the capabilities of the farm dweller community even further.

The high level of knowledge of their rights as farm dwellers and the legitimacy of their claims stands in sharp contrast to the pervasive and deep vulnerability and poor quality of life and more recently, sickness and death from AIDS related infections and disease. The analysis of this study focused on the intersection between the vulnerabilities associated with being a farm dweller and those created, enabled and facilitated by HIV and AIDS. It does not deal directly with the many issues surrounding the land rights and issues of land tenure

### **Key findings include:**

The HIV and AIDS related problems which were found to occur as a pattern in communities of farm dwellers constitute the findings of the study and include:

As a result of HIV and AIDS, there is a significant ***deepening*** of already existing ***vulnerability*** of farm dwellers

There is a sad, unnecessary and deadly lack of understanding of ***HIV and AIDS as a rights issue*** amongst farm dwellers

Farm dwellers vulnerability is located in both poor economic, land and agricultural policies as documented by AFRA, but also significantly ***shaped by gender and by age*** where women and girls are particularly vulnerable, blamed for HIV and AIDS and sexually exploited.

Specific gender findings observed and related in this study showed that:

Women and girls lack control and autonomy over their own bodies, health, sexuality and lives and this plays out particularly in violence against women (sexual and physical).

Women and girls do not know, understand, recognize their rights or have the skills and power to assert these sexual and reproductive health rights.

Community understanding of masculinities feeds the oppression of women and the violation of their rights, particularly their sexual and reproductive rights

All of these gendered impacts are deepened by the hardship, social exclusion and marginalisation that come with being a farm dweller.

The realities of farm dwellers then includes a long and shocking list of conditions that are largely ignored by policy makers:

- ✓ multiple vulnerabilities including lack of livelihoods, food security, access to clean water, sanitation and decent housing, health and welfare services, domestic violence against women, crime, excessive alcohol use, high dependence on the social grants of the elderly
- ✓ specific impacts of HIV and AIDS including high dependency ratios, high number of girl child headed households, early progression to AIDS, premature death, deepening poverty and hunger
- ✓ women and girls cannot inherit land, there is no access to women friendly health services, poor access to sexual and reproductive health services, lack of access to quality treatment for OIs and knowledge about and access to ARV's is poor, a lack of support for women engaged in care for those who are sick and dying. All of this is in addition to the triple shift (external productive labour, reproductive roles in the home and an extended community role)

### **The Recommendations to AFRA include:**

Ensuring that AFRA approach to HIV and AIDS is not a mainstream one where the standard messages and faulty analysis of AIDS projects is replicated. AFRA should plan and implement a response at an internal (organisational/institutional) level as well as external (programme/project) level that addresses both policy and practice changes including:

- ✓ enabling internal dialogue within AFRA to design a relevant and appropriate gendered rights based HIV/AIDS agenda
- ✓ Invest in internal skills building for the AFRA team
- ✓ Engage in strategic thinking and analysis in a planning workshop but importantly, on an ongoing basis to stay responsive
- ✓ Adopt a transformatory response to HIV and AIDS that recognises power as the problem and solution and helps confront the political aspects of these epidemics

Secondly, AFRA should set an activist agenda for it's work with farm dwellers. This could include:

- ✓ Know your (health) rights campaigning and processes
- ✓ Building solidarity between AFRA and other social movements involved in HIV and AIDS and related fields such as sexual and reproductive health and rights and treatment access, gender based violence activism
- ✓ Increase access to gender and HIV/AIDS related justice through partnerships with legal service providers
- ✓ Design and develop materials to support the activist AIDS agenda and ensure these are rights based and gendered
- ✓ Mobilise women to ensure collective action and leadership by women
- ✓ Build leadership skills amongst women farm dwellers
- ✓ Prioritise violence against women as a key issue affecting women's autonomy and dignity
- ✓ Launch and sustain a campaign by farm dwellers to improve reach and quality of social services, particularly but not exclusively health services
- ✓ Lobby for the inclusion of issues of farm dwellers in the Provincial AIDS Plan (2006 – 2010)
- ✓ In work with women and men, challenge notions of oppressive masculinities

## 1. INTRODUCTION

In the post 1994 development agenda, farm dwellers are largely invisible, silent and vulnerable. The term farm dwellers refers to a category of rural women, girls, boys and men, who view the farm as their home, are born on, live on, work on farms without a salary; who consider themselves to have a right to reside on a farm in spite of not having approved documentation to support this; their claims are supported by their history as residents and community of that farm and by the fact that their ancestral graves are located there<sup>1</sup>. These communities have been dispossessed of their tenure rights, first, in the pre 1994 era and now in post apartheid South Africa through policy frameworks that fail to recognize the status and their tenure.

There are approximately six million farm dwellers in South Africa, with most living in KwaZulu Natal. However, statistics only reflect a certain category of farm dwellers which is farm workers. It does not take into consideration other groups who constitute the farm dweller community.

Even after participating as equal citizens in the accessing of their political rights, these communities are still faced with huge challenges for the recognition of their socio economic rights. The farm dweller communities are heavily impacted upon by historical injustice and their lives, health and well-being have been compromised by inadequate policy review and formulation and by the slow pace of delivery by the state.

'The forgotten people: realities and rights of farm dwellers in the context of HIV and AIDS' study (hereinafter referred to as the study) was conducted between August to November 2005 and examined the condition and position of women, girls, boys and men farm dwellers in three areas of KwaZulu Natal, including Greytown, Impendle and Vryheid, in the context of a growing HIV and AIDS epidemic. It was conducted as a partnership between the Pietermaritzburg - based Association for Rural Advancement (AFRA) and the Gender AIDS Forum. AFRA is an independent land rights NGO that aims to redress past injustices, to secure tenure for all and to improve the quality of life and livelihood of the rural people. AFRA works with black rural people in KwaZulu-Natal whose land and development rights have been undermined, whose tenure is insecure and who do not have sufficient access to land and resources to fulfill their developmental aspirations or basic needs. The Association for Rural Advancement (AFRA) works with farm dwellers to help highlight their lived realities, and to enable farm dwellers to have a voice and be visible in the national development agenda.

The Gender AIDS Forum is a Durban based NGO committed to gender justice through transformatory processes and the advancement of the rights of women, girls, boys and men who are marginalized and vulnerable, including those living with and affected by HIV and AIDS.

The purpose of the study was to help inform and shape a strategic and gendered rights based response by AFRA to HIV and AIDS amongst farm dwellers. This would be done through a participatory research process to deepen the understanding of AFRA about how HIV and AIDS are impacting on the daily lives of farm dwellers.

This report provides a broad overview of the research process and methodology, proceeds to describe the HIV related realities observed and articulated by farm dwellers themselves and then provides a collective analysis of the condition and position of women and girls of boys and men farm dwellers in the context of HIV and AIDS. The report ends with findings and conclusions and a set of recommendations based on a data analysis workshop where the participating members of AFRA and GAF staff together with a team of women farm dwellers. Every effort has been made to ensure that this report is reader friendly, accessible and in plain English as well as succinct without losing the necessary richness and depth. The notes from the various data collection and analysis

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<sup>1</sup> AFRA 2005

Processes are available to serve as a body of source data which can be tapped into when and as needed.

## 2. BACKGROUND

AFRA, as a land rights organisation, has been aware for some years about the growing impact of HIV and AIDS on people in the rural communities, particularly as these communities are already vulnerable due to their general lack of recognition and options for accessing to land, housing and social services. AFRA has seen how HIV and AIDS has increased the levels of vulnerability of farm dwellers and deepened poverty and inequality amongst these communities. Whilst AFRA have been able, from time to time to address these concerns, it was difficult to address these effectively and as an integral part of the AFRA agenda for various reasons:

- The issue of HIV and AIDS has been largely invisible and the silence around the issue was hard to break through as these communities themselves were not ready for this
- The community, and hence AFRA as an organisation responsive to community issues, have been preoccupied with the daily realities of landlessness, poverty and inequality and on mounting and sustaining an effective struggle against the violations of their rights in that regard

Over time, the women in these communities began slowly to engage with the realities and impacts of HIV and AIDS on their lives and futures. Women farm dwellers finally began to raise their concerns about HIV and AID and it's impacts on their own personal lives and health, on households and on their communities. In 2004 AFRA was able to commit to embarking on a process of education with women in the community who were now raising concerns in this regard to those AFRA staff working on the AFRA Gender Desk. Because it was the women seeking an HIV and AIDS response and that this need emerged from work with the women on gender, AFRA approached the Gender AIDS Forum, a Durban based Non Governmental organisation to work in partnership with AFRA in addressing this challenge. The purpose of GAF is to raise consciousness and build confidence and competence in policy makers, activists and advocates about the interface between gender and HIV and AIDS and effective approaches to confront and address this interface. Joint analysis and ongoing discussions between AFRA and GAF led to a decision that the need and situation required a more strategic response than a few workshops and events.

The two organisations agreed to start the process with action research to

- establish and deepen understanding about the HIV related realities of farm dwellers
- to meaningfully involve and facilitate the empowerment of farm dwellers themselves in this learning process
- allow for a process where the project or programme design emerged from the outcomes, findings and lessons of the study itself as well as linking the design to what we understand as cutting edge and good or best practice on HIV and AIDS on the one hand and gender on the other

This would then be followed by a strategic thinking, analysis and planning process. Once this phase of the project is completed, a programme which expands the already existing rights based response of AFRA towards a rights based response to HIV and AIDS will be developed. The findings of this study and the collective knowledge and skills base of AFRA and GAF will be used to shape the design of this programme. The common agenda of the two organisations was a commitment to addressing inequality through a gendered rights based approach to the change process at both a policy and practice level.

### **3. METHODOLOGY**

#### **3.1. About the approach**

This study was designed in keeping with the commitment of the Gender AIDS Forum to a participatory knowledge creating approach to research<sup>2</sup> where those most affected by the issues being examined in the study are active participants in both research design, data collection and analysis and wherever possible, write up. This commitment linked in well with the commitment of AFRA to participatory rural appraisal approaches and a research process and outcome that was lead and owned by the farm dwellers as far as possible, building farm dwellers capability for further research and knowledge creation to inform the necessary change processes in these communities.

#### **3.2. Research Design: An overview**

The study was conducted in three stages as follows:

Phase one	Preparation, developing capabilities and design
Phase two	Data collection
Phase three	Data analysis, write up and validation

The design of the research was agreed upon by AFRA and GAF and contracting was based on these agreements. Aspects of the design agreed to included:

- a decision to conduct a qualitative study which would capture the richly textured nature of the lives of farm dwellers and their perceptions and ideas about HIV and AIDS in the context of the struggle for land and other socio economic rights
- a deliberate sampling process where a mix of farm dweller communities was identified and selected. This mix included women and men farm dweller communities in three geographical areas – Greytown, Impendle and Vryheid
- the decision to utilise a mix of data collection processes including focus groups, interviews and direct observation combined with a desk review which was both internal to AFRA and external in terms of identifying responses to HIV and AIDS by others in this sector both locally and internationally
- the drafting, testing and development of interview and focus group schedules and frameworks for observation

Once the design was agreed, the process unfolded as follows:

1. Establishing and preparing the research team
2. Designing, testing and developing the data collection tools
3. Selecting the sample
4. Collecting the data
5. Analysing the data
6. Write up of the analysis, including the findings, conclusions and recommendations
7. Validation of the findings and consensus building about the recommendations
8. Finalisation of the research report

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<sup>2</sup> <http://www.gaf.org.za>

### **3.3. Key features of the research design and process**

The centrality of participation and ownership within the study were demonstrated through the active engagement of both women farm dwellers, as well as women living with HIV and AIDS, in the two day research training, induction and preparation workshop, in the drafting and testing of the data collection instruments and in the 2 days post data collection analysis workshop. The data collection teams were designed to share expertise and experience with a mix of experienced researchers and less experienced ones, amongst them, farm dwellers. The farm dwellers were also recognised as having their own skills set and knowledge base which the more experienced researchers did not have but were able to tap into within this process.

The research teams also engaged individual reflections through the use of personal diaries. They also conducted team debriefings daily and at the end of the process and then the teams collectively conducted an overall debriefing at the end of the data collection process. These debriefings were a critical part of the design as they enabled reflection and review on an emotional, social and intellectual level. They contributed to deepening the experience of research itself, helping to articulate and make explicit the learning and to develop a conceptual framework for the findings. Importantly, the reflection process enabled each participants to grow on a personal and professional level and to enable the study to start a process of change at the individual level.

After the preparation of Draft one, the farm dwellers validated the report after reviewing and making inputs and giving feedback.

This design and special features of this study, including the kind of participation employed, ensured that the bias and standpoint of the other members of the research team were not dominant and that the farm dwellers had the space to articulate their own analysis, viewpoints and perspectives and to challenge positions that did not fit with their own lived experiences. Furthermore, it increased ownership of the process and the outcomes and we hope, deepened the sense of responsibility and commitment of the women farm dwellers themselves to acting on the findings of the study.

### **3.4. Value of the study**

The value of the study is that it engaged a community largely invisible and silent on both a policy and practice level in thinking about and generating options for confronting the challenges to their access to health and health services.

The study created a data set on gender, HIV and AIDS and farm dwellers that does not at present exist in the formal sense. This set forms the basis of and acts as both a catalyst and instrument for shaping an agenda to advance the health rights of women, girls, boys and men in farm dweller communities in the KwaZulu Natal Midlands.

Furthermore, there are possibilities and opportunities presented by the study report for lessons to be shared across geographic areas both on research process, on substantive issues facing farm dwellers in relation to inequality, including gender inequality, HIV and AIDS and lack of access to socio economic rights including health rights.

Finally, the study will be used to inform, guide and shape a strategic medium to long term rights based response to HIV and AIDS amongst farm dwellers by AFRA.

### **3.5. Limitations of the study**

The main limitation of the study was that, due to time and financial constraints, only three communities out of 10 were sampled. This limitation was managed through a deliberate sample which reflected and represented a cross section of communities including: Newcastle, Utrecht, Dannhauser, Vryheid, Estcourt, Greytown, Howick, Mooi River, Eston, and Impendle.

## 4. CONTEXTUAL ANALYSIS

'Farm dweller' is a term used to describe the women, girls, boys and men who view the farm as their home, are born on, live on, work on farms without a salary who consider themselves to have a right to reside on a farm in spite of not having approved documentation to support this and supported by their history as residents and community of that farm<sup>3</sup>. This community have been dispossessed of these rights to tenure first in the pre 1994 era and now in post apartheid South Africa through policy frameworks that fail to recognize their tenure.

This section explores the key factors creating vulnerability and including HIV/AIDS, gender inequality and the position of farm dwellers in the national development agenda. The discussion section then provides an analysis of the intersections between these three aspects of the daily lived realities of farm dwellers

### 4.1. Farm dwellers

The daily realities of farm dwellers is severely impacted upon by the legal vacuum that they have to constantly negotiate. This legal vacuum lead to the call recently by an activist farm dweller

***"Law have mercy on us<sup>4</sup>"***

The legal and policy vacuum has huge social and economic implications and the need for transformation of both the policy and practice frameworks presents this country with an imperative for action. Some of these include:

- Social and economic insecurity Poverty and economic inequality
- High levels of population mobility
- Poor access to social services, particularly health and education
- Low literacy levels as a result of poor access to education
- Social dislocation during forced and 'negotiated' removals. Theses come with consequences such as loss of assets and livelihood sources such as land, equipment and opportunities for livestock and crop farming; poor nutrition; emotional insecurity due to loss of tenure and home which is strongly linked to identity
- Poor access to water and sanitation and the consequences on hygiene, health and general well-being
- Social (dys) functioning including what has been described by farm dwellers themselves as 'alcohol abuse', crime and violence, including violence against women

These conditions and lived realities of farm dwellers set the scene for, amongst other things, the rapid and unchecked spread of HIV and the increased impact of AIDS on the already vulnerable women and girls in particular as well as boys and men.

Research by HSRC et al notes the link between HIV and AIDS and land based livelihoods as follows:

- impact of HIV on land rights
- impact of HIV on land use: research is lacking on the link between HIV and land tenure

According to AFRA documentation there are multiple tenure arrangements operating in South Africa, with varying degrees of security, but most of them are not recognised, supported and valued. Besides the insecurity this creates, this multiple tenure also carries the risk of sidelining many vulnerable people, households and communities from development opportunities. Coupled

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<sup>3</sup> AFRA 2005:

<sup>4</sup> AFRA 2005.

with the legal and bureaucratic recognition granted to titled tenure, this phenomenon reproduces the dual economy and perpetuates inequity.

AFRA staff talk about the way tenure debates often polarize tenure systems into two opposites: the formal (indicated by title or registered tenure) and the informal (indicated by the absence of legal ownership). But this dichotomy can both be unhelpful and mask reality. Firstly the terminology tends to privilege "formal" over "informal" as though formalisation, or titling, is the ultimate solution. Secondly, "informal" is suggestive of a disorganized, chaotic or anarchic "other", which is at odds with what is often a complex, well organized and regulated set of rules and procedures for land allocation, boundary demarcation, adjudication and dispute resolution without titles. Thirdly, given the amount of evidence demonstrating the tendency of titled tenure to deformalise, the dichotomy is itself problematic. Tenure is better represented as a continuum in which the situation is moving towards more informality or more formality. From the point of view of the social reformer, therefore, social legitimacy at a local level may be regarded as being as important as the formalities of the law with regard to property ownership.

The importance of social legitimacy in securing tenure does not address the immediate problems of those people living in situations at the cutting edge of conflicting property values and norms. AFRA staff believe that the most affected such group in South Africa is farm dwellers, many of whom have lived on commercially farmed land owned by whites for many centuries. They view the land as belonging to their ancestors and therefore to themselves, although the owners argue that their titles grant them exclusive rights to the land. While various land laws attempt to give some legal recognition to these indigenous views of property ownership, the dominant system of registered title continues to place farm dwellers at a relative disadvantage to the landowner. This not only affects the capacity of farm dwellers to feel secure in their homes and in the use of land for survival, it also limits their abilities to access municipal and other government services. These realities have resulted in farm dwellers calling themselves the "forgotten citizens", arguing that while other South Africans have benefited from post-1994 reform, they have been neglected because they live on rural land they do not own legally themselves.

"for many poor households, including those devastated by HIV/AIDS, land represents their last line of defence against total destitution, but that first if they absolutely must they will sell it, and second, they are at risk of losing their land against their will"<sup>5</sup>

Research by HSRC et al highlights the denial of HIV in the "farm dweller" community. Whilst farm dwellers in the HSRC research noted many health concerns, these were related to lack of clean water and lack of health care facilities, with only one respondent in the research mentioning HIV as a critical issue. Participants in the KwaZulu Natal survey only raised HIV and AIDS as a health issue only when asked specifically if HIV and AIDS was a problem.

Development practitioners have "growing concern that the pro-poor objectives of land reform are under threat by the HIV and AIDS epidemic"<sup>6</sup>

## **4.2. HIV and AIDS**

The HIV and AIDS epidemics in South Africa have impacted on individuals, households and communities across the country. HIV and AIDS have acted as a spotlight, exposing inequalities, including gender inequality, the worst impact being experienced where poverty and economic inequality is extensive and deep, gender inequality is pervasive and access to public services is

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<sup>5</sup> ibid p 1

<sup>6</sup> HSRC, University of Fort Hare, University of KwaZulu- Natal & Nkuzi Development Association 2005

weak and uneven<sup>7</sup>. Given the extreme poverty and inequality faced by farm dwellers in South Africa there is an expectation that the impact of HIV and AIDS is and will be severely felt.

It is important to acknowledge three successive epidemics<sup>8</sup> when analysing the impact of HIV and AIDS

- the *HIV epidemic* or the *silent epidemic* which is largely hidden and spreading rapidly throughout the country.
- the *AIDS epidemic*, which represents the visible consequences of HIV.
- the *third epidemic*, which moves beyond the medical to the social and refers to the denial, blame, stigmatisation, prejudice and discrimination which is present in every country dealing with HIV/AIDS. "The third epidemic of social, cultural, economic and political reaction to AIDS ... is as central to the global challenge as AIDS itself"<sup>9</sup>

Surveillance data<sup>10</sup> from 2002 in South Africa, shows that the national average rate of HIV prevalence in pregnant women attending antenatal clinics has remained roughly at the same high levels since 1998—ranging between 22% and 23% in 1998–1999 and then shifting even higher to around 25% in 2000–2002. At almost 37%, HIV prevalence among antenatal clinic attendees in KwaZulu-Natal is about three times higher than in the Western Cape—the province with the lowest prevalence.

Based on the country's national round of antenatal clinic-based surveillance, it is estimated that 5.3 million South Africans were living with HIV at the end of 2002. More than half are women.

KwaZulu Natal has the oldest epidemics and still has a set of political, economic and social conditions which, generally, have the effect of driving the epidemics and of deepening the impact of the epidemics at a personal, household, community, societal, institutional level as well as at local, district, provincial and national level.

The factors that have and continue to drive the HIV and AIDS epidemics in the Province include:<sup>11</sup>

- **macro** economic and political factors including political commitment, economic decision making and economic models and frameworks, particularly the neo liberal economic framework of global capitalism which is now the order of the day and that has impacts on access to and distribution of wealth and resources (including land, shelter and housing), employment and livelihoods
- **socio economic factors** which include levels of literacy, population mobility for a range of reasons, including labour migration and political conflict, again on the increase in this province, access to affordable, acceptable, quality and respectful services, including health, welfare and education as well as work and livelihoods which uphold the dignity of those involved. The unequal position of women in society is a key socio economic factor driving HIV and AIDS
- **behavioural factors** includes, essentially, the extent to which sex is safe, safer and where sexual and reproductive health and rights of women and men are accepted, understood and respected at all levels of society including in intimate relationships, at the household level and community and institutional levels. The issue of the use of and access

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<sup>7</sup> Collins and Rau, 2000

<sup>8</sup> Panos 1990

<sup>9</sup> Mann in Panos 1990 p 2

<sup>10</sup> Department of Health 2003 National ANC survey.

<sup>11</sup> Whiteside 2002

to affordable, accessible and acceptable barrier methods such as male and female condoms and dental dams are key here

- **biomedical factors** such as access to safe circumcision, the increased biological susceptibility of women to HIV infection, transmission from mother to child, including during pregnancy, at delivery and through breast milk, transmission through blood transfusions and so on.

It is clear that these factors are interlinked and that what is referred to as "behavioural" factors, for example, are shaped by and occurs in the context of a range of socio economic and macro political economic realities. All of these factors are all driving the epidemic in general in the province and simultaneously, deepen the impact of HIV and AIDS at every level of society.

Also, there is a two way or bi directional relationship between HIV and AIDS and these development factors, which translates to a vicious cycle: Whilst the consequences of HIV and AIDS, described as 'impact' includes the deepening of vulnerability, marginalisation and stigmatisation and the promotion of poor health, low levels of well-being and reduced ability to access rights, these factors themselves when not addressed meaningfully themselves drive or feed the HIV and AIDS epidemics.

It is now clear that poverty is deepened by the increased needs of a single member of a family member who is HIV positive. This is due to increased transport and medical costs and loss of income to the family and lower productivity of women and men who are living with HIV and AIDS.

### 4.3. Gender

*Women are facing a crisis that requires urgent attention. The response to HIV and AIDS must be two-fold: a short-term strategy that needs to, as much as possible, reduce the spread of HIV amongst women and lessen the impact of HIV and AIDS on women. However the long term goal must be to challenge the complexities and inequalities of power relations between men and women in society leading to the transformation of society<sup>12</sup>.*

Sub-Saharan Africa is the only region in the world where more women than men are infected with HIV<sup>13</sup>- 58 % of people living with HIV and AIDS in this region are women. The impact on girls and young women aged 15-24 is even more disproportionate. Girls are 2.7 times more likely to be infected than their boys in the same age group. In Southern Africa this gap even larger - in Zimbabwe for example, girls and young women make up nearly 80 per cent of all young people (15 – 24) living with HIV.

Gender inequality is a central feature of patriarchal society and is characterised by male dominance and oppression over women, whose autonomy and dignity is eroded by this oppression. The forms which masculinity takes in patriarchal societies establishes and maintains male privilege. Male privilege is at the expense of women's right to be equal. The oppression of women occurs at various sites of (male) power. This includes:

- women's body
- intimate relationships
- household level
- community level
- workplace
- institutional level

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<sup>12</sup> Agenda 39, 1998, AIDS, Counting the cost. p13

<sup>13</sup> UNAIDS, World Health Organisation, *AIDS Epidemic Update*, December 2003, Geneva

Farm dwellers are disadvantaged by various forms of inequality: race (the farm dwellers in the KwaZulu Natal Midlands are all Black African); income (they have poor access to income and livelihoods); geography (as rural communities they have greater challenges in accessing services and resources). Women are also further disadvantaged as these are patriarchal societies where women:

- do not have *control over their own bodies*
- do not have *equal access to services, resources, wealth* and decision making about resources and wealth
- are compromised by the status quo in terms of the *division of labour* where women's work is unrecognized, unpaid and where often there is a double shift (work externally and responsible for care roles and household work)

Gender inequality is entrenched in the fabric of our societies through institutions such as traditional structures and religious institutions. In spite of the fact that the South African constitution guarantees equality for women, the practice of gender inequality is resistant to change. In rural areas tradition and religion are often more pervasive and influential and where communities are isolated from mainstream political, social and economic changes. Resistance to transformation that will lead to gender justice and the very notion of women's autonomy and control over their own bodies is generally taboo. Commercial farms are even more isolated within rural areas and the already slow process of gender transformation is possibly slower here.

## 5. CONCEPTUAL FRAMEWORK

The conceptual framework that underpins the analysis of this Paper includes ideas on:

- ***intersectionality***: this refers to the way that the issues of HIV/AIDS, gender, poverty and inequality and the reality of being a farm dweller intersect to create an extreme situation of a toxic mix of vulnerability, marginalisation, discrimination and stigma, as well as denial about the reality of HIV/AIDS and a sense of hopelessness and powerlessness
- ***a gender analysis of HIV/AIDS***: which refers to a systematic process of analysing the condition (realities) and position (power) of women and girls, boys and men farm dwellers. This analysis will, in turn, inform and shape the strategies and tactics for confronting and addressing the structural basis of gender oppression and inequality and the linkages to HIV and AIDS.
- ***gendered rights based response to HIV and AIDS***: at the level of recommendations which includes strategies and tactics for addressing the intersectionality of gender, HIV/AIDS, poverty and inequality in the lives of farm dwellers, we use a conceptual framework based on Moser's practical needs and strategic interests.

Here we also use the Gupta framework, adapted by Tallis<sup>14</sup>, of addressing HIV and AIDS in transformatory ways, as opposed to using the technician ABC (abstain, be faithful, use a condom) which is clearly ineffectual and approaches to HIV and AIDS that further entrench gender stereotypes, are gender neutral or only go as far as being gender empowering without shifting power relations towards transformation towards gender justice.

These three conceptual frameworks are the basis for the analysis of the realities (condition) and rights (position) of farm dwellers lives and wellbeing.

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<sup>14</sup> Tallis, V. [2003].

## 6. FINDINGS: DISCUSSION AND ANALYSIS

The study produced a wide range of data about the shockingly silent and invisibility of the deep and unacceptable level of vulnerability of farm dwellers in the KwaZulu Natal Midlands. This section provides an overview of the findings of the study and then presents an analysis of these findings as they have been observed and examined in the three communities. The approach is to present and discuss patterns in the way that farm dweller communities are experiencing HIV and AIDS and how they are responding to these epidemics in the context of already existing vulnerabilities and declining capabilities. We do not in this process, single out any particular community, neither do we attempt to reflect the full data set with its layered character and many details.

### 6.1. Overview of Findings

The findings of this study showed in general that dwellers have a well-developed understanding of land rights. They are clear about the fact that they have a claim over the use of and secure residence on the land they call home, currently in the control of commercial farmers. Farm dwellers have been and are generally able to articulate the issues, the realities and, importantly, this claim. Those farm dwellers who are willing and able to engage on a political level of struggle for justice are engaged, through the work of AFRA in articulating and asserting these claims through a range of advocacy and activist strategies.

This high level of knowledge of their rights as farm dwellers and the legitimacy of their claims stands in sharp contrast to the pervasive and deep vulnerability and poor quality of life and more recently, sickness and death from AIDS related infections and disease. The analysis of this study focused on the intersection between the vulnerabilities associated with being a farm dweller and those created, enabled and facilitated by HIV and AIDS. It does not deal directly with the many issues surrounding the land rights and issues of land tenure.

The HIV and AIDS related problems which were found to occur as a pattern in communities of farm dwellers constitute the findings of the study and include:

6.1.1. As a result of HIV and AIDS, there is a significant **deepening** of already existing **vulnerability** of farm dwellers

6.1.2. There is a sad, unnecessary and deadly lack of understanding of **HIV and AIDS as a rights issue** amongst farm dwellers

6.1.3. Farm dwellers vulnerability is located in both poor economic, land and agricultural policies as documented by AFRA, but also significantly **shaped by gender and by age** where women and girls are particularly vulnerable

### 6.2. Discussion

#### 6.2.1. As a result of HIV and AIDS, there is a significant deepening of already existing vulnerability of farm dwellers

Farm dwellers are a group and community who are vulnerable due to policy and practice failures on the part of the state to ensure that the rights of farm dwellers to security of land tenure, capability to establish and sustain a livelihood from the land and access to resources such as farming inputs.

The lack of access to social services and the impact of HIV and AIDS in the communities examined within this study has and continues to deepen the already existing vulnerabilities and undermine the capabilities of farm dwellers. Their level of health, development, quality of life and well being is therefore unacceptably low.

*" .... In one household, two months ago, parents died of AIDS. Then the grandparents followed, dying of similar symptoms. The children who were left behind were taken by relatives but were brought back again because of the land issue. They are three children and the eldest is 15 years old."*

*[Mr and Mrs D] Impendle*

*"First, it was my father and mother in law..... then my brother in law died the same week as my sister in law. I also have lost a brother to AIDS"*

*[community health worker] Vryheid*

The daily lived realities, even without HIV and AIDS, of farm dwellers are shaped by multiple vulnerabilities including:

- Lack of ability to plan life even on a day to day basis
- Lack of livelihoods, income and/or employment
- Lack of food security and consequent poor nutrition
- Lack of access to clean water, sanitation, overcrowded housing and living arrangements
- Sickness and disease related to poor nutrition, lack of access to clean water, sanitation and dignified housing and living arrangements
- Lack of access to social services, especially health services and education
- High dependency on social grants for survival, where often extended families of 13 people are living off the old age pension of a grandmother
- Some social impacts include high levels of crime and excessive alcohol use by both the men and the women in some areas such as Impendle. Alcohol is obtained through exchange by the men for labour and by the women for sex. Even those who have no income at all also buy alcohol on credit.
- Increasing levels of domestic violence is also a feature of the social environment here

The state asserts that it is unable to provide services to farm dwellers on commercial farms as this is private property. Hence water, sanitation and education are largely absent. The current legal framework for land rights issues affecting farm dwellers is the ESTA which is inadequate for the needs and realities of farm dwellers and is unable to provide the basis for effective solution finding for the challenges and hardships they face.

The reality of the suspension of development for farm dwellers is that the communities are, even when resources are available, unable to invest in farming as they have no security of tenure whatsoever. Their lack of security and the land size limitations mean that there is insufficient space for livestock . The insecurity has a ripple effect on their ability to secure food in a sustainable way, to generate an income or livelihood and to obtain farming inputs and assets. Furthermore, there are no moves by government to develop the skills of the farm dwellers to farm profitably or to enable effective subsistence farming. Poor nutrition is an outcome and the impact is a greater burden of disease on women, household and communities.

*" we cannot farm because the land is not ours..."*

*"People have no power to do anything because this is not our land..."*

*"we can't start projects because this is not our land and we have no rights over it..."*

*(selection of views from the three areas visited)*

Health services such as clinics are therefore long distances from the homes of farm dwellers. In one case, the clinic was in a forest and was considered to dangerous to go to. Other reports are of patients receiving the wrong medications. In some cases mobile clinics have been negotiated between commercial farmers and the Department of Health. Where these are available, it is once per month and there are only nurses and no doctors. When it rains the roads become impassable and the mobile clinic will not arrive. Between these monthly visits, there are no accessible, affordable health services: people have to travel long distances incurring significant travel costs and often have to consult with private doctors and pay full consultancy fees. In some areas the nearest hospital is 60 kms away. The traditional doctors are more readily available and also often add to the problem as they are unable to effectively and consistently deal with HIV and AIDS. Costs here are also relatively high.

*"Clinics are far away. If you get sick at night it is hard to get transport. Sometimes you call an ambulance at night but it only comes the next morning"*  
[woman participant]  
Vryheid

All of these circumstances set the scene for the rapid and, to date, unchecked spread of HIV and the deepening of the impact of AIDS amongst individuals and households which are already living with HIV and AIDS or affected by these epidemics. Lack of access to water, sanitation, education, and health services is a critical barrier to HIV and AIDS prevention and care, counselling, treatment and support.

Furthermore, the quality of care in the health care institutions creates further barriers to effective HIV and AIDS responses, for example, the attitudes of health care workers makes it difficult for farm dwellers to ask for and receive treatment for STIs, access termination of pregnancy and other sexual and reproductive health and rights services. Availability of medicines in clinics is also an issue – often even after the farm dweller has spent their few financial resources and valuable time on travel to and waiting at a clinic, after a diagnosis, the medicines to treat the illness are not in the clinic and will require a return visit. There are often links between the farmers and the clinic staff so, as was found in Vryheid, in the absence of benefits, some commercial farmers have a company doctor. Farm dwellers told stories about the way these doctors, in the employ of the farmers, would disclose their HIV status to the farmer. Furthermore, many farmers deduct the costs of medical care from the workers salaries.

Finally, ward and district demarcations are not yet finalised and this leads to further confusion and wastage of resources as people are shunted from one facility to another before they can access health and other services.

Some specific impacts of HIV and AIDS are:

- High dependency ratios with high numbers of older women and men in the household and high numbers of children. Young women and men are sick, dying prematurely or in urban areas seeking employment.
- The numbers of (girl) child headed households is increasing steadily and the levels of sexual abuse of girl children is also on the increase
- Early progression to AIDS and premature death
- Deepening poverty as a result of the fact that households lose breadwinners to AIDS, are forced to sell off their productive assets such as farming inputs, equipment and livestock to pay for medical bills and other expenses
- Hunger as the few resources available are given to those who are sick with AIDS related illness and this in turn leads to illness of those who are not infected with HIV and reduced energy levels and inability to work on food security such as food gardens

Even where poverty can be addressed through access to social pensions, the application process is time consuming, costly and slow – some of the factors here are the poor service delivery pace by welfare officials and attitudes of government staff. A huge barrier to accessing grants and pensions is related to lack of documentation of births and deaths.

Unemployment rates are high. Even where there are household members who are employed, these are often low income jobs linked to low education levels coupled with inadequate job creation policies and practice.

Whilst it is clear that the impacts of HIV and AIDS at a personal, household and community level are significant, there are also impacts within the workplace itself. Where farm dwellers are working on commercial farms, they face huge challenges in ensuring they are treated with respect and dignity when ill, something they don't even get when they are well. Farm dwellers working on farms have no benefits and don't earn the minimum living wage. The no work no pay rule applies universally, leading to poor health seeking behaviour and work attendance even when they are severely ill and requiring medical attention. In many cases, farm dwellers who work on these farms get sick and then are sent to a doctor who refuses to issue a certificate and on return to work, the doctor's fees are deducted from the wages. Farmers are quick to replace sick workers.

The impact of all these factors on health seeking behaviour is negative and in the context of HIV and AIDS is dangerous to the health and lives of those who require treatment as there are no incentives to attend health centres for monitoring and treatment.

### **6.2.2. There is a sad, unnecessary and deadly lack of understanding of HIV and AIDS as a rights issue amongst farm dwellers**

Farm dwellers have generally been excluded from responses to HIV and AIDS. The National AIDS Plan for South Africa (2000 – 2005) recognises and lists a range of vulnerable groups and communities and whilst rural people are mentioned the special situation of farm dwellers is invisible. Messages and opportunities for appropriate learning, education and media for engaging them in a consciousness raising process in relation to HIV and AIDS is sadly lacking.

Farm dwellers rely on radio in some cases, but largely rumour and person to person information sharing. This information is often of poor quality, inaccurate, based in the communicators own fears and ignorance and has the effect of stigmatising women, girls, boys and men who are already living with HIV and AIDS.

Ignorance, blame, denial, shame, stigma, discrimination are widespread. They are linked with a sense of being overwhelmed by the arrival of yet another challenge to their safety, security, well being both now and in the future, have served to create hopelessness and powerlessness which in turn feeds the denial and stigma in a vicious cycle.

*"I can't look at AIDS, I find it very difficult"*

*Nompilo*

*[Vryheid]*

*"groups were very vibrant in talking about issues and development until we asked them about HIV/AIDS and then they became silent"*

*research team member*

Key messages in HIV and AIDS work is based on the ABC (abstain, be faithful and use a condom). This message is, globally, ineffectual. We have been using this as a country for some time, it is having no impact whatsoever yet we still persist.

The silence around HIV is pervasive. Even though people see others, including young women and men in their productive and reproductive years, denial and the perpetuation of myths and explaining opportunistic infections in terms of witchcraft are still widespread. There is intense shame associated with HIV and AIDS and the link to sex which is not spoken about at all makes the sense of shame and the stigmatising attitudes and language that much stronger. There were reports of people avoiding efforts at addressing issues of HIV and AIDS. Much of the silence is thought to be due to fear of infection and the consequences and to an already overwhelmed community trying to avoid acknowledging any more problems. There is little personalising of risk of HIV – few people think it could happen to them. The communities have simply not engaged with HIV as a reality and are focused on bread and butter issues.

In this climate, disclosure levels are very low. There are few benefits of disclosing and in fact the social consequences, including exclusion and derision are great. Access to ARV is not a reality in these communities who battle to access basic health and medical care and drugs. Even where there is disclosure to family, they often do not want to deal with this and ignore the disclosure appealing to sangomas for help and healing. Families also would rather be silent about a sick family member than seek help. On the other hand, there were reports in some communities of people wishing to test positive, as this will enable them to get government grants. There is already a known process where one person uses the test results of others to apply for grants and has to pay a bribe to get this approved.

The understanding of and passion for struggle and the claiming of rights, such as land rights, has not filtered through to issues related to HIV and AIDS. The notions of AIDS as a development, human rights, women's rights, health rights, including sexual and reproductive health and rights issue is not known, recognised and understood, including by those people involved in service delivery in both government and in civil society (including religious institutions and community based organisations) as well as in the private sector. The levels of stigma are therefore left unchecked and the violation of the rights of women and men living with HIV and AID both within the workplace, community and through service delivery institutions is neither monitored nor acted against.

Legal service agencies are not actively involved in these areas and where they are involved, are not themselves recognising and confronting HIV and AIDS related discrimination and rights violations.

Sex and sexuality are not spoken about and there is a shroud over these realities. Women who are HIV positive are generally regarded as sex workers.

### **6.2.3. Farm dwellers vulnerability is located in both poor economic, land and agricultural policies as documented by AFRA, but also significantly shaped by gender and by age where women and girls are particularly vulnerable**

The gendered dimensions of the vulnerabilities of farm dwellers and of HIV and AIDS facilitate the deepening of impact on women and girls. There is also an intersection of gender and age in a somewhat unusual and disconcerting way: older women are both the carers of those who are living with HIV and AIDS, they are also reported to be dying of AIDS in unexpectedly high numbers themselves.

The lives of all farm dwellers is characterised by extreme hardship, insecurity of many kinds and a sense of hopelessness and powerlessness. The position of women and girls in this community is characterised by even deeper vulnerabilities and impacts.

These impacts and vulnerabilities have been articulated in gender analysis frameworks and include key elements:

- Lack of control and autonomy over their own bodies, health and lives
- Lack of access to wealth, resources, opportunities for income, livelihoods
- The gendered division of labour

### **6.2.3.1. Lack of control and autonomy over their own bodies, health, lives**

The women on the commercial farms formed the majority of participants in this research process. The research team was also predominantly women. Gender considerations were central to the study as we know that gender inequality is a key factors driving the HIV and AIDS epidemics. We also know that South Africa is a patriarchal society and this province in particular has entrenched cultural and religious norms that reinforce and sustain the dominance of men over women. We also had an assumption that rural communities are less likely to have been exposed to gender transformation processes and more inclined to adhere to traditional norms and values which in many instances deepen women's oppression. This assumption would also generally hold true in commercial farms amongst farm dwellers, except that they may be even more isolated and excluded and hence even more subjected to traditional practices and norms.

Women in general and women farm dwellers in particular have little to no control over their bodies and decisions about their sexuality, sexual and reproductive health and rights.

In then first instance, the women here knew little or nothing about their rights as human beings and had not internalised the notion of women's rights as human rights. This translated to a lack of understanding about their right to control over their bodies, including their sexual rights (including right to sexual pleasure, insist on safe and healthy sex, decide whether, when, how often and how to have sex) and their reproductive rights (including right to decide whether, when and how often to have children, access to contraceptives and termination of pregnancy and access to post exposure prophylaxis).

The study found that:

1. women did not know, understand, recognise their rights or have the skills and sense of power and control to assert these rights in intimate relationships, the household, the community, workplace, institutions and society
2. the impacts of gender inequality on women and girls were similar to those that women in different contexts, including urban women, face, but that, in addition these gendered impacts were deepened by the reality that these women also faced the most untold hardship, social exclusion and marginalisation as a result of their identities as farm dwellers
3. community understandings of masculinities is generally not challenged and play out as being demonstrated through the ability to provide for your children and family and to enjoy the sexual double standard where a man is a man by the number of women he is involved with. In the context of HIV and AIDS, when a man is sick this is regarded as an additional benefit for him as he then has many caregivers

### **Women and girls: Impacts of the intersections of gender, age and HIV and AIDS**

The study found that women and girls in all three areas visited experience a pattern of gender oppression which is demonstrated through

- *gender based violence* which is, interestingly articulated by many as due to the fact that the identities of men are being undermined by the increased control of women in the public realm such as in workplaces as breadwinners, sometimes where a male partner is unemployed. Young women in particular are subject to this form of violence. Gender based violence is inflicted on both wives and intimate partners as well as by sons on their mothers. The women in these situations have no recourse to justice and in fact this is generally accepted as the way things are

- *marriage in general and polygamy* is experienced as oppressive but is an expectation impacting both on women's autonomy and control over their bodies and deepening household poverty. Again, whilst women don't like it, they accept it as their lot and part of culture
- *use of barriers methods* including female and male condoms is low – women and these communities in general know nothing about female condoms and access to male condoms is unreliable and uneven. Men are resistant to the use of condoms and this attitude is reinforced by community leaders. Women and the communities here have no knowledge about the microbicides products that are in research and that will enable women to take control of ensuring safer sex practices
- *older women* are expected to care for the sick whilst their own health needs are generally neglected. They do this without support and guidance. There are reports that numbers of older women infected with HIV is high and growing. Many grannies, get sick and die of AIDS related symptoms. This is an issue of women's right to health and also reduces the access to income as many of these women are supporting large extended families on their pensions and grants.
- *young women* are subjected to rape and other forms of gender based violence. Young women are also forced to leave school first to care for sick parents and relatives. When they become sick there is no one to care for them. There is a high drop out rate from school as a result of teenage pregnancy where girls as young as 16 are already pregnant and 20 year old young women already have two children and are sick and poor
- increasing number of women are thought to be engaged in *transactional sex* as a survival strategy and form of livelihood and also, in some areas, to pay for alcohol
- there are *few forms of resistance* by women to gender oppression and women are generally *not organised* to advance a women's rights agenda
- women generally are *blamed* for infecting their male partners with HIV and mothers are responsible if their teenage daughters become pregnant. A woman infected with HIV is regarded as a sex worker and thought to have misbehaved, they are blamed and support is not forthcoming

*"I am not benefiting from this abusive marriage. I will not leave my husband, but would like to encourage other women to think carefully before getting married"*

women in focus group

*[Impendle]*

*"how can you use a jacket when the sun is hot"*

*(an induna referring to the use of condoms)*

*"she came with the virus"*

*reported as a standard response by communities and extended families*

*[Vryheid]*

### **6.2.3.2. Lack of access to wealth, resources, opportunities for income, livelihoods**

Whilst both women and men in these communities suffer the consequences of the slow pace of delivery and a lack of access to income, livelihoods, social services, women are more compromised by this lack of access.

Some impacts on women's access to services and resources, wealth and assets include:

- According to customary tenure, women cannot inherit the land when her husband dies. She is often evicted and has little rights to farm as a woman
- There is little access to women friendly health services, including relevant and appropriate information on SRHR, including STI management and treatment, and gender sensitive health care workers

- Lack of access to reproductive and sexual health services is poor and there is no recognised package of SRHR services which a women knows she can expect and claim at the healthcare centres that will protect her sexual health
- Lack of regular and accessible treatment for opportunistic infections as well as ARV is generally poor but there are also specific treatment issues for women which these women themselves as well as health care workers are often unaware
- There is a general lack of support (training, materials and nutrition for those women engaged in home and community based care) for women engaged in care of the sick and dying

### **6.2.3.3. The gendered division of labour**

Where women are expected to play certain roles in intimate relationships, the household, community and society and men other roles which are associated with power, decision making and control. Women generally have to work the “double shift” where they are engaged in external productive activity (employment, livelihood and a range of transactional arrangements) as well as carry out their reproductive roles within the household

Women are increasingly taking on roles as breadwinners and creating strategies for stronger food security and livelihoods such as selling vegetables or going out to work. These roles threaten the male partners identities and contributes to conflict.

In the context of HIV and AIDS, women farm dwellers are really engaged in the “triple shift” where they are involved in external productive labour, reproductive roles within the home and an extended community role where they are involved in supporting other women who are caring for the sick and dying. The list therefore includes:

- child care
- infant feeding
- housecleaning
- cooking
- seeking and finding food for family
- caring for sick family members
- attending to arrangements related to educational needs of children such as buying of books and uniforms, addressing problems that children experience in the education system
- producing for sale
- travel to market good produced or bought for sale
- travel to health care centres
- attending in and participating in community events such as church and cultural activities
- preparing for own family and community funerals
- finding and keeping a job
- budgeting and financial management (where this role is not taken “back” by male partners.

When a woman is sick with AIDS or any other chronic illness, she is still expected to carry out these multiple and demanding roles. There is generally no one to care for her. The impact of AIDS on the women farm dweller is certainly a triple jeopardy in these communities.

## **7. RECOMMENDATIONS**

The response by AFRA to the realities and lack of access to health, including reproductive and sexual health and rights amongst farm dwellers must take account of the approach to effectively confronting and addressing HIV and AIDS. It must also address the substantive issues faced by farm dwellers by setting an agenda where these issues are articulated and planned for on both a policy and strategic level.

The recommendations have been set up in such a way that the set that appears under "Approach" strengthen the institutional aspects of addressing HIV and AIDS within a broader development framework. This set of recommendations will enable AFRA to launch a process of change and transformation at farm dweller community level, which is rendered sustainable through key institutional arrangements, including policies and mechanisms, that will systematise the organisational response to HIV and AIDS

### **7.1. APPROACH**

Cutting edge thinking and analysis of what it takes to respond to HIV and AIDS from a rights based perspective suggest that a transformatory approach where power is recognised in its different forms and both confronted (oppressive power) and worked with (enabling power). This proactive approach must be accompanied by a process of resisting technicist notions of behaviour change as the point of entry for HIV and AIDS responses. It must consciously prevent the employment of gender stereotypical, gender blind/neutral approaches to HIV and AIDS and health issues.

Within this framework, it is recommended that AFRA plan and implement a response at both an internal and external level and at a policy and practice level:

#### **7.1.1. Internal dialogue and development**

Enable an internal reflection and review process to develop in a participatory way an approach to HIV and AIDS that taps into the experience of AFRA in working on rights with a focus on land rights

#### **7.1.2. Internal skills building to enable AFRA team members to systematically and as Policy formulation**

Draft, through collective and collaborative approaches, an HIV and AIDS, wellness management or chronic illness policy which sets out principles

#### **7.1.3. Strategic thinking and analysis process**

Where team members and key constituents, including farm dwellers, engage in a process of reflection and consideration of what is considered to be good and best practice for the sector as well as for rights based gendered response to HIV and AIDS. Out of this process, a medium term strategy is developed, funded and operationalised

#### **7.1.4. Adopt a transformatory approach to HIV and AIDS**

Ensure that the AFRA approach to HIV and AIDS is rooted in power, facilitating and enabling communities to recognise and confront and use power to contribute towards a global movement towards a society where women and men, girls and boys are equal and where equality on the basis of sexual orientation, (dis)ability, race, access to wealth is possible. This approach will ensure

that responses to HIV and AIDS are not technocratic but helps build the global social movements which are challenging a global neoliberal agenda with a wide range of entrenched inequalities and vulnerabilities.

## **7.2. SETTING AN ACTIVIST HIV AND AIDS AGENDA**

### ***7.2.1. Know Your (health) Rights processes***

Develop, test and implement a Know Your Health Rights Campaign with and for women, girls, boys and men farm dwellers and emphasise and popularise, within this, the notion of claims of both genders to reproductive and sexual health and rights. This process should be designed so that it addresses the deep hopelessness and powerlessness that pervades the farm dweller community. It must also be designed to provide tools and instruments for farm dwellers to take charge of their own health and wellbeing, asserting their rights in this regard.

### ***7.2.2. Build solidarity***

Establish, develop and sustain solidarity with strategic partners with key health rights organisations, including treatment and also reproductive and sexual health and rights organisations as well as organisations of people and women living with HIV and AIDS and women's rights organisations, including but not limited to those addressing gender based violence

### ***7.2.3. Increase access to gender and HIV/AIDS related justice***

Develop partnerships with legal advice clinics and service providers/agencies to ensure that women and men who face discrimination, stigma and a violation of their HIV/AIDS related gender rights can claim these through conciliation, negotiation processes and litigation where needed and appropriate

### ***7.2.4. Rights based materials***

Develop and distribute relevant and appropriate media and materials with messages to popularise sexual and reproductive health and rights and geared towards males and females of the full range of identities and realities in the communities

### ***7.2.5. Mobilising women for collective action***

Plan and implement a consciousness raising process where women's understanding about gender oppression is developed and where women can become the catalysts for change at a personal level, within intimate relationships, within the workplace, in all institutions and in the community and society at large. This process should be geared towards women as agents of change rather than victims and powerless community members.

### ***7.2.6. Launch and sustain a campaign with farm dwellers to improve the reach and quality of services***

Engage the Ministry of Health, Welfare, Agriculture, Education as well as the municipalities in a process of dialogue with farm dwellers so that the reach of services can be expanded, including on commercial farms for access by farm dwellers. These dialogues should also address issues of service quality and the attitudes of service provider staff and accessibility of medication and materials such as condoms and gloves.

The quality of service is also strongly linked to ensuring and enhancing a smooth continuum of care from one agency to another with the least cost in terms of time and money for the farm

dweller. This requires the establishment and sustaining of an information drive/campaign by government to ensure that rural communities, including farm dwellers, know the services, how they work, what the packages of benefits are and how best to access these efficiently

***7.2.7. Lobby for prioritisation of farm dwellers in the Provincial AIDS Plan***

Engage with the Ministry of Health and Office of the Premier to ensure that in the new Provincial AIDS Plan (2005 – 2010) farm dwellers are recognised as vulnerable and that measures and budgets to address this vulnerability are set in place

***7.2.8. Highlight the injustice of and address violence against women and girls***

Skills building with girls and women and exchange to shift from normalisation of violence against women towards women acting collectively against this form of violence

***7.2.9. Build women leaders amongst farm dwellers***

Plan and budget for sustained opportunities for women to occupy and effectively carry out leadership roles within communities and in advocacy processes and activism

***7.2.10. Challenge notions of masculinity which encourage men to oppress women***

Work directly or partner with organisations working with men in transformatory ways to develop a later of men leaders who act as role models to others in fighting for women's autonomy, equality and work with a small group of men to rise consciousness about gender justice and equality.

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## **9. APPENDICES**

### **Appendix 1: Understanding the impact of HIV and AIDS on farm dwellers**

#### **Values and Principles guiding the research team**

As researchers we agree to:

Integrity: no hidden agendas

Honesty

Professionalism

Transparency of self

Involve people

Confidentiality

Humility

Respect: experience, cultural beliefs, choices

Non-judgemental

Not going in as experts

Willingness to learn

Speak peoples language

Feedback and commitment to do something after the research

## Appendix 2:

### Impact of HIV and AIDS on farm dwellers FOCUS GROUP

#### **You should start this focus group by:**

Introducing the research

Introducing yourselves

Ensure that every one understands and is comfortable with the process

Stress confidentiality

Explain that the focus group will take between 1 – 2 hours

Identify which member of the team will be

Community \_\_\_\_\_

Group facilitator \_\_\_\_\_

Scribe \_\_\_\_\_

#### **Introductions:**

Get each member of the group to introduce themselves.

#### **Community issues**

What are the issues, problems and challenges that your community faces?

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What are the main problems facing women?

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What are some of the main problems facing men in your community?

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What are the issues facing young women, young men?

Issues to explore: violence, intergenerational sex, teenage pregnancy,

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#### **Health Services**

What are the health problems in your community?

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What are the health services accessed by people in the community? Where are the health resources? What are your experiences of accessing health care?

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What is the role of provincial and local government in providing services for health and HIV & AIDS?

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What is the role of community based organisations, churches in providing health services – care and health information to the community?

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**Illness in the community**

What is the level of sick people in the community? Has it been growing? if yes how? Who is sick? [Probe demographics – age, gender]

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What was the picture of illness and death in the community 10 years ago?

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How does this level of sickness affect the community? Household? How does it affect women? Men? Children?

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What happens to people who get sick? Who supports sick people? Who looks after sick men? Who looks after sick women?

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What do people say about sick people in the community?

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**Livelihood issues**

What are the communities current strategies for survival?

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How do illness and sickness impact on your survival?

What is the relationship between the landowner and the employee who is sick:

*Follow up questions:*

What sort of assistance does a sick employee get

How much leave, sick leave? What happens when the sick leave is exhausted

Have sick people who are ill for a period of time lost their job?

Who is the breadwinner, what happens if the breadwinner dies?

Have employees or their families lost their tenure due to illness and /or death?

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**Understanding of HIV and AIDS**

What do people say about AIDS in the community?

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Do you know of people in your community or in other communities who have HIV or AIDS?

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What are some of the ways that your community can prevent HIV infections? [probe strategies for prevention, whether virginity testing is seen as a good option, strategies around care]

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What are the community strategies for dealing with HIV?



## Appendix 3

### Interview Questions

#### Community issues

What are the issues, problems and challenges that your community faces?

What are the main problems facing women?

What are some of the main problems facing men in your community?

What are the issues facing young women, young men?

Issues to explore: violence, intergenerational sex, teenage pregnancy,

#### Health Services

What are the health problems in your community?

What are the health services accessed by people in the community? Where are the health resources? What are your experiences of accessing health care?

What is the role of provincial and local government in providing services for health and HIV & AIDS?

What is the role of community based organisations, churches in providing health services – care and health information to the community?

#### Illness in the community

What is the level of sick people in the community? Has it been growing? if yes how? Who is sick? [Probe demographics – age, gender]

What was the picture of illness and death in the community 10 years ago?

How does this level of sickness affect the community? Household? How does it affect women? Men? Children?

What happens to people who get sick? Who supports sick people? Who looks after sick men?

Who looks after sick women?

What do people say about sick people in the community?

#### Livelihood issues

What are your current strategies for survival?

How do illness and sickness impact on your survival?

What is the relationship between the landowner and the employee who is sick:

*Follow up questions:*

What sort of assistance does a sick employee get

How much leave, sick leave? What happens when the sick leave is exhausted

Have sick people who are ill for a period of time lost their job?

Who is the breadwinner, what happens if the breadwinner dies?

Have employees or their families lost their tenure due to illness and /or death?

#### Understanding of HIV and AIDS

Where do you get your information about health issues?

Where do you get your information about HIV and AIDS?

What do you know about HIV and AIDS?

Do you know of people in your community or in other communities who have HIV or AIDS?

What do people say about AIDS in the community?

What are some of the ways that your community can prevent HIV infections? [probe strategies for prevention, whether virginity testing is seen as a good option, strategies around care]

What are the community strategies for dealing with HIV?

Explore: what language is used to discuss and describe HIV and AIDS.

Issues of stigma, discrimination, disclosure

Where do people sick with AIDS go to for help? What advice do people get from health care setting? What advice do people get from traditional healers? [explore issue of households getting poorer in their efforts to deal with HIV and AIDS]