“TO WHAT EXTENT ARE PARTICIPATORY-BASED PROGRAMS EFFECTIVE IN EMPOWERING A COMMUNITY AFFECTED BY HIV/AIDS?”

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A RESEACH REPORT FULFILLING A MASTER OF ARTS IN DEVELOPMENT STUDIES

BY RYAN SCOTT MCDONNELL

Though the words and ideas recorded in this research report are my own, they bear the imprints of many people who participated in this process, a select few of which I would like to thank here:

My most heartfelt thanks goes out to the people of Forth Street, Kliptown for their willingness to share about their lives and experiences. Their stories not only give color and life to the text, but also provide a critical context in which to examine participatory development theory. In the same manner, HIVSA's organizational candor and transparency throughout the research process allowed me to understand their work in a much deeper and more meaningful way.

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CHAPTER ONE: A BRIEF INTRODUCTION

This study aimed to examine the effectiveness of participatory development in empowering communities to respond to the social problems of HIV/AIDS. The research question was addressed through an understanding of the contrasting theories surrounding participatory development, set within the context of South Africa's current AIDS epidemic. A single, critical case study was developed through a partnership with a non-governmental organization called HIVSA (literally H-I-V-S-A), working in Soweto, Gauteng Province, South Africa.

The central research question was as follows:

To what extent are participatory-based programs effective in empowering a community affected by HIV/AIDS?

Throughout the research, participation was engaged in the following ways:

1. Firstly, what defines participation within the context of humanitarian development? This question examined the form, character, nature and scale of participation within development.
2. Secondly, what is the definition or understanding of participation within the community analyzed through this research?
3. Thirdly, does HIVSA's program facilitate community participation and, if so, how?
4. Finally, is participation helpful in empowering those infected and affected by HIV and AIDS within the community examined through this research?

People's *participation* has been widely adopted by development policy makers over the last twenty years. Participation transfers control from the powerful to the powerless. Supporters claim that participation offers a direct means of empowering those who participate. Because of these claims, participation has been widely applied throughout the developing world. Participation offers a solution to development practitioners who look for effective means to empower vulnerable, powerless people. This has represented a massive change in policy – at least verbally – from the top down plans for development from the decades following the Second World War to a growing emphasis on bottom up approaches.

Participation often, but not always, happens at a *community* level. Community participation is important because it offers an opportunity to build upon and strengthen existing bonds of social capital.[1] Community participation is often encouraged because it allows the overlapping needs of community members to be addressed in a cost effective and efficient manner.

Currently, there is a paucity of research about the correlation between community participation and the social effects of South Africa's HIV/AIDS epidemic. The AIDS epidemic arguably presents the primary developmental concern facing the region today. The current situation presents an interesting environment for existing research: the epidemic is growing. The number of affected households and communities is growing daily. It is critical that a more detailed understanding of community participation be developed as a prospective means of assisting communities in dealing with the social effects of HIV and AIDS.

The theory in support of participatory development has been constructed and articulated by Robert Chambers.[2] The body of knowledge and application of participatory development has significantly evolved over the last fifteen years. Although participatory development is characterized as both dynamic and adaptable approach to development, it has not been without significant critique. Theory testing allowed the research to examine the existing theory and its critiques against a detailed case study.

Thorough description is a fundamental precursor to theory testing and theory generation in social science research. Over the last ten years, a broad descriptive understanding of the social effects of HIV and AIDS in South Africa has been well documented, and this is dealt with in detail in Chapter Two. A thorough description of the growth of participation in development is discussed in Chapter Three. For this research, the data gathered

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[1] *Social Capital*, like participation and empowerment, has reached "buzz word" status within the field of development and is often seen as a panacea. Popularized by the writings of Robert Putnam and others, social capital theory is an attempt to understand mutual trust, respect and participation between people who are not related but live or work within close proximity to each other. An individual's economic success is often attributed to high levels of social capital. An individual becomes successful because of her relationships to those around her. For example, the success of micro loans used in Grameen lending models, depends in part upon the level of social capital of the group borrowing the money.

[2] See Robert Chambers, Whose Reality Counts? Putting the First Last (London: ITDG Publishing, 1997) and Robert Chambers, Rural Development: Putting the Last First (Prentice Hall, 1995).

through the case study is critical in providing a baseline understanding of participatory methods used to enhance empowerment of those affected by the AIDS pandemic in South Africa's township communities.

The case study focused on a community-based program called *Areiketsetse Le Bana*. In the Sotho language Areiketsetse Le Bana means "Let us do it for ourselves and our children". HIVSA established Areiketsetse Le Bana in the township of Soweto to support communities affected by HIV and AIDS. HIVSA began in 1996 as an initiative of The Perinatal HIV Research Unit (PHRU), located at the Chris Hani Baragwanath Hospital.

> HIVSA's aim is to enable HIV infected and affected people to build resilience through an innovative community-based program, thereby encouraging them to reach their full potential.[3]

HIVSA believes that risk is lowered when communities take initiative with their problems. HIVSA desires communities to seek solutions that mitigate risk by lowering the stigma around testing and to practice safe and responsible sexual behavior, thus helping individuals access anti-retroviral treatment and other local governmental and non-governmental services.[4] HIVSA and the Areiketsetse Le Bana program offer a tangible application to examine participatory development theory. The Areiketsetse Le Bana program claims to allow their beneficiaries to play an important role in the process of development.

This research provides a basis for subsequent theory development and future research through the combination of two existing bodies of knowledge. Understanding the Areiketsetse Le Bana program in light of the relevant theory may have application in similar communities throughout the region. When viewed more generally in the context of global disease affliction and illness, the research supplements the existing discourse that exists on the welfare and protection of millions over the coming decades.

To date, there has been very little written about the failure or success of participatory development in the field of health in Southern Africa. *Participatory Development in South*

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[3] 11 November 2006 <www.hivsa.com/hivsa/index.stm>.
[4] Ibid.

Africa by Ismail Davids, Francois Theron and Kealeboga Maphunye provides a broad overview of participatory development in light of South Africa's history and challenges. As excellent as this resource is, it doesn't provide any information about the intersection between participation and poor township community affected by HIV/AIDS. There have also been studies conducted about the scale and nature of the South African's political participation post-Apartheid.[5] These may be helpful in a very broad sense, although they also lack the intersection of these specific issues explored in this paper. Because of the lack of local resources available, this research will contribute to building a localized body of literature to understand participatory development in the South African context. Local knowledge of a program that claims to be participatory may also make development practitioners more effective as they design and adapt programs in South Africa.

A more thorough understanding of how community participation assists communities to deal with the social effects of HIV/AIDS has some policy implications, from local community development efforts to global health initiatives. By understanding decision-making in the context of individuals, households and communities, more effective programs that build upon indigenous knowledge can be developed. As opposed to a top-down approach of prescribing what policymakers and program managers see as adequate, implementers can use this information to develop complementary social safety-net programs that are more effective, cost-efficient and relevant to the needs of those infected and affected by HIV.

METHOD OF RESEARCH

The AIDS epidemic has broad social ramifications for the lives of infected individuals, their families and their communities. Participatory development claims to work with and augment existing social structures to produce beneficial outcomes in the lives of people.[6] A detailed and specific case study was integral to understanding participatory development in the context of South Africa and HIV/AIDS. A case study provides the flexibility and focus on the description necessary for this topic.

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[5] Ebrahim Fakir, Political Participation in South Africa (Paper presented to the 5th conference of the International Network – Education for Democracy, Human Rights and Tolerance, Foreign Ministry, Berlin, May 14 – 15, 2003.)

[6] Robert Chambers, Whose Reality Counts? Putting the First Last (London: ITDG Publishing, 1997)

Framing the research within a longitudinal design would have allowed measurement of change in the community over periods of time. Information would have been gathered through multiple data collection periods in an attempt to capture changes over time. It would have also been an effective means to establish causation through temporal order. However, the costs would have been extremely high. The time frame allotted for performing this study added an additional constraint. Thus, the case study design presented a more efficient method for collecting and analyzing the data.

Levels of Analysis

The focus of this study was a single street in Kliptown, Soweto where the Areiketsetse Le Bana program is operating. The study examined the community on multiple levels. The research sought to understand the physical aspects of the community: location, size, education levels, employment and access to educational and religious institutions. The research also examined the social climate of the community including understanding about HIV and AIDS, levels of inclusion and exclusion and existing social networks within the community. Secondarily, the research examined the effect of gender and generation on the intervention. Past studies of this nature have also listed crime, stigma, and poverty as factors that have had disempowering effects. The research was conscious of how crime, stigma, and poverty affect people's participation although this was not a primary focus of the study and subsequent analysis.

Descriptive Case Study

Descriptive case studies[7] involve in-depth examination of the unit of analysis. The unit of analysis has some skill, problem, or trait that is unusual. Descriptive case studies require the researcher to base the research on a theory. Within this research project, the descriptive case study approach highlighted individuality, rather than just restating general trends in participatory theory. HIVSA's intervention within the Kliptown community provided a unique opportunity to examine the intersection of participatory theory and a community severely affected by HIV and AIDS. The conclusions drawn from this case study are based on the comprehensive data gathered about the specific community.

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[7] Ran Greenstein, ed. Research Methods Training Manual (Johannesburg: University of the Witwatersrand, 2003)

Descriptive studies frame the research using both implicit and explicit theories. Implicit theories identify what is important and what is extraneous within the case. In this study, the implicit theories focus on how participation is valuable in empowering those affected and infected by HIV and AIDS. The explicit theories establish the body of knowledge surrounding participatory development.

Theory Testing[8]

The general design of the research was guided by a thorough understanding of the theoretical framework surrounding participatory development. The theory in support of participatory development has been constructed and articulated by Robert Chambers. It has shown a significant and thoughtful evolution over the last fifteen years, as the body of knowledge and application of participatory development has changed. However, there are also significant critiques to Chamber's ideas, which are explored in Chapter Three. This specific case study examined the effectiveness of participatory development when dealing with HIV/AIDS at the community level. Thus, theory testing allowed a critique of the existing theory through the analysis of the case study.

Single Case Study

Although case studies can be either single or multiple, single cases are most often used when verifying or disputing a theory.[9] Single-case designs require careful investigation to avoid misrepresentation and to maximize the investigator's access to the evidence. These studies can be holistic or embedded, the latter occurring when the same case study involves more than one unit of analysis. The individual case study constitutes a whole study, in which facts are gathered from various sources, measured against the relevant theory and conclusions are drawn from the facts.

In the case of participatory development there is a clear and lively body of literature creating well-formulated theories regarding how participation should be structured. The research has sought out a single case that embodies the elements of participatory development theory. This makes the case *critical*, thus supporting the external validity of the research. Lynn Davey, in *Practical Assessment, Research & Evaluation* describes the importance of critical case studies:

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[8] Ibid.
[9] Ibid.

> Critical Instance Case Studies examines one or a few sites for one of two purposes. A very frequent application is the examination of a situation of unique interest, with little or no interest in generalizability. A second, rarer, application entails a highly generalized or universal assertion, which is called into question, and we can test it by examining one instance.[10]

For this specific research project case study research provided needed flexibility during the data collection process. There was preliminary examination into the Areiketsetse Le Bana program and a detailed research schedule was constructed in consultation with the staff. Despite significant forethought, there were a few surprises and rabbit trails to follow. The flexibility of the case study design allowed freedom to explore additional aspects of HIVSA and the community. Many anecdotes emerged from these exercises, some of which are included in this document. Much of this unexpected information collected proved extremely useful in providing nuanced answers to the research question. Other information distracted away from the central tenets of the research. This made the data collation and analysis both interesting and difficult. However the case study methodology allowed room for those anecdotes to be shared. Ultimately the case study data collection process allowed for an inclusive mechanism to approach and answer the research question.

Retrospective and Prospective

Retrospective and prospective designs are important to establish causality in temporal order.[11] Retrospective design looks back on a specific event or time and reconstructs the data from the community's memories and perceptions. Prospective research follows events as they happen and records the direct and indirect empirical effects from the intervention.

The research examined a single street where the Areiketsetse Le Bana program had been running for one year. The nature of this research topic necessitated looking both retrospectively and prospectively at the community. The community in Soweto that is the

[10] Lynn Davey, "The application of case study evaluations." Practical Assessment, Research & Evaluation. 1991, 21 March 2006 <http://PAREonline.net/getvn.asp?v=2&n=9>

[11] William Axinn and Lisa Pearce, Mixed Method Data Collection Strategies (Cambridge: Cambridge University Press, 2006) 36.

focus of the research began Areiketsetse Le Bana program in November 2005. The research followed the community's progress for one year- through to November 2006. Data was collected retrospectively for those months before the research began. At the end of the data collection period there was a total of twelve months of data. While it would have been fascinating to expand the study for a longer timeframe, the time and cost restraints of the research did not allow for an extended case study. Finally, because the program had only been running for one year, there was no additional information available.

Pre-determined questions provided guidance during the interview sessions. The questions also attempted to establish temporal order – especially surround the process in which the Areiketsetse Le Bana program was developed and implemented on 4th Street, Kliptown. However, I found the process of establishing temporal order extremely difficult. Many respondents had difficulty in accurately stating the sequence of the events surrounding Areiketsetse Le Bana's intervention. This was especially true when working with the community members, although several of the HIVSA staff found some difficulty remembering. Certain events or aspects of the Areiketsetse Le Bana program were remembered, while other aspects were almost completely forgotten. Correctly sequencing events involved repeating variations on the same question several times to the respondents.

Data Collection

The primary methods of data collection employed were semi-structured interviews, direct observations and examination of HIVSA's internal and external documents.[12]

Thirty semi-structured interviews were conducted with members of the community and HIVSA staff. Sixty percent of the interviews were with community members; the remaining forty percent were with HIVSA staff. Within the former group it was critical to correctly represent the community. It was imperative that both gender and generation be accurately represented. It was also essential that the research accurately reflect the perspectives of community leaders and other community residents.

[12] Note: HIVSA documents consulted throughout the research process are listed in the *Works Cited* Annex 1 at the end of this paper.

Interviewees were guided by pre-determined questions that focused on aspects of HIVSA's program relating to the research question. Respondents were asked to comment about their interaction and participation with HIVSA's program. Despite the pre-determined guiding questions, interviewees were strongly encouraged to give feedback that moved well beyond the guiding questions. Most of the interviews resembled conversations, where a dialogue developed between both parties. This method provided clarification into unclear issues and raised additional topics around the research question. Whenever possible, data was verified with other interviewees to ensure the authenticity of the findings.

Direct observation also occurred during frequent visits to the community. Much of it involved watching street residents go about their daily routines. Through this process I struck up conversations with many of the street residents. Conversations were always casual and often initiated by the local people. Similar observation and subsequent conversations occurred in HIVSA's offices. Although the impressions from these exercises were somewhat subjective and not always directly related to the research question, they provided texture and context with which to evaluate the research.

HIVSA was extremely approachable throughout the research process. Through the terms and conditions surrounding the research, interviewees were able to refuse to answer any question. However, the transparency of HIVSA as an organization was extremely helpful to the research process. In addition to allowing interviews with staff and program beneficiaries, they also provided access to many external and internal documents. These proved to be a treasure trove of information on the problems, challenges and accomplishments of the Areiketsetse Le Bana program.

POTENTIAL DESIGN PROBLEMS

Reactivity

One of the primary concerns raised in the case study design is that of reactivity. The single case study provided prolonged and in-depth research into key aspects of the community. The process of data collection was conducted in a way that was as unobtrusive as possible, although the fact that the primary researcher was not only an outsider but also a foreigner may have affected the reactivity of the data collection. (For further information see the section on *Access* below.) Direct observation was done as

unobtrusively as possible, so as to not unnecessarily produce reactive effects within the community.

History and Maturation[13]

One of the benefits of working with the case study design is that if research is done properly, it lowers the problems associated with history and maturation. Within this research, proper case study research allowed for a wide description, taking into account historical factors that may affect the community's reaction to HIVSA's participatory program. In the same way, the establishment of temporal order through the prospective and retrospective designs also controlled for maturation effects throughout the period studied.

Access

From the outset, HIVSA expressed interest in participating in this research project. HIVSA provided un-hindered access to their beneficiaries. After receiving information about the research project, community members were extremely open to share about their experiences with the Areiketsetse Le Bana program, participation and empowerment. However, even given these obvious boons, there were natural issues of access. Natural concerns arose due to the fact that the primary researcher is white and a foreigner. However, the willingness of the HIVSA staff and beneficiaries to work with an external researcher countered many of the natural issues of access.

Language

Working in Kliptown, Soweto, presented situations where it was necessary to use a translator when speaking to the beneficiaries of the Areiketsetse Le Bana program. Many of the beneficiaries in the HIVSA program do not speak English as their first language or were not comfortable answering questions in English. When this was the case, the interview was conducted in the respondent's local language through the assistance of an external translator. However, the conversation often moved back and forth between English and Sotho or Zulu. All interviews with HIVSA staff took place without the use a translator. Staff were completely comfortable conducting interviews in English.

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[13] Greenstein.

As previously stated, participation and empowerment are often ambiguously defined. Although staff and beneficiaries appeared to be relaxed during the interview and comfortably answered questions, they also provided very ambiguous definitions for participation and empowerment.

Mortality and Dropout

For the twelve months covered in the research period, there were births, deaths and movement of individuals in and out of community. While some of these deaths were due to natural causes, many were undoubtedly AIDS-related. Despite both normal population fluctuation and deaths due to the AIDS epidemic, the population remained fairly constant during the period of research. Depending on the length of a case study, movement into or outside of the study group can be a factor that changes research results. Neither HIVSA staff nor community members mentioned significant changes during the 12 months covered in this study or immediately before. Additionally, no births of deaths were reported during the period of data collection. It was deemed that neither the birth and death rates or population migration of the community had a considerable effect on the results of the research. s

Generalization

Despite their strengths, case studies have some potential problems when they are generalized. Like all non-experimental approaches, they are merely describing what is occurring, and have difficulty establishing causality. Second, there is considerable room in case studies for researcher bias to creep in. These concerns are magnified when an ill-trained researcher conducts the study. Despite the findings of this research, I would caution anyone from making any broad generalizations from the research findings until further studies are conducted.

Ethical Issues

The research design involved comprehensive observation and research into potentially sensitive issues. Within South Africa the high prevalence of stigma surrounding HIV/AIDS has been extremely well documented. As with any research involving human subjects, voluntary participation and informed consent from all participants was absolutely critical. The individuals interviewed were made fully aware, verbally and

through written documentation, that their feedback would be used in an in-depth analysis of their community's response to the HIVSA program. The research was also submitted and approved through the University's Ethics Committee.

The essential aim of this research was to understand the effectiveness of participation in empowering members of the Areiketsetse Le Bana program. The descriptive nature of the research examined participation and empowerment in the context of a community critically affected by HIV/AIDS. However, questions and observations remained focused on the strength or weakness of participatory approaches and individual empowerment. Confidentiality and anonymity was guaranteed to all members of the Areiketsetse Le Bana program who were respondents in the study through anonymous reporting.

Although the research was not a specific evaluation of HIVSA, the research worked closely with the staff and organizational policies implemented by the organization. In this case written consent from HIVSA to examine organizational policies and contact program participants and staff was also necessary.

CHAPTER TWO: THE SOUTH AFRICAN AIDS EPIDEMIC, SOCIAL AND HISTORICAL CONTEXT

INTRODUCTION

With estimates ranging from 4.6 to 5.6 million individuals infected with HIV in South Africa, the country maintains a national prevalence rate of approximately 11.4%.[14] AIDS is unique and particularly devastating in that it overwhelmingly afflicts the most economically productive segment of society – the population aged 15 to 45 years old. This creates an acute void within rural and urban labor force.[15] Highlighting the overwhelming burden on South Africa's productive population, an estimated 15.6% of 15-49 year old South Africans, including a disproportionate 17.7% of women, are believed to be HIV-positive.[16]

The South African AIDS epidemic is deeply intertwined with inequalities found across many areas of society. Shula Marks has identified several of factors that influence high-risk behavior of sexually active South Africans. They are: "…impoverishment and disenfranchisement, rapid urbanization, the anonymity of urban life, labor migration, widespread population movements and displacements, social disruption and wars." [17] The scope of these factors has made it exceedingly difficult to respond to South Africa's AIDS epidemic.

This research understands the South African AIDS epidemic as complicated and diffuse. The complex nature of the South African epidemic has resulted in a vast and varied literature. This chapter attempts to condense much of the social history and modern issues surrounding the epidemic. Specifically, the chapter focuses on the migrant labor movement, the urban population surge of the 20th century resulting in slums and townships, gender inequality, as well as the current responses to the epidemic. These factors have also been central to the development of South Africa's modern townships, such as Kilptown, Soweto. South Africa's current AIDS epidemic (as well as other health concerns) cannot be explained without a thorough understanding of the country's social

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[14] Shisana and Simbayi 2002. p. 45.
[15] Ibrahima Coulibaly *The Impact of HIV/AIDS on the Labour Force in Sub-Saharan Africa: A Preliminary Assessment*. Program on HIV/AIDS & the World of Work. International Labour Organization: Geneva, Switzerland. 2005. <www.ilo.org/public/english/protection/trav/aids/publ/rpa3.pdf >. Accessed 6 July 2006. p. 1.
[16] Shisana and Simbayi, 49.
[17] Shula Marks, "An Epidemic Waiting to Happen?" African Studies Volume 61, Number 1, 1 July 2002: 13-26.

and political history. Examining disease through a social lens is a rapidly expanding field, encompassing many aspects of social science and health research. It is critical to understand South Africa's AIDS epidemic within a social model of health and illness.

THE SOCIAL MODEL OF HEALTH

Although sexually transmitted diseases always happen within a social context, HIV has been historically addressed primarily through biomedical interventions. The apparent success - at least in a Western context - of the biomedical tradition leaves little room for a sociological understanding of health and illness. Biomedical approaches isolate specific localized pathological lesions as the cause for illness. "The cornerstone of the biomedical model is the belief that illness can be reduced to pathological lesion, such as an inflammation or a cancer, within the confines of the body."[18] Thus, the isolation and treatment of lesions explained the cause of illness. Proponents of the biomedical approach established a cause and effect relationship between pathological lesions and the disease.

Social scientists began to reject the notion that disease need only be explained by the identification of pathological lesions. Instead, they called for an increased *social* understanding of how disease is spread and how society responds to disease. Friedson argued that "Illness may or may not be based in biological reality, but is always based in social reality."[19] Today, many social scientists identify that the inability to control the spread of HIV is partially a result of the failure of policy makers to effectively understand the diverse social factors surrounding the epidemic. There is growing consensus that a sociological approach to illness provides critical insight to the understanding of illness. The sociological approach to illness offers an alternative paradigm for understanding health.

Initially, the biomedical aetiological framework posited that illness was always caused by biological factors. The medical field could not ignore the merits of this early research. Armstrong wrote, "The traditional medical model was largely concerned with the identifying the immediate biophysical insults that caused disease but could raise no

[18] David Armstrong, "Social Theorizing about Health and Illness," The Handbook of Social Studies in Health and Medicine ed. Gary L. Albrecht, Susan C. M. Scrimshaw, Ray Fitzpatrick (London: SAGE Publications Inc., 2000) 25.
[19] Armstrong 31-32.

objection to an analysis for investigating the social distribution of those same factors."[20] However, early social theorists identified social factors, such as poverty, as major contributors to illness.

Johannes Siegrist identified three paradigms that were developed by social scientists to explain causality of disease.[21] The first attempted to demonstrate that medicine had achieved the legitimate right to define who was ill and who was not; what was biologically abnormal and what was normal. The second framework was based on the concept of heritage - that either inherited traits or learned behavioral practices increased susceptibility to certain diseases. *Exposure and Resource*, the third paradigm, "maintains that society determines the health of individuals mainly by exposing them to specific health-detrimental risks in their social environment."[22] Proponents of this model emphasize that individuals learn to survive in spite of the risks present in their everyday surroundings. Although proponents of the biomedical and the social models initially appeared to take exclusive stances, neither model is complete in itself, and over time, both frameworks have continued to borrow elements from each other to increase their effectiveness.

The elements of biologically based immunity, germ-based disease, psychological stressors and social structure all impact on how HIV is manifested within a population. Whereas the biomedical model was effective towards diminishing the incidence of diseases like polio, the sexually-transmitted nature of HIV and its unique effect on the immune system have necessitated that a blended approach - the psychosocial - approach be adopted to alleviate the ravage of millions.

History and culture have dramatically affected the context in which AIDS has ravaged South Africa. Charles Crothers wisely stated that HIV/AIDS does not easily fit into one area of academic discourse but, rather that, "understanding HIV/AIDS requires

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[20] Armstrong 26.
[21] Johannes Siegrist, "The Social Causation of Health and Illness," The Handbook of Social Studies in Health and Medicine ed. Gary L. Albrecht, Susan C. M. Scrimshaw, Ray Fitzpatrick (London: SAGE Publications Inc., 2000) 100-101.
[22] Siegrist 101.

penetrating to the core of cultural, economic and social structures and the lives people live within these. So mobilizing appropriate social science knowledge is a broad task."[23]

HISTORICALLY UNDERSTANDING AIDS IN SOUTH AFRICA

Through the course of the last hundred years, South Africa's cultural practices have been radically altered. The distinctive combination of migrant labor and urbanization especially since the discovery of minerals in the second half of the 19th century, together with segregation and Apartheid policies created a highly mobile society. Increased mobility, paired with a vastly modernizing[24] population has also contributed to the disintegration of many traditional African practices surrounding sexual behavior. South Africa's social configurations have created diverse conduits through which sexually transmitted diseases and now HIV have spread. Understanding South Africa's sexual networks are helpful in incorporating "a social dimension into research that has, for the most part, focused preciously on the individual (knowledge and attitudes) and on behavior and practices."[25] Thornton argued: "The sexual network, although largely invisible, is unlike the invisible networks that link people in other epidemics. The networks through which the virus flows are not easily disrupted by the public health initiatives, and wealth alone has no impact on its spread."[26] This next section will discuss the vast sexual network that has developed throughout South Africa and through which disease has spread.

The Migrant Labor System

The discovery of gold in present-day Johannesburg created a rush of migrant mine workers to the Witwatersrand. During the 20th century, South Africa became the epicenter of mineral extraction on the continent. The mineral rush resulted in the employment of vast amounts of migrant labor from across Southern Africa in an attempt to extract the country's vast wealth.

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[23] Charles Crothers, "Social factors and HIV/AIDS in South Africa: A framework and summary," Society in Transition (2001) 5.

[24] Urbanization, the wage labor system as well as Western cultural and religious influences had a profound "modernizing" affect on Africans in the late 19th and early 20th centuries. These changes will be highlighted throughout this chapter.

[25] Robert Thornton, Unimaginable Community: Sex, Networks and AIDS in Uganda and South Africa. Unpublished Manuscript (as of July 2006), 25.

[26] Ibid.

The migrant labor industry has probably received an inordinate amount of attention within the country's AIDS dialogue.[27] The danger of overemphasizing South Africa's migrant labor industry as the primary vector in HIV transmission is that it detracts from other contributing social patterns. Just as there is a danger in focusing only on the infectious nature of the virus or the biological drugs to fight the illness, focusing on only one aspect of the South African social structure is similarly perilous.

The diffuse nature of South Africa's AIDS epidemic has made it difficult - if not impossible - for social scientists to pinpoint the agents of transmission. Unfortunately, this has not stopped holding up the migrant labor system as a scapegoat. However, this does not imply that migrant laborers have not assisted in transmitting HIV across South Africa. Their sexual activity and mobility has facilitated the spread of disease - historically and today. It is important to remember that South Africa's migrant labor system had significantly declined in importance when the AIDS epidemic began. However, the legacy of South Africa's migrant labor history is a highly mobile society – one in which disease can easily be spread.

Mobility cannot completely account for the spread of the sexually transmitted diseases throughout South Africa. Instead, South Africa's migrant labor practices helped erode traditional social customs and introduced new practices that led to the destabilization of the population. This facilitated engagement in sexual activity that facilitated the spread of disease. Walker writes:

> The connection between syphilis and migrant labor was not always present. This alerts us to the critical importance of social and cultural factors in promoting or inhibiting the spread of STIs. It must be emphasized that cultural and social factors cannot be totally divorced form material circumstances.[28]

Mineworkers were not permitted to relocate their families to the mines. Instead, mineworkers lived in all-male hostels in close locale to the mines. For much of the 20th

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[27] Leah Gilbert, Terry-Ann Selikow and Liz Walker, Society, Health and Disease (Gauteng: Ravan Press, 2002) 141. & "Mines and Communities" 23 January 2008 <http://www.minesandcommunities.org/Action/press1583.htm>

[28] Liz Walker, Graeme Reid and Morna Cornell, Waiting to Happen (Colorado: Lynne Reinner Publishers/Cape Town: Double Storey Books/Juta, 2004) 65.

century, South Africa's migrant labor system was politically endorsed on the grounds that Africans were unsuited for life in urban areas.[29] Migrant laborers were often isolated from the rest of the population, although this was not always the case. Thus, mineworker's existence became restricted to living and working in the mines punctuated by short periods of return to their rural homelands.

In many cases isolation provided a deterrent to the miners' sexual activity. At the outset, men worked shorter periods of time working within the mines, returning to their homelands several times a year. Initially, there were no women present in mining areas. The absence of women was an early restraint to the spread of sexual transmitted diseases.[30]

Long-term sexual relationships with women from outside the homeland had the potential to weaken laborer's ties to his rural land. The homeboy networks often characterized urban women as 'diseased'. The networks developed colorful stories and songs about laborers who deserted their wives and families for urban woman, only to contract venereal diseases. These values were promoted through the rural circumcision schools. Before heading to the mines, young men were warned of the danger of having sexual relations with urban women. While away from the homelands, mine workers were encouraged to engage in alternative activities to channel their sexual desires, primarily through intercrural or non-penetrative male-to-male sexual contact with other mineworkers. Also, highly emotional ritual dancing was performed as a critical outlet for laborers' desires.[31]

The restraints provided by the homeboy networks and circumcision schools waned overtime. In the 1930s and 1940s a syphilis epidemic that began to spread through the mines and then into the reserves. Walker noted "Promiscuity of this sort fostered the spread of STIs. Venereal diseases in maternity cases at [one hospital] grew from 1% of patients in 1938 to over 20% in 1948."[32]

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[29] Simonne Horwitz, "Migrancy and AIDS: A Historical Perspective" *South African Historical Journal,* 2002.
[30] Ibid.
[31] Walker.
[32] Ibid.

Another contributor to the weakening of the traditional restraints on sexual practices was the growing influence of Christianity. Before the introduction of Christianity, attitudes toward sexuality were markedly open. "In Xhosa society, 'Sexual gratification is valued positively at all ages. Adolescence is seen as a time when sex should be practiced vigorously.' The problem was 'how to allow this without the price of being paid in terms of social disorder… and the impregnation of potential wives.'"[33] In Pedi, Mpondo and Zulu cultures this usually resulted in typically accepted intercrural sexual practices. This process was strictly regulated with strong social and economic consequences for individuals who violated the customs. In Zulu culture, mothers or older women would regularly examine young girls to ensure their virginity was intact.[34]

It appears that initially monitored adolescent sexual inquiry existed alongside Christianity.[35] However, "The onset of puberty did pose societies with the problems of how to cope with a burgeoning adolescent sexuality which could easily result in pregnancy." [36]Delius and Glaser stressed that the growing influence of Christianity reduced the importance of traditional methods of non-penetrative sexual activity among youth. In their view,

> It seems likely that missionary Christianity undermined pre-existing forms of sexual socialization. It led to the dismantling of the forms of youth organizations that had played a key role in this process. It contributed to the abandonment of techniques like limited intercourse that had provided a controlled outlet for adolescent sexuality. And the growing influence of Christian values helped shape an inter-generational silence on sexual matters that became especially damaging as other forms of sexual education withered.[37]

In many cases, any traditional practices opposed to Christianity were removed -- often due to their association with 'devil worship'. However, Christianity offered no additional outlets created for sexual education and/or expression. Sex became an act performed

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[33] Peter Delius and C. Glaser "Sexual Socialization in South Africa: A Historical Perspective," African Studies, 2002: 5
[34] Delius and Glaser, 7-8.
[35] Delius and Glaser, 4.
[36] Delius and Glaser, 5.
[37] Delius and Glaser, 11.

between two people in the cover of darkness, outside of the traditional shaping of behavioral values. Sex retreated to the shadowy corners of traditional African existence.

URBANIZATION

The departure of vast amounts of African males from the reserves and the breakdown of traditional order reduced the incentive for women to remain in the rural areas. After desertion by their husbands and increased poverty, many women migrated to the urban centers with the hope of a better life in the expanding cities.[38] Regardless of their reason for leaving, the departure of many women in the 1930s began the century's massive urbanization movement. Once again high mobility provides a conduit in which sexually transmitted disease could spread.

Despite the massive movement of women towards the cities, some chose to remain in the rural areas. However, the disintegration of traditional practices removed many social safety nets and increased women's' vulnerability. Community networks that had cared for women who were widowed or abandoned had slowly unraveled in the midst of South Africa's social upheaval. These changes depleted rural women's resources. In the rural farming areas women were dependant on men for physical labor and representation in court. In many cases, women's increased vulnerability led them to use transactional sex as a bargaining tool.[39]

Although the white minority government and many traditional African leaders supported the migrant labor system for different reasons, both groups viewed the process of 'detribalization' with serious apprehension.[40] For the state, there was fear that 'modernization' would cause the black population to revolt against the white minority. For some traditional African leaders, detribalization undermined traditional authority. Thus, customary law, the colonial practice of indirect rule, was implemented to allow chiefs control of the indigenous population. Some traditional African leaders and the white minority government broadly supported this policy. As more and more men left the rural areas, women became the primary focus of customary law. "The presence of

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[38] Philip Bonner and Noor Nieftagodien, Kathorus: A History (Maskew Miller Longman (Pty) Ltd, 2001) 4.
[39] Karen Jochelson, The Color of Disease: Syphilis and Racism in South Africa, 1910-1959 (Oxford University D Phil, 1993), 128.
[40] M. Vaughn, "Syphilis and Colonial East and Central Africa: The Social Construction of an Epidemic'" Epidemics and Ideas: Essays on Historical Perception of Pestilence, ed. T. Ranger and P. Slack (Cambridge University Press, 1992).

women in towns encapsulated fears about the consequences of urbanization for African social and family life, and for white control of the African population."[41] In addition, as Delius and Glaser noted, there was a marked increase of sexual violence against young women in the rural communities.[42] This is discussed in greater detail below.

Women started moving into the cities in search of a better way to earn a living. However, employment opportunities for women in the urban areas were extremely scarce. Well into the 20th century, in the cities, only a few African women were employed in the formal sector. Denied legitimate employment, many poor African women turned to the brewing of illegal liquor and entered into transactional sexual relationships as a means of supporting themselves.

In South Africa factors such as the decline of the traditional order, the dominant idealized European values for female behavior, and the legitimate fear of urban centers becoming hotbeds for disease, created a context in which women could be demonized for their role as the conduits of sexual disease was created. "The presence of women in towns encapsulated fears about the consequences of urbanization for African social and family life, and for white control of the African population."[43] Urban crowding and disease outbreaks worried South Africa's white minority rule. As a result, various planning initiatives throughout the 20th century forced many South Africans into racially segregated townships in close enough to the urban centers to provide a labor force but further away than the old locations so as to assert greater control over them.

As South Africa's economy swelled in the mid-1960's thousands of Africans poured into urban townships around Johannesburg. Although many urban housing projects were constructed throughout the greater Johannesburg area, they were woefully inadequate for the burgeoning workforce.[44] As a result huge numbers of squatter camps began to dot the expanding townships. Services, such as schools, also expanded, but they could not keep up with the demands of the students.[45] Urban townships, like Soweto, became representative of South Africa's urban poor in the midst of the anti-Apartheid struggle.

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[41] Jochelson,128.
[42] Delius and Glaser, 11-12.
[43] Jochelson, 128.
[44] Bonner and Nieftagodien, 88-89.
[45] Bonner and Nieftagodien, 68.

It is imperative, that one understand how South Africa's social history helped create a highly mobile and urban population with vast and complicated sexual networks. In urban areas the population was almost exclusively confined to burgeoning townships, often through forced removals of people, such as the area of Dukathole in 1957.[46] Poverty and social dislocation were the hallmark characteristics of black townships, elements that still remain present today. As we try to understand township communities such as the one examined in this research, we must learn how these direct and indirect causes shaped attitudes, ideas and behavior.

GENDER INEQUALITY

Gender inequality has been tantamount to the spread of HIV within sub-Saharan Africa.[47] Women are socially more susceptible to the disease. Gender marginalization has contributed not only to the spread of the disease, but also to how treatment and prevention campaigns have been structured and received. At the time of research, among South African women of childbearing age, 17.7% of women are believed to be HIV-positive.[48] The infection rate makes it appallingly clear that AIDS is having a profound effect on women. The disease etiology also indicates that women are more susceptible to contracting HIV.

"Gender is perhaps one of the most crucial factors contributing to vulnerability to HIV and the impact of HIV/AIDS."[49] Gender defines power roles, and acceptable behavior is defined in part by gendered constructions of sexuality. "Gender inequality in the broader context encompasses all aspects of life, including attitudes towards sexuality, religious beliefs, cultural practices and poverty. These issues have the potential to increase or reduce women's vulnerability to HIV both directly and as mediated through programs."[50] Mane and Aggleton argued that what women know about sexuality is partly determined by gendered constructions of sexuality.[51]

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[46] Bonner and Nieftagodien, 35.
[47] C. Baylis and J. Bujra, "Discourses in power and empowerment in the fight against HIV/AIDS in Africa," in P Aggleton, AIDS, Safety, Sexuality and Risk, ed. P Davis & G Hart (London: Taylor & Francis. 1995)
[48] Olive Shisana and Leickness Simbayi , Nelson Mandela/HSRC Study of HIV/AIDS (Household Survey 2002), 49.
[49] P. Mane and P. Aggelton "Gender and HIV/AIDS: What do men have to do with it?," Current Sociology, November 2001, Vol. 49(6): 25.
[50] V. Tallis "Gendering the response to HIV/AIDS: Challenging Gender Inequality," *Agenda,* 2000, 44: 65.
[51] Mane and Aggelton, 25.

Pelser notes that Africa's gender imbalance to HIV/AIDS must be explained.[52] He also says that women are more likely to be infected at a younger age then men within South Africa. In addition, younger women are also expected to care for relatives who are sick with HIV/AIDS.[53] This statistics suggest that women will be either pulled from the educational system or from productive employment, further increasing their vulnerability.

Thus, poverty and lack of voice increases women's vulnerability to high-risk situations. Pelser wrote that "the epidemic is shifting towards more vulnerable categories of people: young women, ethnic minorities and the poor in particular appear to face disproportionate risks of infection. These are also the categories more likely to be missed by prevention campaigns and deprived of access to treatment."[54] The growing marginalization of African women has created a situation where sex is a commodity used as a bargaining tool. Anne Mager ominously wrote about the mid 20th century, stating, "As fertility lost its value, sexuality gained its importance."[55] This statement remains relevant today, as gender imbalance in both rural and urban environments continues to affect power relations and social and sexual control.

Gender inequality within sexual relationships excludes women from positions of control and decision-making. Although women's vulnerability has been widely recognized, prevention programs targeted at women are often ineffective. Women are usually powerless to negotiate sexual decisions. There is broad consensus that interventions aimed at empowering women through HIV/AIDS programs have consistently ignored the role that men play in the equation. This makes the mainstream prevention methods "beyond what women can apply" within their sexual relationships.[56] The focus on women as underpowered agents with the expectation that increasing their options for preventative measures ignores the reality that women are often unable to effectively negotiate or control their sexual encounters.[57] Tallis argued that an over-emphasis on

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[52] A. Pelser, "The Dynamics of HIV/AIDS in South Africa," Strengthening local government and civic responses to the HIV/AIDS epidemic in South Africa, ed. Van Rensburg et all. (Centre for Health Systems Research and Development) 2002: 20.
[53] Pelser, 25.
[54] Pelser, 20.
[55] Anne Kelk Mager, "The People Get Fenced: Gender, Rehabilitation and African Nationalism in the Ciskei and Border Region, 1945-1955," Journal of Southern African Studies, December 1992 Vol. 18, No. 4: 772.
[56] V. Tallis, "Gendering the Response to HIV/AIDS: Challenging Gender Inequality," Agenda, 2000: 65.
[57] Tallis, 64.

women in HIV prevention campaigns often "adds to women's burden of HIV."[58] With high risk of contracting the disease, indicating that even within socially legitimate relationships, women lack the power to assert control over their bodies and may have a false sense of security about their exposure to contracting HIV.

There is growing consensus that prevention campaigns must target men as well. Foreman declared, "Persuading ten men with several partners to use condoms, sterilize needles or have fewer partners has a far greater impact on the epidemic than enabling 1,000 women to protect themselves from their only partner. The ten men are at the beginning of a chain of infection. The 1,000 women are its last link."[59]

Combating women's social vulnerability to HIV and AIDS is not simply a matter of focusing prevention strategies on men.[60] Interventions must be understood through the societal expectations of what is acceptable behavior for men. Foreman wrote "Men are expected to be physically and emotionally strong, to take risks and to have frequent sexual intercourse, often with more than one partner."[61] Cultural norms that accept polygamy and multiple sexual partners are a challenge to prevention strategies that underneath are really strategies to change cultural norms.

To extend on social expectations for men, in many African cultures, masculinity is defined by high-risk, sometimes violent, behavior. Within Southern Africa, the high-risk behavior by migrant mine laborers has been well documented by Walker and Reid. Their analysis of a study of Basotho migrants working in the gold mines of Carletonville in the 1990s, led them to conclude that these attitudes about masculinity create a social context in which men and their sexual partners are placed at high risk. However, masculinity and male behavior should be understood as varying significantly from culture to culture. Foreman acknowledged this social context when he state, "The problem is less the attitudes of individual men than those of societies in which they live, attitudes which lie at the heart of the epidemic."[62] Perceptions about a society's stability

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[58] Ibid.
[59] M. Foreman, AIDS and Men: Taking Risks or Taking Responsibility? (Panos/Zed Press, 1999) xi-xii.
[60] NOTE: Prevention campaigns have shown that increasing the focus on men should not decrease prevention efforts for gender equality focus for women. Women are still at risk and must be made well aware of that fact.
[61] Foreman, 14.
[62] Foreman, 15..

only add to the complexity about what motivates high-risk sexual behavior. Thus, while an historical cultural norm had accepted multiple sexual relationships within a monitored and prescribed set of guidelines, the instability and denigration that Apartheid practices increasingly imposed upon the majority population – especially the erosion of tightly knit rural communities and the growing poverty among women – helped to increase acceptance of these high risk practices.

An escalation of violence may be linked to the heightened sexual aggression of mineworkers: "On the one hand were notions of 'bravery, fearlessness and persistence in the face of the demands of underground work'... On the other hand was masculine sexuality, which one of the study's informants expressed in a particularly striking sentiments when he observed, 'There are two things to being a man: going underground and going after women.'"[63] Campbell described the experience of mineworkers' powerlessness to protect themselves from the risk of being seriously injured or killed as "an important feature of the contextual backdrop in which miners' sexual identities are negotiated."[64] She continued, "One informant commented that the risk of HIV/AIDS appeared minimal compared to the risks of death underground, and suggested that this was the reason why many mine workers did not bother with condoms."[65] As hazards to mineworkers increased, aggressive attitudes that helped workers cope with the risks in mining spilled over into interpersonal relationships.

Walker contended that the often-fatal danger of mine labor eventually led to high-risk sexual behavior. She argued that although aggressive masculinity was present in the mines from the beginning, predatory sexuality developed much later.[66] As traditional restraints, such as the circumcision-school, disintegrated mine workers began to engage in increasing amounts of transactional sex. Though the causation of the change in values may be disputed, it was only later, through the effects of change over a long period of time, that disease transmission began to occur on a large scale. The urbanization associated with the latter part of the 20th century profoundly affected the social fabric of both the rural and urban communities.

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[63] Walker, Reid and Cornell, 64.
[64] C. Campbell, "Migrancy, Masculine Identities and AIDS. The Psycho-Social Context of HIV Transmission on the South African Gold Mines," Social Science Medicine 1997: 277.
[65] Ibid.
[66] Walker, Reid and Cornell, 65-66.

Development theorists and practitioners have examined female as a *means* of achieving development goals and as an *end* in itself. Women have a greater sense of efficacy or belief in their personal abilities to become involved when they believe that they can make a difference.[67]

Approaches to dealing with HIV must take into account the behavior of individuals within their social context. Prevention strategies for women must understand their ability to effectively negotiate in a sexual context. Prevention strategies for men must recognize the social context in which men are reared and the values and expectations that their social context places upon them.

The resources cited in this paper identify blame casting for those who cause HIV. It is typical of world history to blame disease on others and South African history is not different. Philips wrote that the movement of young men "to and within South Africa…. has long been a key mode of transmission of epidemic diseases in modern South African history…all share the young-man-as-vector characteristic."[68] Philips also stated, that with regard to the AIDS epidemic,

> "It is likely that syphilis, the dominant heterosexual clade of HIV-1 in South Africa, was introduced into the country's interior via a similar men-to-the-mines route. Thus, just as it is believed that the diamond and gold rushes of the late 19th century 'heralded the spread of STDs and endemic syphilis… into the interior' from the coast[69], a century later it was probably migrant mineworkers primarily from Malawi who brought AIDS to the Witwatersrand."[70]

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[67] Joan Wharf Higgins, "Citizenship and empowerment: a remedy for citizen participation in health reform" Community Development Journal 1999: 2-3.
[68] H. Philips, "HIV/AIDS and the Context of South Africa's Epidemic History," AIDS and South Africa: The Social Expression, ed. K. Kauffman and D.L. Lindauer (New York: Palgrave-MacMillan, 2004) 32.
[69] Karen Jochelson, "The Origins of Sexually Transmitted Diseases in Nineteenth and Twentieth Century South Africa and the Development of Racially Segregated Approaches to Treatment," Histories of Sexually Transmitted Diseases and HIV/AIDS in Sub-Saharan Africa ed. P. Setel, M.Lewis and M. Lyons (Greenwood Press, 1999) 219.
[70] Ibid.

"To be able to blame others is psychologically reassuring,' wrote Mary Crewe. '[T]he fact that it is their fault divides 'us' from 'them'. We are innocent, at the mercy of fate; they are guilty and have behaved in such a way as to put us all at risk. We have been invaded from without, polluted by some external agent.'[71] Pelser agreed, noting how men blame women for the spread of HIV and women blame men.[72] Women's lack of control in sexual encounters (and the male's strong resistance against condom use) rooted heavily in culturally related male-dominated society creates a situation where women have a lack of control in sexual situations.[73] Gender has, and will continue to play a critical role in how sexual identities are established. Recent studies have continued to confirm males dominant roles in negotiating sex in South Africa, often with little consideration to their female partners.[74]

CURRENT RESPONSES TO THE EPIDEMIC

In 1990, Chris Hani, senior leader of the African National Congress (ANC) and anti-Apartheid activist, warned that:

> "We cannot afford to allow the AIDS epidemic to ruin the realization of our dreams. Existing statistics indicate that we are still at the beginning of the AIDS epidemic in our country. Unattended, however, this will result in untold damage and suffering by the end of the century."[75]

Despite cautionary tales, HIV has ravaged South Africa. With estimates ranging from 4.6 to 5.6 million individuals infected with HIV, the country maintains a national prevalence rate of approximately 11.4%.[76]

In the mid-1990s, the first ANC government "identified AIDS Awareness as a special presidential project and doubled the budget for combating AIDS."[77] It abolished policies

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[71] H. Philips, "HIV/AIDS and the Context of South Africa's Epidemic History," AIDS and South Africa: The Social Expression ed. K. Kauffman and D.L. Lindauer (New York: Palgrave-MacMillan, 2004) 32.
[72] Pelser, 30.
[73] Pelser, 43.
[74] Walker, Reid and Cornell, 40.
[75] Chris Hani, in a speech to a conference of the African National Congress on Health in Mozambique. (Hani was assassinated in 1993.)
[76] Shisana & Simbayi , 45.; and Dorrington, Rob, Debbie Bradshaw, Leigh Johnson & Debbie Budlender. *The Demographic Impact of HIV/AIDS in South Africa – National Indicators for 2004*. South African Medical Research Council, Centre for Actuarial Research and Actuarial Society of South Africa: Cape Town, SA. 2004. <www.mrc.ac. za/bod/demographic.pdf>. 20.

that violated human rights, such as mandatory testing and segregation of infected individuals. There has been a positive ethos on creating a framework to "live positively." This same spirit was also mirrored in aspects of the private business sector.[78]

Today, the South African government's AIDS policy has been conflictual at best, primarily due to the controversial positions and inaction by President Mbeki and some of his cabinet members. South Africa's Minister of Health, Manto Tshabalala-Msimang, has long opposed antiretroviral treatment for AIDS patients. She resisted "mother-to-child transmission prevention until forced to do so by a Constitutional Court ruling and she resisted the introduction of highly active antiretroviral therapy (HAART) for AIDS-sick people until a cabinet revolt in late 2003 forced her to back down on this as well. Since then, the public sector roll out of HAART has gradually gained momentum, but it has been uneven and continues to be constrained by a marked absence of political will at highest political level."[79]

The current president has actively denied the reality of HIV; its epidemic proportion, its propagation by gender-biased practices, and the willingness to use drug interventions to alleviate suffering. While the arguments presented here point to the complex nature of preventing further infection, the government has consistently denied the benefits of the traditional biomedical model to combat the epidemic.

It is clear from the continued increases in incidence and mortality that the majority of HIV prevention efforts are not working. Most of the current intervention strategies are aimed at changing sexual behavior. The failure of these efforts to stop the spread of AIDS in Southern Africa demands a reevaluation of the current approaches on sexual practices.

Today there is a marked silence surrounding HIV in South Africa by the government, despite the strong efforts by civil society. At the time of his writing, Judge Edwin Cameron is the only African government official who has publicly admitted to being HIV+. This final point must be underscored. Although there are other HIV+ activists within South Africa's history, with many having heart-wrenching stories, Cameron's is a

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[77] Philips, 44.
[78] Philips,45.
[79] N.J. Nattrass, "South Africa's Rollout of Highly Active Antiretroviral Therapy: A Critical Assessment," Journal of Aids, 2006.

lone voice among the continent's government bureaucrats and politicians. Cameron's boldness, despite the stigma surrounding even his privileged position makes his story significant. It should be noted that several other leaders, including former President Nelson Mandela, have admitted that their children have succumbed to the disease.

CONCLUSION

The historical context surrounding the transmission of HIV in South Africa makes it difficult to pinpoint a single vector as the causative factor. Stereotypes, such as those attributed to migrant workers spreading HIV, must be socially contextualized. The epidemic must be seen in its proper context that takes into account social behavior and cultural norms. In this context, the South African epidemic is so diffuse that blame casting is not useful in constructing responses to HIV and AIDS. The diffuse nature of the epidemic has made the South African response extremely difficult to address.

CHAPETER THREE: HANDING OVER THE STICK TO CLIMB THE LADDER

INTRODUCTION

The previous chapter established the diffuse nature of the HIV epidemic within South Africa. Past interventions have been difficult to formulate partly because the epidemic is so complex. State interventions have clearly lacked the local understanding necessary for success. Participatory development may be a useful intervention strategy because it claims to be fundamentally concerned with creating community-driven responses shaped by local knowledge. However, one should not view community participation as a panacea but examine it critically, in light of the real impediments surrounding HIV/AIDS–related development responses.

Participatory development claims to offer an alternative to traditional 'top down' development methods, that empowers individuals and communities. Participatory approaches to development have evolved from the belief that mainstream development is ultimately ineffective. [80] Traditional approaches to development failed to involve individuals and communities to seek appropriate solutions to their own problems.[81] Proponents of participatory development believe that participatory methods engage families and communities to seek sustainable solutions that are informed by the intrinsic knowledge base of the community.[82] To facilitate true change, development practitioners create an environment that allows a "two-way interchange of decision making, views and preferences."[83] Local knowledge is to be put first in development, not just as a way to gather information but also within the implementation of development initiatives. By embracing local knowledge development goals are effectively reached and individuals and communities are empowered.

Over the last seven years, there has been significant evaluation of participatory methods of development. As participation has gained a foothold within the development dialogue, supporters have expanded both the definition and methodology surrounding

[80] Chambers, 2.
[81] Chambers, 59.
[82] Guy Bessette, Involving the Community: A Guide to Participatory Development Communication (Ottawa: International Development Research Centre, 2004)
[83] Ismail Davids, Francois Theron and Kealeboga Maphunye, Participatory Development in South Africa: A Development Management Perspective (Pretoria: Van Schaik Publishers, 2005), 19.

participation. More inflammatory perhaps, is the considerable critique about the participation's effectiveness in realizing development objectives. Some critics suggest that participation might do more harm than good. The lively debate surrounding participation's effectiveness will be discussed in greater detail in the remainder of this chapter.

BACKGROUND TO PARTICIPATORY DEVELOPMENT

In the late 1970s development practitioners sought alternatives to traditional development methods. Development theorist Robert Chambers became the primary evangelist for participation in development through his tales of the successes of programs that relied on the participation of beneficiaries' involvement in the assessment of their own needs. The participation movement became an alternative approach to traditional, "top down," development methods.

Chambers argues that many development practitioners continue to fail to grasp the reality of underdeveloped communities. Chambers attributes some of this failure to reductionism by development practitioners. From the 1950s, development had been characterized by reliance on external expertise to assess the needs of beneficiaries. Early development theory depended heavily upon classical economics. Chambers argues that preoccupation with economic models does not allow for a nuanced understanding of development. Thus, in attempting to solve the problems of the poor, development practitioners may ignore the nuanced reality of the communities. Without local partnership, development practitioners will be unable to grasp local realities.

The participation process itself must be problematized as well.[84]Chambers states that within participation there is an inherent willingness to change or adapt policies through interactions with beneficiaries.[85]Participation is characterized as a dynamic process, rather than something that is static and exact. Chambers critiques the 'culture of precision' that persists in academia. "An overarching problem is that participatory development cannot be planned in this way: its course is not foreseeable; it is not a sea

[84] Chambers, 43-44.
[85] Chambers, xvii.

voyage, nor a Swiss train journey."[86] The localized approach to development thus creates a lack of a "systematized ideology".[87]

Participation in development emerged as tool to bring a local perspective to development projects. Chambers has expanded his definition of participation to "a growing family of approaches and methods to enable local people to share, enhance and analyse their knowledge of life and conditions, and to plan, act, monitor and evaluate."[88]

Consistent throughout Chambers' evolving application of participation in development is a necessary power transfer. To facilitate true change, development practitioners must "hand over the stick" to beneficiaries.[89] Development practitioners look to the beneficiaries for answers, rather than imposing outside assumptions on the people. "Deprivation as poor people perceive it has many dimensions, including not only lack of income and wealth, but also social inferiority, physical weakness, disability and sickness, vulnerability, physical and social isolation, powerless, and humiliation."[90]

Development theorists, such as Heiko Henkel and Roderick Stirrat, argue that the broad adaptation of participatory programs has radically changed mainstream development policy. They write: "It is now difficult to find a development project that does not in one way or an other claim to adopt a 'participatory' approach involving 'bottom-up' planning, acknowledging the importance of 'indigenous' knowledge and claiming to 'empower' local people."[91] A new orthodoxy has emerged, diametrically opposed to the grand, systematized, development interventions of the past.

ARNSTEIN'S 'LADDER OF CITIZEN PARTICIPATION'

Chambers has expanded his definition of participation to "a growing family of approaches and methods to enable local people to share, enhance and analyse their knowledge of life and conditions, and to plan, act, monitor and evaluate."[92] Despite

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[86] Chambers, 43.
[87] Bill Cooke and Uma Kothari Participation: The New Tyranny? (London: Zed Books, 2001) 159.
[88] Chambers, 102.
[89] Chambers, 117.
[90] Chambers, 45. (Beck, 1994)
[91] Heiko Henkel and Roderick Stirrat, "Participation as Spiritual Duty; Empowerment as Secular Subjigation," Participation: The New Tyranny, ed. Bill Cooke and Uma Kothari (London: Zed Books, 2001) 168.
[92] Chambers, 102.

Chamber's highlighting the merits of participation and detailed application of participation, he fails to comprehensively define participation. His descriptions do not fully encompass the range of participatory configurations. The fault is not with Chambers alone; throughout the field of development, the term participation is used ambiguously. This ambiguity has often led to poorly structured development programs.

Sherry Arnstein's early work may be helpful in this process. As participation was entering into the mainstream dialogue for planners, government officials, and development workers in the 1960's, Arnstein developed a helpful model for understanding citizen participation. Her design, called "The Ladder of Citizen Participation," presents eight categories of citizen behaviour, ranging from non-participation to participation.[93] Though developed initially as a tool for planners, her detailed mapping of participation has become a seminal aspect of participatory development.

The transfer of power or active empowering assumes a central position in Arnstein's analysis. Power holders are consistently present throughout Arnstein's model. Individuals or groups may claim power for social, political, historical, generational, or gendered reasons. Power is practised through a range of institutional actors, which may include government officials, non-governmental organization (NGO) workers, health care workers, and religious or lay leaders.

As one approaches the higher rungs of the ladder of participation, the level of empowerment increases. True participation cannot happen without the transfer of power. "Without redistribution of power [participation] is an empty and frustrating process for the powerless."[94] Arnstein argues,

> Informing citizens of their rights, responsibilities, and options can be the most important step toward legitimate participation…emphasis is placed on a one-way flow of information – from officials to citizens – with no channel provided for feedback and no power for negotiation. Under these conditions, particularly when information is provided at a

[93] R.S. Arnstein, "A Ladder of Citizen's Participation," Journal of the American Institute of Planners Vol. 35: July 1969 217.
[94] Arnstein, 216.

> late stage of planning, people have little opportunity to influence the programme designed for their benefit[95]

Arnstein divided the ladder's rungs into three main categories of non-participation, degrees of tokenism, and citizen power. The bottom two rungs are labelled *Manipulation* and *Therapy.* These rungs are used to either 'cure' or 'educate' people, however no real participation happens. With manipulation, participatory language is used as a ruse to gain popular support but any decision-making process still remains with the power holders. Therapy is based upon the belief that powerlessness is equated with mental illness: "What makes this form of 'participation' so insidious is that citizens are engaged in extensive activity, but the focus of it is on curing them of their pathology' rather than changing the racism and victimization that create their 'pathologies.'"[96] Although Arnstein classifies therapy as the second rung on the ladder she states that it may offer the greater affront to human dignity.[97]

The next three rungs *Informing, Consultation,* and *Placation* are classified as 'degrees of tokenism'. Arnstein calls informing an important initial step in creating true participation, though she cites several examples of when information only flows from those who have power to those who do not. As the rest of the chapter explains, the reality that may development programs revolve around a one-way information flow is one of the strongest critiques of participatory development. Like informing, consultation can also be helpful but is often conducted with less than pure intentions. Although consultation involves information gathering about attitudes, problems, and/or hopes, the individuals are rarely aware of the context surrounding the information gathering process. Arnstein provides an illustration taken from several urban areas in the United States:

> Survey after survey has 'documented' that poor housewives most want tot-lots in their neighbourhood where young children can play safely. But most of the women answered these questionnaires without knowing what their options were… Had the mothers known that a free

[95] Arnstein, 219.
[96] Arnstein, 218.
[97] Ibid.

> prepaid health insurance plan was a possible option, they might not have put tot-lots so high on their wish lists.[98]

Although consultation is a higher rung on the ladder of participation, Arnstein points out that this degree of participation "offers no assurance that citizen participation and ideas will be taken into account."[99] *Placation* is the inclusion of a few select powerless individuals within a coalition of powerful individuals. Placation often happens when organizations are forced to integrate a participatory element into programs. Here as well is an inherent power imbalance. The select powerless can usually be outvoted by the powerful or are under represented due to the inability to effectively articulate their position.

In the instance of *Partnership*, the powerful and powerless work together. Within the project, program, or committee there is power sharing. This rung is most effectively accomplished when the less powerful are highly organized and articulate. *Delegated Power* exists when the less powerful can effectively hold leaders accountable for their actions. Although this is moving towards citizen control, individual delegate their power others. At the very top of the ladder is *Citizen Control.* Broad application of this last scenario is quite rare, although within individual projects it is often used. Within citizen control, the least or the have-nots manage the entire job of planning, policymaking and/or program administration.

Throughout this paper Arnstein's "Ladder of Citizen Participation" will be employed as a reference point for evaluation of participation and a categorized definition. When assessing HIVSA, research observations will be categorized according to Arnstein's model. In the same way, participatory literature will be evaluated by Arnstein's model.

CRITIQUES OF PARTICIPATION

Chambers and others have presented an ongoing and dynamic internal critique of participation's methodology. One might compare Chambers to a mechanic tinkering with a car engine: he is always looking for better ways for economically and socially marginalized peoples to participate in their own development process. In *Participation: The New Tyranny,* editors Cooke and Kothari progress beyond the methodological

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[98] Arnstein, 219.
[99] Ibid.

shortcomings of participation. Instead, they present challenges to participation as a development approach. Their work is a cautionary tale that highlights both the ineffective and, at times, oppressive nature of participation. Despite the lofty goal of empowerment through participation, as outlined by Chambers, this is rarely achieved and is often masked by alternative goals and top down control.

Cooke and Kothari feel that the wide application of participation in development demands a thoughtful critique. "We came to realize that the very difference of public and private accounts of participatory development was in itself a cause for concern."[100] Although their essays encompass a broad range of critiques, three fundamental challenges to participation emerge from the text.[101] Firstly, is the "tyranny of decision-making and control." This brings into question how the process of participation, as outlined by Chambers and others, may interfere with existing decision-making processes within the communities. Instead of being helpful and empowering, participation may simply get in the way. Secondly, the authors present the "tyranny of the group." Concerns are raised that the hierarchical dynamics of a group may not give voice to the less powerful in the group. For example, in societies where much importance is attached to older males, group dynamics may not adequately encompass younger females' needs and perspectives. Thirdly, Cook and Kothari explore the "tyranny of the method," where the book examines how reliance on participatory approaches ignores other approaches to development.

All three challenges offer meaningful critique to participation and it's application to development. While, the challenges are helpful in understanding concerns and potential pitfalls in using participatory development tools, none of the critiques completely undermine participation's importance. The critiques serve as important caveats, both for Chamber's theory and it's application, like HIVSA's program.

EMPOWERMENT THROUGH PARTICIPATION

Because of the disempowering nature of HIV and AIDS, empowerment is an important aspect of AIDS care. Like participation, it is important to look at empowerment as a *means* of achieving other goals and as an *end* in itself.

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[100] Cooke and Kothari, 2.
[101] Cooke and Kothari, 7-8.

Joan Wharf Higgins writes, "Citizens who participate in community organizations often feel more empowered or have a greater sense of control than non-participants even before embarking on the participation experience. These citizens have a greater sense of efficacy or belief in their personal abilities to become involved when they believe that they can make a difference."[102] Development consultant Jo Rowlands has attempted to synthesize empowerment literature together to create a concise definition:

> In the context of the conventional definition, empowerment must be about bringing people who are outside the decision-making process into it. It is about individuals being able to maximize the opportunities available to them without or despite constraints of structure and size… It is concerned with the processes by which people become aware of their own interests and how those relate to those of others, in order both to participate from a position of greater strength in decision-making and actually to influence such decisions… Empowerment is more than simply opening up access to decision-making; it must also include the processes that lead people to perceive themselves able and entitled to occupy that decision-space.[103]

The research will utilize Rowland's definition of empowerment. Her definition is helpful because it acknowledges the importance of both collective and individual empowerment. It also recognizes that empowerment can be a means of realizing development objectives and a legitimate end to improving the wellbeing of an individual or community.

EMPOWERMENT OR DISEMPOWERMENT?

Even the vocal supporters of participatory development recognize the power structures always exist and that these power structures can directly support or detract from the participatory process. Critics are sceptical at the way in which power relationships can significantly change the nature and form of participation. The differences between development practitioner (who can be viewed as an "outsider") and recipient ("insider") can create a major unbalance in power relations, which participatory development may or may not be able to hurdle. Beneficiaries may be more likely to make decisions that

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[102] Higgins, 2-3.
[103] Jo Rowlands, "Empowerment Examined," Development in Practice, May 1995: Volume 5.

please, or that they hope will please, the development practitioner. Arnstein's idea of informing is important to recall here, especially with the often one-way flow of information, from powerful to powerless.[104] However, even Arnstein's detailed model presents a fairly specific situation about power relationships. Her writings in the 1960's about power and participation in urban planning initiatives within North America are relevant to a discussion of South Africa today but must be applied very cautiously. The situations are remarkably different.

Hildyard, in an article entitled *Pluralism, Participation and Power,* presents a chilling critique of community participation informed by his observations in India:

> Not only does consultation tend to be desultory, but even where meetings are held, the voices of the people rarely appear to be listened to. Local people become a ghostly presence within the planning process – visible, heard even, but ultimately they are only there because their involvement lends credibility and legitimacy to decisions that have already been made.[105]

Some critics fear that participation will be used as a form to legitimize the pre-determined decisions made by development practitioners. If participation only continues to encourage dominance of one group over another, then participation may be doing more harm than good. Participation may only be top-down dominance imposed from the bottom-up. There has been widespread support for local expertise in solving some of the technical issues of development.

> The genealogies and histories of development in general, and participatory practices in particular… further explicate how a misunderstanding of power underpins much of the participatory discourse. This identification of the (mis)interpretations of how and where power is expressed within participation compels us to reconsider the notion of empowerment, and the claims to empowerment made by many participatory practitioners. Since an understanding of the concept of

[104] Arnstein, 219.
[105] Hildyard N. "Pluralism, Participation and Power: Joint Forest Management in India," Participation: The New Tyranny? ed. Bill Cooke and Uma Kothari (London: Zed Books, 2001) 59.

> empowerment is based on particular realizations of its root concept, 'power', and since this, as some of the chapters in this book argue, has been simplified in the theory and practice of participation, the meanings ascribed to the condition of empowerment and the claims made for its attainment for those who have been marginalized must also be subjected to further scrutiny.[106]

COMMUNITY

Difficulties also arise in defining the term community. Many development practitioners have assumed that a community is a homogenous entity and thus participation by members of the community means equal representation. Critics fear that the less powerful in the community will be overlooked. Thus "by not recognizing that knowledge is produced out of power relations in society and through practitioners' acceptance of 'local knowledge' as some kind of objective truth, participatory methodologies are in danger of reifying these inequalities and of affirming the agenda of elites and more powerful groups."[107] Therefore, development practitioners must revisit what *community* means. Guijt and Shah, in their book entitled *The Myth of the Community,* state:

> In many cases where participation has been pursued something is going wrong. Despite the stated intentions of social inclusion, it has become clear that many participatory development initiatives do not deal well with the complexity of community differences, including age, economic, religious, caste, ethnic and, in particular, gender. Looking back, it is apparent that 'community' has often been viewed naively, or in practice dealt with, as a harmonious and internally equitable collective. Too often there has been an inadequate understanding of the internal dynamics and differences, that are so crucial to positive outcomes. This mythical notion of community cohesion continues to permeate much participatory work, hiding a bias that favors the opinions and priorities of those with more power and the ability to voice themselves publicly.[108]

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[106] Cooke and Kothari, 14.
[107] Cooke and Kothari, 146.
[108] Guijt and Shah "The Myth of the Community: Gender Issues in Participatory Development," Intermediate Technology Publications (London: 1998) 1.

South African sociologist Belinda Bozzoli offers some assistance in problematizing community. In her introduction to *Class, Community and Conflict,* Bozzoli writes: "Few words have wider currency than that of 'community' in South Africa today."[109] Unlike other terms that express social group identity, community is most often viewed in a positive light. "The good connotations of 'community' rest in its ability to conjure up images of supportiveness; of a place of kinship ties, of rest and rejuvenation; of cross-class cooperation. However, the myriad uses of the term, the vagueness with which it is approached, and the romantic connotations which it holds, make it all the more mysterious as a concept."[110] Borrowing from the work of Benedict Anderson, Bozzoli suggests that communities are the fabrications of intellectuals. They are useful tools in theorizing about a group, although the group's identity may be imposed from the outside.

Participatory interventions rest heavily on a community mobilized towards action. Participatory literature assumes that there are shared goals and ideals within the community. The realization that community is a widely used, highly disputed and oft-romanticized concept must be integrated into the critical analysis of participatory interventions.

PARTICIPATION: A COST-SAVING MECHANISM?

When empowerment in participatory development is lost, or sidelined what else do we have? Some might argue that participation greatest success is its ability to be used as cost-saving mechanism. If this is indeed the case, then the widespread adoption of participatory tools with development over the last 15 years demands some investigation. The World Bank has traditionally been known for it's top down approaches to development. And yet the World Bank has increasingly integrated participatory development into their policies and programs.[111] "Indeed judging from the Bank's 1997 *World Development Report,* such support exists within the more influential quarters of the World Bank for participatory approaches appears to derive not from a concern for the

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[109] Belinda Bozzoli, ed. Class, Community and Conflict: South African Perspectives Braamfointein, South Africa: Ravan Press (Pty) Ltd, 1987) 4.
[110] Ibid, 5.
[111] Participation and Civic Engagement, 2 February 2006. <http://web.worldbank.org/WBSITE/EXTERNAL/TOPICS/EXTSOCIALDEVELOPMENT/EXTPCENG/0,,menuPK:410312~pagePK:149018~piPK:149093~theSitePK:410306,00.html>

democratic rights of local people but from a perception that participation helps save on 'transaction costs' of projects."[112] While a pragmatic approach to development is fine, one must ask what sort of effect this will have on the nature of participation? If the goal of participation is to save money, then what effect will that have on empowerment and power transfer? Why do empowerment and participation so often get lost in the midst of competing ideas? Perhaps it is best to return to Chambers for his answer. He writes: "Putting the first last is harder. For it means that those who are powerful have to step down, sit, listen, and learn from and empower those who are weak and last."[113]

CONCLUSION

Participation is radically restructuring how individuals and communities interact with development. In providing the need definitional critiques of participation, Arnstein's "Ladder of Citizen Participation" is extremely helpful. Not all behavior or programs that are labeled as participatory effectively engage individuals in participation. Thus, this research will approach programs labeled as participatory with considerable caution. On Arnstein's ladder, the rungs falling under non-participation and degrees of tokenism will not be included as true participation. Only the top three rungs- *partnership, delegated power,* and *citizen control* are truly participatory.

Critiques of participation are helpful in examining the nature, form, and character of participation. Specifically, this research addresses the issues raised by participatory development's critics. They are helpful in providing a rich and detailed analysis of participation. They specifically address issues of power and control, cost saving, and problematize the concept of empowerment.

Despite the potential for negative social outcomes, few critics are completely against beneficiary involvement in his/her own development. Even Cooke and Kothari, who remain the strongest critics of participatory development, are still optimistic. They admit the undeniable benefits to democratic decision-making and the sharing of ideas and knowledge.[114] However, critics play an important role in developing a nuanced understanding of the participation in development.

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[112] Cooke and Kothari, 59. (Citing the 1997 "World Development Report" World Bank, Washington, DC.)
[113] Chambers, 2.
[114] Cooke and Kothari.

CHAPTER FOUR: THE AREIKETSETSE LE BANA PROGRAM

INTRODUCTION

In November 2005 a humanitarian organization called HIVSA developed a program called Areiketsetse Le Bana. Working with a single street, the program works to alleviate the suffering of communities affected by HIV/AIDS by providing access to social grants and identification documents. In addition Areiketsetse Le Bana provides street residents with important training in parenting skills, food garden creation and HIV/AIDS health-related care. Community members play an integral part within this process. The program is run in the peri-urban communities of Kliptown, Devland, and Freedom Park. This research focuses on Fourth Street, Kliptown, a location where the Areiketsetse Le Bana has been running since the program's inception.

A NOTE ON THE RESEARCH DESIGN AND DATA COLLECTION PROCESS

It should be noted that the data outlined within this chapter was gathered through a series of conversations with people in a manner that tried to embody the very best aspects of participatory research. Participation in development is deeply concerned with local peoples' attitudes, feelings and concerns. Research participants were consulted about their own ideas and attitudes about HIVSA and their community.

It may be helpful to mention how the use of semi-structured interviews is an attempt to reflect the "give and take" that participation in development seeks to provide. In Chapter Three we discussed Chamber's evolving model of participation, where there is a "two-way interchange of decision making, views and preferences"[115] involving both development practitioner and development beneficiary. In semi-structured interview data-collection methods the informant and the researcher also share critical roles. The informant has key information about a specific subject, but the manner in which that information is extracted and contextualized by the researcher is also important. The leading questions provided in the data collection process sought to engage participants in providing information relevant to the research topic. However, the open-ended nature of the questions also gave ample opportunity for informants to shape the dialogue in

[115] Ismail Davids, Francois Theron and Kealeboga Maphunye, Participatory Development in South Africa: A Development Management Perspective (Pretoria: Van Schaik Publishers, 2005), 19.

their own manner. Most of the responses informants provided were clearly linked to the Areiketsetse Le Bana program in the community. As often happens in conversation, there were also tangents explored that did not always appear to be "on topic." When this was the case, my research assistant and I worked extremely hard to sleuth out links to the research questions and topics. Needless to say, some of the information provided was certainly linked more tenuously to the program or to community participation. However, in an attempt to share the mood of the research experience and the perspective of the residents of Fourth Street, Kliptown with my readers, I have included much of the additional dialogue in the next two chapters. I have chosen to expatiate only on responses more directly linked to my research question and literature review.

This approach, I hope, provides a more nuanced understanding of the Fourth Street community, their participation and empowerment and attempts to create a true two-way interchange of ideas. The responses and analysis recorded in the following chapters are an imperfect but wholehearted attempt to connect, to understand and to illustrate the responses of a community quite different from that of the researcher.

KLIPTOWN: YESTERDAY AND TODAY

As one of the oldest communities in the township of Soweto, Kliptown bears a unique history. In the early part of the twentieth century, black South Africans were forcibly moved to this area, after present-day Newtown in central Johannesburg was burnt to the ground in a government sanitization effort. Initially established as a tented camp, the township was divided into African, Indian and colored areas. Soon brick houses and shacks began to dot the landscape and replace the tents. During Apartheid this multi-racial community withstood many forced removals.[116]

In 1955 (the very same year that women's pass laws were successfully implemented) the African National Congress signed the Freedom Charter in Kliptown's center. The charter declared, as first among its principles, "South Africa belongs to all who live in it, Black and White". This document became the basis for which South Africa's constitution was based upon. Today, the place where the Freedom Charter was signed has been commemorated by the Walter Sisulu Square of Dedication.

[116] Philip Bonner and Lauren Segal, Soweto (Maskew Miller Longman (Pty) Ltd., 1998)

At the time of this writing, Kliptown retains much of its early multiculturalism. This is evidenced in the vast daily market at its center. Throughout Soweto people travel to Kliptown during the day to buy and to sell. Goods from throughout Africa can be purchased in the bustling market. The area's history of multiculturalism makes it a place where immigrants from surrounding countries can more easily begin a new life in South Africa.

In 2005 columnist Neil Fraser provided this colorful description of Kliptown life:

> Most are unemployed. During the day, they walk the streets, talking, gambling, and shopping. They meet outside Lucky's Shoe Repairs or the sangoma's shop to gossip; they wash or rebuild cars at Bob's Place with pickings from the scrapyards. Life is lived on the streets as much as possible. Houses that front the promenading Main Street are prized observation spots from where one can greet and meet acquaintances and do deals. The typical Kliptown front stoep doubles as a living room, complete with sofas and orange-crate seating and within hailing distance of neighbors.
>
> The living room is a hair salon, grocery shop and advice centre. Homework, committee meetings and soccer spectating take place around the kitchen table. Hospitality is a celebration of the neighborhood 'superfamily', given and received with no formality. Guests simply arrive and take part in whatever is going on - cooking, eating, repairing the door lock, throwing a screed, peering under the scrap car's bonnet.
>
> Kliptown is a great example of the best use of public space… the streets are not just used as thoroughfares "but as common ground for public life".[117]

Fraser's commentary on Kliptown is quite vivid, though perhaps slightly idealized. Although it correctly states the energy present within the community, it misses much of the essence of the community. Despite it's rich history, most of Kliptown stands in contrast to Soweto's burgeoning development. A large number of informal dwellings crowd the area – despite government housing programs. Scant plumbing and sewage

[117] 12 February 2007 <http://www.joburg.org.za/citichat/2005/june27_citichat.stm>

infrastructure means that much of the community depends on portable toilets that line the street. At the time of data collection, Kliptown has no schools or recreational areas.

The South African government has identified Kliptown as a site for a regeneration program. A budget of R439 million has been set aside for the area's economic renewal. Currently, low-income housing is being constructed to deal with the problem of overcrowding in the squatter camps.

The research focused on the community of Fourth Street, Kliptown. Located near the train tracks, Fourth Street boasts five or six permanent dwellings visible from the street. These houses seem grand next to the perilous looking shacks that peak out from in-between them. The road is dirt; cavernous ruts flowing with weeds, trash, and murky water punctuate the broad ridges of hard-packed clay. When it rains these tiny streams re-adjust their course, changing the road's topography.

A large Zionist church stands sentinel at the top of the street, beckoning residents to a seemingly endless succession of prayer services. Although almost dark within, one observes men and women of all ages packed into the pews and standing in the aisles and even at the windows. Many of the unemployed find solace within the arms of the church.

At first glance the street seems quiet. In the absence of a passing train, a tinny radio purrs a tribute to the late singer Lebo Mathosa. A few people gather at the larger of the two tuck shops and an elderly woman ambles down the road advertising hot fat cakes. However, a quick venture into the recesses behind the houses reveals a hidden world. Humble shacks made of corrugated aluminum, plywood and plastic sheeting seem to spill against each other in a struggle to expand. Strung with rags and brightly colored laundry, narrow alleys chaotically wind between the shacks.

The dwellings are teeming with people. Women engage in the seemingly endless task of clothes washing. A pot of porridge might simmer on an outdoor stove, although most eat bread. Throngs of dirty children and a mangy dog play. A baby cries. Here the air is thick with the smoke of wood burning fires and kerosene. None of the shacks have electricity or running water.

Men sit in groups under the shade of a tree or in the quiet darkness of one of the buildings. Although unemployment in Soweto is close to 50% it feels like it might be much higher.[118] Soft laughter filters from a group as a carton of home-brew or a cigarette is solemnly passed from member to member. There is peacefulness in their somber ritual – as though they have accepted that life has beaten them. Though they smile, their eyes look listless.

THE CREATION OF HIVSA

The Perinatal HIV Research Unit (PHRU) was established in 1996 to study mother-to-child HIV transmission. The PHRU works in conjunction with the University of the Witwatersrand and is based in Soweto at the Chris Hani Baragwanath Hospital. Today the PHRU has expanded to lead studies on many different aspects of medical and social HIV research.

Six years later, HIVSA began as an initiative of the PHRU. HIVSA acts as the psychosocial arm of the PHRU. As stated on their website: "HIVSA's aim is to enable HIV infected and affected people to build resilience through an innovative community-based program, thereby encouraging them to reach their full potential."[119]

HIVSA desires communities to seek solutions that mitigate vulnerability by lowering the stigma around testing, practicing safe and responsible sexual practices, encouraging access to anti-retroviral treatment, and ensuring that the community has access to local governmental and non-governmental services.[120]

HIVSA's broad portfolio of programs offer psychosocial support to people living with or affected by HIV/AIDS in Soweto and the Bohlabela district of Limpopo Province. They include children's camps, food garden programs, men's health initiative and the Areiketsetse Le Bana program. There is a specific focus on meeting the needs of children and helping households do so.

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[118] John Murphy, "Some rise but most sink in Soweto's sea of slums" Baltimore Sun 6 October 2002. <http://www.baltimoresun.com/news/printedition/bal-te.soweto06oct06,0,1711288,full.story>
[119] 5 January 2008 <www.hivsa.com/hivsa/index.stm>
[120] Ibid.

CREATION OF THE AREIKETSETSE LE BANA PROGRAM

Before establishing Areiketsetse Le Bana, HIVSA had been operating camps attended by children from Soweto, including Kliptown. The camps offered hundreds of at risk children a positive form of recreation, while providing a thoughtful venue for AIDS education and empowerment. Despite the success of the camps, HIVSA desired to create an additional, more comprehensive approach, to meet the needs of Soweto's children.

Kliptown became a major focus of a joint Save the Children and HIVSA assessment. Kliptown's Fourth Street was chosen for the pilot program of Areiketsetse Le Bana based on the magnitude and variety of needs. One of the HIVSA staff said that Fourth Street was the worst of all of the streets surveyed. However, it should be noted that there are very few child-headed households on Fourth Street; most orphans live with members of their extended family.

HIVSA approached several donors and in January 2005, the humanitarian organization - Save the Children Norway/Zimbabwe - requested that HIVSA develop a community-based program with an annual budget of US $100000. Together, the donor and HIVSA conducted a baseline assessment of at-risk communities Soweto and Limpopo. Data was collected from parents and caregivers through questionnaires and one-on-one interviews. They also facilitated focus groups attended by important community and religious leaders, children and teachers- all separated by cohort.

Although the questions primarily focused on the needs of children, HIVSA recognized that programs that brought parents and the community into the process were more successful. Due to HIVSA's experience working in Soweto they assume that most of the population is affected or infected by HIV, thus they did not seek to quantify this through the survey.

Four primary themes emerged from the survey:

- There were extremely high levels of poverty in the areas surveyed, of which children were the most vulnerable.
- Many adults and children lack birth certificates and/or government issued identification documents.

- Individuals eligible for government support programs (e.g. disability grants or school fee bursaries) do not receive them because they lack official identification.
- Child-headed households and orphans are especially vulnerable to economic shocks because they lack identification documents.

Because of HIVSA's specific focus on the needs of children, the data collected was interpreted in light of children's needs. HIVSA staff developed a model to explain how children's development is threatened and vulnerability is caused. The model lists six situations that could threaten child development and increase vulnerability. The South African government has created a situation where children's vulnerability can be mitigated through the provision of need-based child grants. These services require both the child and the parent or guardian to have government issued identification. As a result, the provision of these identification documents and obtaining of need-based grants is a major focus of the program.

However, HIVSA realized that the provision of grants and ID documents for children and their parents or guardians is not enough. Parents need education on how to care for their children and to mitigate their own risks, thus equipping them to give their children proper care. Education programs must be targeted to address household-specific issues.

There are many grants available through South Africa's Department of Social Development. These include, but are not limited to, foster care grants, child support grants, emergency grants, old-age grants and disability grants.[121] Throughout the past few years, South Africa has decentralized the process for obtaining such grants, partly through the creation of offices within high poverty areas, such as the township of Soweto. Within South Africa, grants provide significant assistance to the poor and largely unemployed community. This social safety net ensures that children, the aged and disabled don't fall through the cracks. Despite efforts by the South African government to make grants increasingly more accessible, many individuals are unable to access the grants due to incorrect or nonexistent personal documentation.

[121] Department of Social Development, 23 January 2008 <http://www.socdev.gov.za/>

Michelle Schorn, Director of HIVSA's Adolescent Psychosocial Support Programs, began to develop a program to link people to critical services. The new program, called *Areiketsetse Le Bana*, allows intensive focus on a single community. Within this context, a street demarcates a community, representing between 250 and 600 inhabitants. The original design suggested that HIVSA staff would help community residents obtain the proper identification documents and enroll them (if eligible) in government support programs. HIVSA's in-depth knowledge of the communities would provide a natural link for the introduction of HIVSA's other programs and those of other civil society organizations.

Michelle said that the program design relied heavily upon Maslow's hierarchy of needs: primary needs such as food, shelter and safety must be met before one can pursue higher needs such as education and self actualization. Thus, the program first focuses on the provision of identification documents and social grants. After these needs are addressed, the community's educational program could begin.

However, when the donor scaled down the annual funding to just US $65000, Michelle needed to cut the program costs without sacrificing content. She decided that if the community played a greater role in obtaining identification documents and grants, the program could run with significantly less staff. Michelle was somewhat aware of Soweto's Apartheid-era history of Street committees. Street committees were established in townships across the country as a counter to the undemocratically constituted Black Local Authorities.[122] The latter were perceived as tools of the apartheid government and therefore not representative of people's wishes. Street committees were established as alternatives by creating vehicles 'people's power', in which ordinary citizens, street by street, were supposed to participate actively on matters that directly affected their daily lives. These issues ranged from dealing with domestic disputes (wife battery or infidelity) to disputes between neighbors to community wide political issues. In the midst of the oppression of Apartheid, the street committees governed areas where black South Africans were able to exert control over their day-to-day affairs. ANC hero Walter Sisulu said about Street committees "There is a growing tendency for the ungovernability [of Apartheid-era townships] to be transformed into elementary forms of

[122] Bonner and Segal, 1998.

people's power."[123] At their height street committees were regarded as representing ideal forms of participatory democracy.

Working from this knowledge, Michelle decided that communities should self-select leaders, called Street Guardians, who act as the liaison between HIVSA, partnering organizations and the inhabitants of the street. HIVSA would give Street Guardians rigorous training to assess their community's needs and help their neighbors access government services, such as need-based grants. By utilizing community members HIVSA could cut costs and possibly revive a piece of Soweto's unique history.

HIVSA's senior staff initially identified participation as an essential cost-saving tool but as the program took shape participation became one of the primary components of Areiketsetse Le Bana. Participation allowed communities to join together to fight AIDS as a common enemy, just as communities had drawn together to fight oppression during the Apartheid regime. HIVSA's decision to integrate community members into their own development process aligns with the global movement towards greater beneficiary participation.[124]

One can't move forward without briefly acknowledging the caveats that begin to show themselves in the initial design. Michelle proposed the integration of participation not because of it's success as an "industry best practice" but because of it's cost saving characteristics and perhaps to a lesser extent because of the historical cache that it brought to the Areiketsetse Le Bana program. The primary goals of the program were determined by outsiders. Initially, at least, the program was developed in a way that ignores local knowledge inherent within the community to shape policy that is grounded in the concerns and the desires of local people. Although the program design was developed only after the initial assessment was done, the program utilizes a framework for understanding and prioritizing human needs developed by an outsider.

And yet the Areiketsetse Le Bana was born. In the Sotho language, Areiketsetse Le Bana means "Let us do it for ourselves and our children." In that spirit, Areiketsetse Le

[123] Cowell, Alan. "Blacks in South Africa Now Seek Local Power" New York Times 1 April 1986.

[124] For a more detailed discussion on the adoption of participatory principles into development practice, please refer back to Chapter Three.

Bana seeks to empower community members to play a critical role in the process of their own development. The program's vision statement is: "We will reduce the effects of HIV and AIDS on the lives of children through collaboration with the community and other key stakeholders." The program's mission statement is: "We are committed to improving the lives and well being of children in the greater Soweto area. We will accomplish this by: teaching communities how to access resources that are already available within the communities, establishing a network of support services and assistance among the community members themselves, compiling a user friendly referral system/data base, peer education work shops."[125]

The objectives of the program are to:[126]

- Contribute to decreasing the impact of HIV and AIDS on the everyday lives of children from birth and youth up to 18 years
- Increase the proportion of orphans and vulnerable children accessing basic social services
- Reduce high risk behavior amongst children and youth up to 18 years
- Develop an effective and user-friendly referral system within the community to best meet the needs of local people
- Increase the number of community supported initiatives for orphans and vulnerable children in target areas.

By increasing access to government issued social grants, HIVSA seeks to create a safety net for the residents of Fourth Street. For a community that probably has a high HIV prevalence rate, this program allows families to provide for their children and prepare for the future.

After Areiketsetse Le Bana was established in Fourth Street in November 2005, the program has been rolled in other communities throughout Soweto. Further streets have been identified through the initial survey and through other HIVSA programs and partnering non-governmental organizations. At the time of writing there are a total of eight streets participating in the Areiketsetse Le Bana program: five streets in Kliptown

[125] HIVSA document 4 November 2006.
[126] It should be noted that these program objectives were created by HIVSA, based on the information gathered through their baseline survey. The community of Fourth Street did not play a direct part in the development of these objectives.

and three in nearby Devland and the informal settlement of Freedom Park, also in Soweto.

Fourth Street was chosen as the focus for this research because it has the longest running Areiketsetse Le Bana program. HIVSA staff also claimed that Fourth Street residents have greater participation than other streets.

KEY ACTORS WITHIN AREIKETSETSE LE BANA

The actors in the Areiketsetse Le Bana program operate at three distinct levels: The HIVSA staff, including those work out of the Baragwanath and Kliptown offices, Street Guardians and street residents. Despite these divisions there are overlapping roles and responsibilities.

HIVSA Baragwanath Staff provide oversight to HIVSA's portfolio of programs, including Areiketsetse Le Bana. This office attracts operational funds and works with the Areiketsetse Le Bana staff to set a budget for the program. It also provides Areiketsetse Le Bana with promotional materials and accounting services.

Working from their office in the center of Kliptown, the Areiketsetse Le Bana staff identifies and manages the streets participating in the program. They provide critical training to Street Guardians, teaching them how to help community members obtain birth certificates, identity documents, immunization cards, need-based grants, pensioner grants and unemployment funds. As necessary, they write letters to relevant government agencies requesting documentation on behalf of program members. They also facilitate relevant training workshops for community, based on the community's specific needs. The two team leaders provide managerial support. The three field workers are assigned to several streets. Although the job responsibilities require a fair amount of independence, most staff members work together when possible.

There is a general willingness by the HIVSA staff – and especially those that work on the Areiketsetse Le Bana program – to work in a collaborative manner. Although all of the staff have had at least a high school education, they have see themselves very much as insiders. They greet the older women in the communities they work in as "auntie" and approach the younger street residents as friends. Also, Michelle's leadership style is

extremely lateral. One can see that she works very hard to maintain an approachable persona; she is open to feedback and critique from her field workers. Many decisions about the Areiketsetse Le Bana program (including funding and program design) are made in an extremely collaborative manner. In the meetings that I attended at Areiketsetse Le Bana, Michelle shared information and the much of the decision making process with her staff. She acknowledged several times throughout our conversations, the importance of program staff shaping the Areiketsetse program. Thus, the way the Areiketsetse Le Bana office is run could be described as participatory.

Street Guardians assist street members in obtaining birth certificates, identity documents, immunization cards, need-based grants, old-age grants, and unemployment funds. The Street Guardians also identify households and individuals throughout their community requiring school uniforms, school fees, and food parcels. They provide the link between the street residents and the HIVSA staff.

Street members work to access identification documents, grants and attend meetings and workshops facilitated by both the community and the Areiketsetse Le Bana staff. Street members also elect the Street Guardians. The election process is described in greater detail below.

The majority of street residents who participate in the Areiketsetse Le Bana program are women. Although men hold other positions of leadership in the community, residents primarily view Areiketsetse as a women's group. One of the two Street Guardians dryly remarked, "Few men have attended. Young men don't come unless there is food." There are very few men in the community, some are off at work and others are looking for work. Those that are present, are in their homes, watching others perform household tasks and sitting around with other men. A HIVSA staff member described men's behavior of smoking and drinking as 'escapism' from the real issues affecting their well-being.[127] It should be noted that although men rarely become active members of Areiketsetse Le Bana, they often benefit – albeit indirectly – from the program. Men benefit, however, when their wife or mother or child obtains a government grant or other assistance through the program. Grants either lessen their burden to provide or help to line their pockets.

[127] Interview with HIVSA staff member conducted on 10.26.06

STRUCTURE OF THE AREIKETSETSE LE BANA PROGRAM

From the initial introduction the community is made aware of the services that Areiketsetse Le Bana can offer the community. Based on their specific needs, the street members identify programs that they would like to see integrated into their community. Because needs differ between communities, the Areiketsetse Le Bana program takes on markedly different characteristics in each community. Areiketsetse Le Bana welcomes this diversity.

This is how the Areiketsetse Le Bana program begins in a community: Staff members begin to raise awareness about the Areiketsetse Le Bana program through word of mouth and through written invitations a few days before hosting an informational community meeting. During this time Areiketsetse Le Bana staff often get to know community members and identify needs based on verbal questionnaires addressed to street residents. On Fourth Street, most members recounted consistent stories about the introduction of the Areiketsetse Le Bana program. A typical story would go like this: "Before the first workshop they gave us invitations. They also went house-to-house two days before the workshop. On that day HIVSA explained themselves to the community.**"** A few Fourth Street members did not receive an invitation or did not attend the initial informational meeting. However, membership within Areiketsetse Le Bana is open to all who reside on the street. HIVSA indicated that there was some interaction with existing social structures and leaders prior to the intervention through HIVSA's baseline assessment. The data collection process didn't reveal any interaction between HIVSA and other community resources at the time of this research.

Informational meetings often happen on Saturdays. Theoretically, this allows for better attendance by community members because fewer people are at work. Usually attendance for such a meeting is very good. (In a community such as Fourth Street, Kliptown, very few people are formally employed.) Attendance for the informational meeting on Fourth Street was very good. HIVSA estimated that almost half of the adult population showed up for the initial meeting. Typically, people pour out for such a meeting- with some eager to receive the services provided by Areiketsetse Le Bana and a few hecklers. This latter group is most often composed of those who have had interactions with humanitarian organizations that have made empty promises. It should

be noted that these meetings almost always have food. This is often a huge attraction for street residents.

As in many small communities, information travels very fast through word of mouth. Those who have already heard about the program have informed their neighbors about the services Areiketsetse Le Bana can bring to their street. Still Areiketsetse Le Bana staff spend significant time explaining the scope of the program. They explain that Areiketsetse Le Bana connects community members to government social services and runs a series of training workshops. It was also clear through the interviews with staff members that the baseline assessment conducted by HIVSA in Kliptown previous to the implementation of the Areiketsetse Le Bana program helped spread they news throughout the community about HIVSA.

Many members of the street may not have any government issued identity documents, such as birth certificates, identity documents, and immunization cards. Not having any of these documents may prevent community members from accessing government-related services. A parent who does not have proper identity documents will have difficulty obtaining identification documents for their children. Sometimes the problem of documentation goes back several generations. These document's importance makes obtaining them a critical aspect of the program. Once community members have obtained proper identity documents they will have a much easier time accessing government services. The types of services would include (although are not limited to) enabling community members to access Old-Age Grants, Unemployment Insurance Fund (UIF) grants, child-support grants (given to primary care givers and guardians), or any other sort of need-based grant for which the community member might be eligible. In addition Areiketsetse Le Bana helps school children obtain school uniforms and access free meals for children 0-18.

The brief story below is an excerpt from an Areiketsetse Le Bana program report. Mpho's story is typical for Soweto.

In Kliptown there is a 14-year-old girl called Mpho. She fell pregnant and was abandoned by her boyfriend. She lives at home with her mother who is unemployed and was unwilling to assist her with caring for her child. Since she was only 14 years old she did not qualify for obtaining an identity document (you have to be 15 years old to apply for an identity document). Without an identity document she could not apply for a birth certificate for her baby. This then excluded her from applying for a child support grant. She was forced to give up school and stay at home to take care of her baby.

After she was enrolled onto the project, staff was able to negotiate with the department of home affairs on her behalf. The department of home affairs then made a concession and allowed her mother to apply for the birth certificate on her behalf. The department of social services then also allowed the mother to apply for a childcare support grant on her daughter's behalf. This then allowed Mpho to pay for her child to attend a local day care centre and return to school. She now feels that she has a chance at a real future for her and her baby.[128]

Street Guardians play a primary role in helping community members navigating the bureaucracy in obtaining government services. During this introductory meeting, Areiketsetse Le Bana staff explains to the street members that they must self-select community members to serve as Street Guardians. HIVSA encourages the community to choose leaders that are representative of the street through both age and gender. Anyone can be nominated and elected. The general trend seems to be to elect women over men as the Street Guardians. This is most likely because Areiketsetse Le Bana is composed primarily of women. Fourth Street's, Street Guardians are literate, which has made their job significantly easier. One of the Street Guardians is an older women, generally well-respected with a depth of experience. Research respondents described her as "trustworthy". The other Street Guardian is a younger woman. She was also spoken about in the highest regard. She was described several times as capable. Her brisk and efficient manner certainly conveyed a sense that she would help to get things done. In other communities where the Areiketsetse Le Bana program is running, HIVSA has enrolled non-literate Street Guardians an adult education program. HIVSA staff informed me that this was critical so that Street Guardians could assist other residents in accessing services.

All community members who attend that initial meeting are eligible to nominate and vote for the Street Guardians. A few angry members of the community accused Areiketsetse

[128] HIVSA Program Report, June 2006.

Le Bana of not allowing members of the community to vote if they did not have IDs. Their story was discounted through several sources. It seems that these individuals had tried to obtain official identification documents but were unable to access them for a variety of reasons, all outside of the control of HIVSA, and were very angry.

After being elected the Street Guardians go through a rigorous training on how to help their neighbors access government services. The training focuses on how to navigate the various government departments (Home Affairs, Social Services, Education, etc.) and how to assess the needs of a community. Initially, the training period lasted for five days, for a period of two to three hours. Now the training has been condensed into two days, although Areiketsetse Le Bana is considering lengthening it again. Generally, Areiketsetse Le Bana and HIVSA staff seemed willing to adapt program methodology if there is a better way to do things.

After their training, the Street Guardians begin the collaborative process of assessing their community's needs. Areiketsetse Le Bana staff builds relationships with community members primarily through the Street Guardians. The Staff's role is to support the Street Guardians.

The Areiketsetse Le Bana staff offers the following training workshops to street members:

1. **Community Emergency Response Team (CERT):** The Johannesburg Fire Department offers this training program. It runs for four days a week for an entire month. The program focuses on basic First Aid and safety.

2. **Parenting Skills Workshop:** This three-session workshop is run in conjunction with the Family Life Association, a local non-governmental organization.

3. **Food Garden Workshop:** HIVSA Staff runs this five-session workshop over a two-week period. The workshop focuses on soil preparation, sustainable planting, watering, composting, and basic nutrition. Participants are provided with seedlings to start their own food garden.

4. **HIV/AIDS Information-Hour:** Areiketsetse Le Bana staff runs these eight, two-hour sessions twice a week. The training focuses on HIV prevention, treatment, dealing with opportunistic infections, human rights, positive living, nutrition and AIDS care.

The ultimate goal for HIVSA's Areiketsetse Le Bana program is get all eligible street members to obtain proper identification documents and social grants. In addition, the program works to expose street members to the knowledge from the training workshops. It is difficult to assess the effectiveness of the training component of the Areiketsetse Le Bana program. Community members who had attended cited the sessions as helpful and interesting. However, HIVSA staff lament that getting good attendance for the sessions has been quite difficult. Fourth Street has been seen as successful because a majority of the eligible residents have received these services.

PARTICIPATION ON FOURTH STREET

There are several distinct forms of participation happening within Fourth Street, Kliptown. However, it is important to understand that not all street members participated equally. Some of the residents participation in every possible avenue. On Fourth Street this includes the two Street Guardians as well as a few other residents. The rest of the Fourth Street Areiketsetse Le Bana members participate in one or two of the venues for participation as facilitated by Areiketsetse Le Bana.

CONSULTATION

Consultation, as defined by Arnstein, was the first form of Areiketsetse Le Bana-facilitated participation on Fourth Street. It is also one of the most widespread ways in which residents can participate. This form of participation initially occurred through HIVSA's assessment of the Fourth Street community. After the initial meeting, Street Guardians and an Areiketsetse Le Bana staff member visited most houses on Fourth Street to better understand the needs of the community. It was not clear why some houses were not visited. Household needs were noted by the Street Guardians and were met- as provided under the Areiketsetse Le Bana program model.

HIVSA's initial assessment of the community, as well as the later assessment by the street guardians, results in a knowledge transfer that is a form of participation. Both

Areiketsetse Le Bana staff and Street Guardians learned key information about the community and it's members through this process. The Street Guardians were clearly empowered through their participation in this knowledge transfer. They cited that it was helpful for them to understand Fourth Street's problems as systemic throughout their community, as opposed to seeing them as isolated events.

However, the street residents participated in an entirely different way. Residents were consulted about their needs, with a specific focus on identification documents. Although Arnstein rightly notes that consultation "offers no assurance that citizen participation and ideas will be taken into account"[129] those who were consulted generally feel as though HIVSA did respond to their needs. Interviewees appreciated the time and the effort that HIVSA staff and Street Guardians took to understand what was really happening on their street and helped to craft a program that responded effectively to those needs.

Arnstein cautions that if individuals providing knowledge are not often aware about how information might be used.[130] She says that consultation also provides the informers with "no assurance that citizen participation and ideas will be taken into account."[131] Within the context of Fourth Street, the residents were very cognizant of what was going on as they provided information to HIVSA staff and Street Guardians. Their awareness was primarily due to HIVSA openness. Most residents felt that their needs were addressed by HIVSA intervention.

Critics of participation suggest that "local knowledge" gathered from insiders is not always indicative of what people want or need. Instead, individuals provide information based upon what they perceive that "outsiders" can provide.[132] In the case of Fourth Street, residents may be pleased with the outcome of HIVSA's program only because that is what they believed it was feasible for HIVSA to give them.

It should be noted that several interviewees expressed dissatisfaction that they were not consulted enough. One 26 year-old widow and mother of two stated: "Even though I am the mother, I am not involved… they come and find the size of the children, and bring

[129] Arnstein, 219.
[130] Arnstein, 219.
[131] Ibid.
[132] Cooke and Kothari, 8.

the uniforms. We don't see them. I don't have direct connection with them… nor [do I know] what week [HIVSA] are coming." This is a very important critique of the form or participation that HIVSA used. This woman clearly felt isolated from the process and felt that HIVSA and the Street Guardians were muscling her into doing something without her full-consent, let alone participation. However, it is important to view the negative responses in context. Street residents often dismissed other residents critiques of the program because their had been misunderstanding or additional issues going beyond the focus of the Areiketsetse Le Bana's program. Typically, the response of the community was very positive toward the program. HIVSA staff acknowledged that not every community member were always happy with their services, although most were.

PARTICIPATION IN TRAINING WORKSHOPS

In this participatory appraisal of the community, the staff and Street Guardians learn important knowledge about street residents. The opposite happens through the training workshops HIVSA sponsors within the community. Within the training workshops, key information is passed from the staff of Areiketsetse Le Bana to the street members.

On Fourth Street, HIVSA has offered the "HIV/AIDS Information-Hour", "Food Garden Workshop", and "Parenting Skills Workshop". At the time of this writing, they have not offered the Johannesburg Fire Department's "Community Emergency Response Team Workshop." Generally, the Areiketsetse Le Bana staff cited Fourth Street's attendance at these workshops as good. Forty-two street members attended in the "HIV/AIDS Information-Hour" workshops. Twenty-two street members attended the "Food Garden Workshop". Eleven members attended the "Parenting Skills Workshop."

The research showed that there was greater attendance by the younger residents at HIVSA-sponsored trainings. Staff members shared that the youth were typically more willing to attend the workshops. Staff thought they culturally the older street members seemed less comfortable in talk about issues of sex and sexuality in the "HIV/AIDS Information-Hour". Staff cited that older street members were resistant to attend the parenting and food workshops because they felt that they cast doubt on their ability to care for their families. However, when street residents were asked why they did not attend trainings they simply said they were too busy.

Although the training sessions on Fourth Street were very well attended, it is important to understand that in this case attendance does not mean that residents actually integrated the information into their lives. Throughout the interviews, many of the street members mentioned that they and their neighbors often went without food, a poignant reminder about the overwhelming unemployment and poverty throughout the community. The reoccurring phrase that community members used was to “sleep without food”. And yet, twenty-two Fourth Street members had attended the food garden training. The informants who had attended the workshop said that the training was very helpful. They said that in the future they hoped to have a garden. However, very few of the attendees have actually ever planted a garden of their own – despite the training and the free seedlings provided by HIVSA. In fact, only three Fourth Street members are currently gardening to provide their own food. The gardens planted on Fourth Street are both beautiful and bountiful. The three women who tend their gardens are able to share some of the produce with others in need. Michelle Schorn, stated that she has found that street members have a hard time seeing the long-term benefits of a garden, despite enjoying trainings. In other streets where the Areiketsetse Le Bana program is running, implementation of the food garden training has been somewhat more successful.

It should be noted that some Fourth Street members may have been less inclined to plant gardens by the fact that some street members received food parcels from other humanitarian organizations. The households that received food parcels were identified as needy through the Areiketsetse Le Bana staff or Street Guardians. The provision of these food parcels was certainly not a regular occurrence, although there seems to be common knowledge throughout the community that food parcels were distributed to some of the street members.

When asked how they participated in the Areiketsetse Le Bana program most street members responded that they participate through attending the training workshops. Respondents overwhelmingly referenced participation through attendance of the training workshops even if they were also involved in a more active manner – as many of the respondents were. Several respondents referenced attendance of the training workshops as participation even though they had never actually attended a workshop. Still, in their mind at least, participation equaled attendance.

HIVSA's training workshops might perhaps be best understood in light of the unfolding understanding about how knowledge is used in participatory development. Both insiders and outsiders have critical sources of knowledge. If good participation involves a two-way "interchange of knowledge",[133] then HIVSA's information sessions provide an important vehicle for HIVSA to share information about services and build skills and knowledge. With this said, the discussion of the previous chapter has already shown us that knowledge transfer alone does not result in a high level of participation.

PARTICIPATION THROUGH ACTION

By far the most active way in which Street Guardians and residents can interact with the Areiketsetse Le Bana program is by obtaining of identification documents and/or government grants. Street Guardians are encouraged to teach other Fourth Street residents to acquire identity documents and/or government grants without the direct help of HIVSA. Program staff are able to assist Street Guardians as necessary, however the community members themselves do the bulk of the work. Practically, HIVSA sees this as a way that community members can participate in their own development process.

HIVSA provided the following outcomes for the Fourth Street community:

- 25 birth certificates
- 13 identification documents
- 1 unemployment fund grant
- 3 disability grants
- 10 child-support grants
- 19 school fee exemptions
- 18 school uniforms
- 2 enrolled in school
- 1 orphan in crèche
- 1 certificate amendment (ID amendment)
- 2 disabled put on home based care services
- 20 orphans put on feeding scheme

Although the figures reported do not clearly show how many people were actually helped, HIVSA estimated that about 60 or more individuals were assisted through the

[133] Davids, Theron, Maphunye, 19.

program. The research questions didn't quantify the amount of people assisted either, although 60 individuals is probably an accurate number.

It should be noted that some individuals' only interaction with the Areiketsetse Le Bana program was through being helped to obtain an ID or grant but did not attend any meetings, including the initial consultation. There where members of the community interviewed who remained completely un-involved in the program leadership and consultation but still benefited materially from the program. One woman stated that she knew hardly anything about Areiketsetse Le Bana (nor did she want to) but that she was happy that her daughter had somehow received support through this program. Most of these uninvolved individuals speak very highly of the program, although they are clearly not interested in being involved in any sort of hands-on manner.

When Street Residents were asked if they thought that working to obtain the grants and IDs was participation, most street residents said that they didn't think it was. Although very few of the community members saw obtaining identification documents or grants as participatory, they may be participating and not fully realizing it. Robert Chambers expanding definition of participation encompasses locally inclusive ways "to plan, act, monitor and evaluate."[134] Residents of Fourth Street have played a part in the planning of the Areiketsetse Le Bana program, especially in identifying the community's needs. The program design allows the street residents, led by the Street Guardians to play an active role in participating (or to use Chamber's term "act") to find solutions to their needs. This process fits within the empowerment dialogue as well because by learning how to get their grants and IDs individuals are "being able to maximize the opportunities available to them."[135]

Most of the people who got grants themselves are very happy. Here is the story of one young woman interviewed in the data collection process:

> "When HIVSA first came to our street I thought it was a joke. I thought these people [Street Guardians and HIVSA staff] were board and just wanted to waste my time by asking me questions. But then I saw that

[134] Chambers, 102.
[135] Jo Rowlands, "Empowerment Examined," Development in Practice, May 1995: Volume 5.

> people were being helped. [At the time] I felt so bad because I didn't get help for anyone. No one was working. I was struggling. It was so hard. And then they taught me how to get a birth certificate for my child and obtain a social welfare grant. They also taught me that life can change for the better."

Her gushing account is the sort of story one might find in a donor report. The individual not only received the birth certificate and grant but also learned to get these items by herself. Undoubtedly, life has changed for the better for her and her child. Arnstein however, always stresses the importance of a *power transfer* in true participation. Thulani Makoba, Team Leader for the Areiketsetse Le Bana program, said:

> In the township- no matter where it is- people become proud when they participate. We created Areiketsetse Le Bana because we want people to be proud. We want people to say that *I* got my ID myself… By participating we have taught them to catch their own fish.

The Areiketsetse Le Bana program is certainly giving communities like Fourth Street the skills and knowledge so they can do things for themselves. As the name implies, Areiketsetse Le Bana, means to do it for yourself and your children. Residents are helping the program live up to its name.

However, there is no clear power transfer in this process. As one approaches the higher rungs of the Ladder of Participation, the power transfer should grow greater.[136] The transfer of power is a critical part of true participation, as defined by the theory. If a power transfer is absent here, then what kind of participation is happening? People are learning to help themselves, although this action is outside of the high level participation set forth by Chambers and Arnstein. When we look at what HIVSA is actually saying about the Areiketsetse Le Bana program, what they are calling *participation* seems a lot more like *self-help.*

Perhaps participatory programs without clear power transfers – programs that do not allow those at the bottom to hold the reigns - simply become self-help programs?

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[136] Arnstein, 216.

A CONTINUING KNOWLEDGE TRANSFER

It is important to note that although not every street member attended training workshops or went through the process of obtaining a grant or identification document, street residents shared the information obtained through the Areiketsetse Le Bana program throughout Soweto. Every day the HIVSA Kliptown office receives calls and visits from those who desire Areiketsetse Le Bana to come to their community. During my interviews at the Kliptown office, HIVSA received such calls. Street residents also share knowledge gathered through the Areiketsetse Le Bana program with others. For example, Fourth Street residents who have learned how to access IDs and grants through the Areiketsetse Le Bana program have shared that same information with people outside of Fourth Street. Information sharing isn't a rung on Arnstein's Ladder of Participation. However, she would probably tag this sort of participation as fairly low level because it fails to result in a power transfer. It lacks the weight that comes from a transfer of power from one person to another. It does however, transfer knowledge from one group to another.

ADDITIONAL FORMS OF PARTICIPATION

There are additional important forms of participation that exist within Fourth Street, Kliptown that should not be discounted. It seems that aside from the meetings that Areiketsetse Le Bana has facilitated, some of the community members have also held their own meetings. As far as the research could tell, these meetings work in a complementary fashion along with the Areiketsetse Le Bana program. Although not organized by Areiketsetse Le Bana, street members seem to think that additional meetings allow the community to discuss other important issues. These meetings might suggest dissatisfaction with HIVSA, although it seems as though they act in a way that supplements the Areiketsetse Le Bana program. One issue that has been discussed several in several meetings was that of safety. Another important form of participation is the volunteering by street members in a children groups and crèche. The crèche happens twice weekly and the children's group happens just once a week.

These latter issues reference and undercurrent of community led participation and empowerment happening on Fourth Street. As has been said earlier, many street residents were unsure of what empowerment means or were unable to identify it in their

own lives. However, by setting up childcare, child education and community meetings a handful of Fourth Street residents are creating something that is very unique. Higgins states that: "Citizens who participate in community organizations often feel more empowered or have a greater sense of control than non-participants. These citizens have a greater sense of efficacy or belief in their personal abilities to become involved when they believe that they can make a difference."[137] In this situation, Fourth Street residents are getting involved in something they believe they can make a difference in. The focus within their community meetings on neighborhood security may be because they feel as though they can actually make a *difference* in their community.

One elderly woman provided an enthusiastic report about the change elicited within Fourth Street. This respondent has had less than two years of formal education and now spends her days caring for her husband who has been paralyzed by a stroke. She said the following: "The program has brought people together. Before [Areiketsetse Le Bana] people used to keep their problems to themselves… now they speak to others about their problems." She is not alone in her enthusiasm for the program. Many feel as though the program has breathed new life within this poor community. People in Fourth Street speak about how they are now more "aware of their own interests"[138] because of HIVSA's initiative. It may be that one of the lasting legacies of the Areiketsetse Le Bana program is that it has acted as a catalyst for community led participation on Fourth Street

[137] Higgins, 2-3.
[138] Jo Rowlands, "Empowerment Examined," Development in Practice, May 1995: Volume 5.

CHAPTER FIVE: FURTHER ANALYSIS

INTRODUCTION

Hopefully, the previous chapters have given adequate background and context to begin analyzing the information gathered through the data collection process. Chapter Two provided a broad overview of South Africa's social history as it relates to HIV and AIDS. Chapter Three established the ongoing dialogue and debate surrounding participation and empowerment within development theory. The data and presented in Chapter Four provides descriptive information of a localized example of a participatory-based program. This final chapter seeks to investigate the form, scale, nature, and character of the participation and empowerment happening within Fourth Street, Kliptown in light of the literature explored through this research. Specifically, the chapter explores participation and empowerment by an examination of the locality, the program and the community's engagement in the Areiketsetse Le Bana project. The chapter also looks briefly at the sustainability of such an endeavor.

PARTICIPATION IN PROGRAM DESIGN

As has been stated before, participation was integrated into Areiketsetse Le Bana's design, by HIVSA staff as a cost-saving mechanism. HIVSA staff have cited participation as a fundamental aspect of the Areiketsetse Le Bana program design. One might understand the participation facilitated by the Areiketsetse Le Bana's program as happening in almost an *accidental* manner. Michelle Schorn, Director of HIVSA's Adolescent Psychosocial Support Programs and primary architect of the Areiketsetse Le Bana program, was only colloquially aware of the Soweto's history of street committees. Michelle was also unaware of the primary dialogue about participation in development facilitated by Chambers and others. Despite HIVSA's lack of understanding of the scope of participation used in development, it would be incorrect to think that Areiketsetse Le Bana was completely isolated from the trends within development. Participation has swept the development field by storm – preaching the gospel of empowerment through participation.[139] Had Areiketsetse Le Bana been developed ten years before, participation might not have taken such a central role in the program's structure. Perhaps the donor might have been less willing to accept a 'participatory solution' to a

[139] See Chapter Three.

paired down (or cost effective) development intervention. In this way the 'accident' can be partially explained by the paradigmatic shift in current development dialogue.

The Areiketsetse Le Bana program design is not static. Within HIVSA there is a pragmatic approach to program design and management. Led by Michelle, the staff continually assessed the Areiketsetse Le Bana program in an attempt to implement the program in a more effective manner. Despite their limited knowledge about their history, Soweto's Street Committees are viewed as an important and relevant legacy to develop responses to today's problems. Throughout the research, HISVA staff identified participation as a critical component of the program's success. As a result, participation will most likely remain a critical part of the Areiketsetse Le Bana program as long as it continues to be seen as central to the program's success.

It is imperative that the research looks critically at the types of participation – or supposed participation – facilitated by the Areiketsetse Le Bana program. Several key questions arise; especially surround how HIVSA defines participation and the way in which participation is practically integrated into Areiketsetse Le Bana. This will be addressed in greater detail later in this chapter.

PARTICIPATION, EMPOWERMENT AND HIV/AIDS

The second chapter of this research report attempted to provide a very concise social history of the epidemiology of HIV/AIDS within South Africa. It should be noted that a comprehensive study of this topic is far beyond the scope of this research project. However, this chapter does focus on South Africa's current health dilemma because HIV/AIDS has become a central concern and barrier to development. The history presented in Chapter Two is helpful in understanding not only the public health and poverty vortex that many South African's find themselves in, but also because these same challenges present a fascinating and often difficult context for participation to be implemented. The latter is most strongly exhibited in the discussion surrounding the dis-empowerment that is brought about through the HIV/AIDS dilemma. These challenges are as true for Kliptown as for any other peri-urban township within South Africa. Admittedly, there could be numerous additional lenses through which participation could be examined in South Africa. For example, a purely political history of Kliptown or Soweto could also provide a helpful localized understanding of participation in this

community. For the sake of this research paper, the discussion surrounding South Africa's encounter with HIV/AIDS has provided more than enough to discuss.

It is important to note that there are some significant assumptions made in the research report about how *affected* Fourth Street is by HIV/AIDS. As stated in the previous chapter HIVSA assumed that most of the population was either affected or infected by HIV, although this number was not actually verified. The various restraints placed upon my research, including both ethical concerns and the current social climate, did not allow me to confirm this assumption. Thus, the report moves forward based upon HIVSA's educated guess and national and regional projections about the magnitude of the pandemic and it's relevancy to Fourth Street, Kliptown.

One ongoing theme within South Africa's development dialogue has been how the AIDS crisis and the socio-historic context have dis-empowered many individuals, especially women. The description of the community members and setting in which the research was conducted has been an attempt to contextualize, as much as is possible, Fourth Street, within the broader South African problem. The individuals encountered through the data collection process were primarily unemployed women who are extremely vulnerable at a variety of levels. The lack of identification documents is a telling reminder of how these residents are outside of the radar screen of the government. Most are unemployed, surviving on informal trading. Contextualizing these individuals within the historical analysis provided in Chapter Two shows a problem with national ramifications that has continued for generations.

Despite clear concerns for the vulnerability of the residents of Fourth Street, Kliptown, the social leveling provided by the Areiketsetse Le Bana program has been admirable. Given the magnitude that gender, and to perhaps a lesser extent generation, effect South Africa's current conversation about HIV/AIDS, my analysis of Kliptown would be woefully deficient without a discussion of the interplay between these issues and participation on Fourth Street. The data collection interviews with staff, street guardians and street residents sought in part to determine whether age or gender provided more or less access to participation in HIVSA's Areiketsetse Le Bana program. In the case of the Fourth Street, Kliptown, the leaders who emerged, and the individuals who became most involved in the Areiketsetse Le Bana program are not the typical power brokers. Within

Areiketsetse Le Bana, women strongly participate in the meetings and obtaining of grants. The program has provides an opportunity for involvement and a voice for individuals who may be marginalized within society.

In this sense, the intervention by HIVSA *does* empower. The Fourth Street residents active in the Areiketsetse Le Bana program are individuals who might otherwise be marginalized or voiceless within their community. In the case of Fourth Street, Kliptown, the colorful and varied responses of residents (and not just street guardians) show a marked change, not only in their physical or material situation (by obtaining grants) but also in the way they speak about the control they have received in their lives as a result of the HIVSA intervention. The process of engagement in HIVSA's program allows residents to be more hopeful about their future or that of their children. Also residents express that they might also play a role in determining their own future for themselves or their families. One example of this is a young woman in her late 20s who sells cigarettes and crisps to her neighbors. She says: "Before [the] Areiketsetse Le Bana program we were just sitting around. I was sitting at home; now I have respect. I can do something about myself."

UNDERSTANDING STREET GUARDIANS

The Street Guardians play a pivotal role in the design of the Areiketsetse Le Bana program. Of all the street residents, Street Guardians are clearly the most engaged in the program and in helping community members link to services. They also provide an important "voice" to HIVSA from the street residents. The community-selected Street Guardians act as a liaison between HIVSA and the community. They provide that critical connection between the back and forth knowledge transfer. Both parties have critical knowledge for the development of the community.

An important issue that could affect how others participation throughout the program is the Street Guardians themselves. First, it is important to consider how one might wonder if the gender of the Street Guardians effects the depth of their impact. The two female Street Guardians are certainly making an impact within the primarily female Areiketsetse Le Bana members of Fourth Street. However, the program might look entirely different if one (or both) of the Street Guardians were male. Age is much less of an issue on Fourth Street. Within Fourth Street, the two Street Guardians are of different ages – one young

and the other middle-aged. In most group dynamics, clear and consistent leaders do emerge from groups. This simple observation is often missed within Chamber's reveries about the leveling powers of participation. Strangely, this oft-observed social rule is not a central theme of the critiques about participation. The critics of participation rightly caution that participation may be commandeered when an individual emerges as a result of some existing community status, such as gender (usually male), age, and/or due to economic or educational prowess. However, this does not appear to be the case within Fourth Street.

Trust is also another important factor that affects how the rest of community participates. If the community doesn't trust the Street Guardians then they might not be able to effectively link HIVSA and the community. The two Street Guardians on Fourth Street that were described as energetic, friendly and open. One interviewee described the Street Guardians in the following manner:

> Yes, they are good people. They interact with people and persevere to listen to peoples' problems. Everyone I know likes them. No one has a problem with the Street Guardians.

Of course, not everyone is fully pleased with the Street Guardians. One informant, who hinted that she might be HIV+, was not terribly pleased with the Street Guardians.[140] Her critique differed sharply from the rest of the sample. This woman felt that Street Guardians had revealed her sensitive personal information to other community members. She mentioned that Street Guardians had disclosed both HIV-status and information about households' economic situation. She was extremely cautious not to clearly indicate in her answer whether or not she had been the victim of such behavior. Despite her displeasure with the Street Guardians she did feel that the Areiketsetse Le Bana program was generally helpful to the people of Fourth Street.

It is important to understand that many of the critiques of individuals may be linked to rifts predating the creation of the Street Guardian position or the arrival of the Areiketsetse Le Bana program. In the same way, grudges and discontents color individuals perceptions of reality. Although this was apparent from the research with the

[140] This informant also indicated that Areiketsetse Le Bana had helped put her on medicine, possibly ARVs.

Fourth Street community, this was never actually referenced by Chambers or any of the subsequent critiques of participation in development.

When it comes to evaluating the levels of participation within the community, the Street Guardians clearly have had the greatest amount of participation. The Street Guardians would probably be seen somewhere between the *placation* and *partnership* rungs on Arnstein's Ladder of Participation. Arnstein described the process of *placation* as including a few powerless people, when a group is forced to bring greater amounts of participation into their program. For HIVSA, seeking to develop a program with limited funds, was "forced" to integrate participation as a cost saving mechanism. There is a power imbalance between HIVSA staff and the Street Guardians. Because the Street Guardians hold only the position yielded to them by the HIVSA program design. The Street Guardians position could also be described as *partnership*, where the powerful and powerless work together. Despite the power imbalance, staff and Street Guardians work together not just because HIVSA was forced to integrate participation as a cost saving measure but also because of the character of the HIVSA staff. The HIVSA staff do not delineate strong barriers between themselves and the people they serve. HIVSA's lateral style makes the Street Guardians stakeholders within the Areiketsetse Le Bana program. The powerful and the powerless are working together for a common goal.

PARTICIPATION OF STREET RESIDENTS

Although many of the participants were able to identify some aspect of participation within the Areiketsetse Le Bana program, they saw their own participation (or others participation) as isolated events, and not as a part of a broader participatory development initiative. During the interviews, most respondents referenced one or two specific ways in which they had participated (e.g. going to a meeting or contributing to the assessment) and not in the way they were shaping their own path. Chambers asserts that beneficiaries are keenly aware that they are participating in their own development process. When Chambers, Arnstein and others speak of participation in development, they describe beneficiaries as conscious actors that recognize that they are participating in something.

Just because Areiketsetse Le Bana staff and beneficiaries have not referenced the terms participation and empowerment in the interviews, does not mean that participation or empowerment are absent on Fourth Street. Similarly, it does not mean that participation, when referenced, only exists in the manner that is described by the respondents or by Chambers. As has been said before, the Areiketsetse Le Bana program is not aware of participatory theory as developed by Chambers. Thus, their definitions and illustrations of participation and empowerment in their community are often slightly different than Chambers or Arnstein's definitions.

Participation is certainly happening through the initial assessment by HIVSA staff. This participation might best be described as falling on the rung of *consultation* on Arnstein's 'Ladder'. Arnstein states that although consultation can be helpful because individuals have the opportunity to share about their own experience. Chambers would agree, that here an important knowledge transfer between development practitioner and beneficiary. Although when individuals are consulted, there is no guarantee the ideas will be taken into account. Yet within Fourth Street, despite the power imbalance that exists between beneficiary and staff, it seems that most individuals feel as though staff members have listened to the community's needs. The Areiketsetse Le Bana program has limits of course. Although staff and Street Guardians listen to and record all of the needs stated by street residents, they are only able to assist with those that are in their program design. That said, Areiketsetse Le Bana attempts to make referrals to other civil society service providers on behalf of street members whenever possible.

The workshops and community meetings offer another venue for participation. The general consensus among beneficiaries is that participation is *information sharing.* One community member said "We participate when we have a meeting." For her and many others, something unique happened in their community when people gathered together to discuss. Although the general theory accepts information sharing as a form of participation, it is not considered as active a form of participation. Areiketsetse Le Bana has certainly not implemented the most sophisticated form of participation, as outlined by Arnstein and others. Nor is its current form without critique from the field of development. Also, meetings do not happen regularly enough to constitute a very high level of empowerment.

Surprisingly, few beneficiaries referenced obtaining of identification documents and grants as participation. However, Chambers would consider those actions as higher levels of participation[141] Community members do play a very critical part in getting the grants and identification documents.

The central concern with obtaining identification documents and grants is how beneficiaries - or participants – lack full decision-making power for their community. Despite HIVSA lateral structure, there is a power relationship between Areiketsetse Le Bana and the residents of Fourth Street, simply because the residents are in need. Although beneficiaries can influence the program by the knowledge they provide, they can't fundamentally change the design. Essentially, there is no power transfer. HIVSA hasn't "handed over the stick."[142] Individuals can "help themselves" but they are not in a decision-making capacity. For residents of Fourth Street, their only power lies in their ability to reject or accept the program that HIVSA has offered to them.

This has potential ramifications for empowerment, which we will explore in the next section.

EMPOWERMENT ON FOURTH STREET

One initial concern is that that when asked to give definitions of empowerment, some of the HIVSA staff failed to give an accurate definition. While one shouldn't judge a program by the responses of one or two staff members, it made sense to at least mention it in this research. When one staff member was asked to talk about empowerment on Fourth Street, she said "But there is too much of pride… they want people to bring everything to them… they want it all… they are very lazy. We black people are very lazy." Because of the strong links between empowerment and participation within the literature, it was assumed that the HIVSA staff would be able to elucidate about empowerment. However, even when some staff gave cognizant definitions of empowerment, they were unable to concretely connect it to specific examples of empowerment in the program. For example the staff member who defined empowerment as "teaching people skills to do things for themselves" had a hard time

[141] Chambers, 102.
[142] Chambers, 117.

connecting that statement examples where that was happening in HIVSA training programs.

Despite some apparent staff weaknesses, this is not to say that empowerment is not happening on Fourth Street. Essentially, empowerment is happening to two separate groups within Fourth Street, the Street Guardians and the street residents.

The Street Guardians are playing an active role within the community and within the design of the Areiketsetse Le Bana program. They hold a position of power that has been delegated to them through their community and HIVSA. Their community elected them to their position. HIVSA, through their program design, relies heavily on their support and trust. Arnstein wrote that "Without redistribution of power, [participation] is an empty and frustrating process for the powerless."[143] In contrast, the experience of the Street Guardians has been one that has expanded their worlds and allowed them to lead. One Street Guardian said the following of her experience: "The Areiketsetse Le Bana staff paved the way… Empowerment is happening. I can see it in myself."

Within the Fourth Street community, it seems as though participation and empowerment have both occurred. However, they often happen in separate contexts. Many street residents identified the knowledge transfer through the meeting and workshops as empowerment. They seemed to understand the knowledge transfer through the axiom that 'knowledge is power.' More than the content of the meetings, people remember the conversations and trust that is built within the community at these events. One Fourth Street residents said that the meetings are positive because "people are more open to talk about their problems... Before that it wasn't happening."

One young resident indicated, "Our community is very complicated. We blacks, we are different, some take matter seriously… they say why doesn't she do something for herself? Who do they take seriously? They take [wealthy neighbor] seriously because he is rich. If you are sick or not working they don't take you seriously." The community member went on to say that since the arrival of Areiketsetse Le Bana she had been taken more seriously by other street residents. Since Areiketsetse Le Bana has arrived in the community she has had somewhere to go for help. And she has people to listen to

[143] Arnstein, 216.

her problems. Interestingly enough, it is not the other street residents that she speaks with when she has a problem. She instead goes to one of the HIVSA staff members that she has built a relationship with.

Almost all Fourth Street residents (even those who did not directly receive grants, IDs, school uniforms, etc.) have described a change in their community. One resident summed up many responses when she said: "It has brought people together. She says that before people used to keep their problems to themselves… now they speak to people about their problems." However, it is unclear if the community change Fourth Street residents speak about is due to the addition of tangible goods or the process of obtaining key documents. Community members have also participated in the obtaining of their identification documents, birth certificates, and immunization cards. It is difficult to tell if people have been empowered because they *have received* these documents or because they *have gone through the process* of obtaining these documents. On one hand, participatory theory would tell us that one is empowered by participating. Thus, as street residents go through the process of obtaining their identification documents or grants they are empowered. On the other hand, the community's vulnerability has been reduced by the donation of school uniforms, food parcels and need-based grants. Joan Wharf Higgins writes, "Citizens who participate in community organizations often feel more empowered or have a greater sense of control than non-participants even before embarking on the participation experience."[144] Street residents do have a greater amount of control, not over the Areiketsetse Le Bana program, but of their own lives through the security provided to them by the grants.

Essentially, the connection between participation and empowerment generated by the Areiketsetse Le Bana program is unclear. There is certainly empowerment happening for many individuals through factors other than participation. Additionally, not all residents are empowered at the same level.

SUSTAINABILITY

Sustainability is a core issue concerning both development donors and practitioners. And in quite a different way, the sustainability of a program profoundly concerns the beneficiaries of development interventions. While, it is not the purpose of this paper to

[144] Higgins, 2-3.

discus sustainability in development initiatives, it should be said that the endless cycle of program start up and shut down often leaves beneficiaries more vulnerable (as they have become dependant upon the aid provided) and extremely dissatisfied with humanitarian programs in general. Within the interviews conducted for this research, beneficiaries mentioned how they had been initially quite skeptical of Areiketsetse Le Bana because they had been disappointed in the past as programs suddenly ended, without warning. It seems that staff of HIVSA have tried to address this. HIVSA certainly desires to create a program that is sustainable. Thulani Makoba, Team Leader for the Areiketsetse Le Bana program, said:

> We want people to do things for themselves after we are gone. A donor is funding Areiketsetse Le Bana. What happens if we are no longer here or we no longer have funding?

Thulani is referencing an important aspect of development. The first aspect of sustainability is fairly direct: *Will this program last*? The second aspect is closely related yet slightly more subtle than the first: *Will the community be empowered to seek solutions to their existing problems and find solutions to new problems that arise?* Both are critical issues to engage with.

HIVSA has structured the Areiketsetse Le Bana program in a way that it depends very little on HIVSA. They have trained Street Guardians to show Fourth Street residents how to obtain an identification document or government grant. Street Guardians are well versed on the exact steps that one must take to obtain these goods and services. Theoretically, a well-trained Street Guardian could teach eligible individuals throughout Soweto to access identification documents and grants. From HIVSA's perspective, the Areiketsetse Le Bana program on Fourth Street has come to a logical end because all eligible residents have identification documents or grants. They have also participated in several training programs.

But does that mean that the participation and empowerment facilitated by Areiketsetse Le Bana will be sustainable? Not necessarily. It some ways, Fourth Street residents participated together for a set purpose, during a set time. Before November 2005, many of them did not have identification documents and government grants. Now many of

them do. One year after Areiketsetse Le Bana arrived, there is significantly more income present on the street. Perhaps, just as the Apartheid era street committees waned in importance at the dawn of the new democracy, so also will the participation on Fourth Street.

However, the Street Guardians do not see their role as finished. At the time of this writing, Charlotte - the older of the two Street Guardians – played an instrumental role in addressing the recent sexual abuse of child within the community. After the community members found the abused child, Charlotte brought her to the local police station. Charlotte then assisted the child and family in communicating information about the crime. Through her action the rapist has now been brought to trial. The Street Guardians also expressed their willingness to help new members of the community to access identification documents and grants – as long as the residents are eligible.

CONCLUSION

The Areiketsetse Le Bana program is credible because they have tried deeply to put people first. People are at the center of their efforts, both in within knowledge transfers and also in the way that people are involved in their own development process. Consultation has helped ground the development initiatives in the reality of the Fourth Street residents needs and experience. However, for real empowerment to happen, at least as Chambers and Arnstein define it, a significant power transfer still needs to happen with the program design. Participation and empowerment, as implemented and exhibited in the A.L.B. program, presents scenarios that would be critiqued by both Chambers and his opponents.

Participation happens in varied, murky and often unexpected ways. Despite the structure of the Areiketsetse Le Bana program, identifying real participation was not as clear-cut as Chambers or even Arnstein has indicated. Without being tied to Chamber's theory and lacking a static definition of what participation means, it is no wonder that the Areiketsetse Le Bana program's approach to participation is ambiguous and at times convoluted. Broadly speaking, my research experience in Kliptown has not changed my mind fundamentally about participation. I knew that a critical look at a participatory program could elicit complex examples of participation; examples that are far more

shadowy than Robert Chambers might lead us to believe. And even when participation and empowerment happen, they often occur in an unexpected manner.

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HIVSA RESOURCES

Areiketsetse Le Bana Program Reports- January, March and June 2006

Areiketsetse Le Bana Power Point Presentation

ADDITIONAL WEBSITES

City of Johannesburg www.joburg.org

HIVSA www.hivsa.com

Joint United Nations programme on HIV/AIDS: http://www.unaids.org

Nelson Mandela/HSRC Study of HIV/AIDS - Household Survey 2002 <http://www.hsrcpublishers.co.za>

World Bank www.worldbank.org